



Pacing for people with M.E.

A detailed guide to managing energy, rest and activity for adults with mild/moderate M.E.



Our vision is a world without M.E.



Foreword

Myalgic Encephalomyelitis (M.E.) affects an estimated 250,000 people in the UK, and around 35 million people worldwide. Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or M.E./CFS is often given. We also hear from some people who've been given a diagnosis of post-viral fatigue syndrome (PVFS). This can make it confusing for many.

Action for M.E. uses the terms M.E., CFS and M.E./CFS because we do not wish to withhold support from those who have been given a diagnosis of CFS, as opposed to M.E.

Pacing is a self-management tool. It is a technique to help you take control of the balance of activity and rest, and learn how to communicate to other people about the balance that usually works best for you.

The information set out in this booklet is not a recommendation. Instead, we aim to support you to make an informed decision about which management approach you may or may not want to consider trying. It is based on the practical experience and clinical practice of healthcare professionals and therapists, and the feedback Action for M.E. has received from people with M.E. It includes examples and practical tips.

Because everyone's manageable level of activity is different, it's essential that any health professional who may be supporting you understands M.E. and how it affects you.

We are enormously grateful to Pete Gladwell, Clinical Specialist Physiotherapist, Bristol NHS M.E./CFS Service, for the considerable time, energy and experience devoted to helping write this booklet, and, for their invaluable and detailed feedback:

- our Patient and Carer Reference Group
- our Trustees, Alison Deeth, Sue Hardy and Phil Murray
- Action for M.E. supporter Glen Buchanan
- Action for M.E. Medical Advisors, Dr Gregor Purdie and Prof Julia Newton
- people with M.E. quoted in this booklet who shared their pacing experience online and for our Big Survey
- views shared on the discussion thread about this booklet on the Science4ME discussion forum.

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Read this first

This booklet is aimed at adults with M.E. who are new to pacing, perhaps because they are newly diagnosed, and at those who are familiar with the concept but would like a refresher.

You might find it helpful to also share it with the health professionals, carers or family/friends supporting you. Because everyone's manageable level of activity is different, it's essential that they understand the limitations imposed by M.E., and specifically how these impact you.

This booklet is, by necessity, long and detailed. Pacing isn't easy, and most people tell us they have found one or more aspects of it challenging. The knowledge, skills and strategies take time to learn and develop, which can be difficult with M.E., especially for someone more severely affected.

Bearing this in mind, this guide can be read in short sections – please don't try to take it in all at once! – and the skills can be practised one at a time until you build up your own approach to pacing. Like so many things in life, it takes time to learn how to put theory into practice in real life.

The essentials of pacing are covered on 14 pages in the “Your step-by-step pacing guide” (pages 14 to 27). Other things you may find useful in your self-management toolkit come under the “Pacing as part of self-management” section (pages 28 to 52).

Deciding to try pacing, or any other management approach, is your decision. You should fully understand what a particular approach involves before you decide to go ahead with trying it.

Other people may share a particular approach that has helped them; throughout the booklet, we have included some experiences of pacing (the quotes in orange), shared in our 2019 Big Survey of more than 4,000 people with M.E.

While this can be helpful in considering how to move forward, please remember that this booklet is not a substitute for medical advice from an appropriately qualified healthcare professional, who has experience of M.E. and understands how it affects you.

What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a long-term (chronic), fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems.

Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time. People with M.E. experience debilitating pain, fatigue and a range of other symptoms linked to post-exertional malaise.

Post-exertional malaise is an increase in symptoms after using even small amounts of energy; this may be delayed by up to a day or two. Along with post-exertional malaise, people with M.E. may experience:

- flu-like symptoms (often called “general malaise” by doctors)
- recurrent sore throat, with or without swollen glands
- muscle, joint and/or nerve pain
- headache or migraine
- twitching muscles or cramps
- sleep disturbance, such as unrefreshing sleep, difficulty getting off to sleep or sleep reversal
- problems with concentration, thinking and memory (often called “brain fog”)
- problems with the nervous system, including poor temperature control and dizziness on standing or sitting up
- hyper-sensitivity to light, sound, odours, some foods or some medications
- digestive problems, such as nausea, loss of appetite or Irritable Bowel Syndrome.

Around one in four people with M.E. are severely affected by the condition. The 2007 National Institute for Health and Care Excellence (NICE) guideline for M.E. (a reviewed and updated edition is expected December 2020) notes that management of severe M.E. is “difficult and complex, and healthcare professionals should recognise that specialist expertise is needed when planning and providing care.”

There is growing evidence from experts in the field of M.E. that a number of sub-groups exist within M.E., which likely explains the huge variation in the progression of the illness.

Identification of sub-groups will, it is hoped, help specialists to personalise treatments and improve outcomes for people with M.E.

At the time of writing, coping with M.E. focuses on managing the consequences of the illness and maximising the opportunity for improvement, where possible. This is where pacing and self-management have an important part to play.

People with M.E. who contact Action for M.E. for support tell us that accepting the need to pace themselves can be extremely challenging, especially if they are used to being very busy or active before they became ill. Those who are newly diagnosed often need time to adjust to the reality of living with M.E., and accepting that they will need to make some changes to manage this. Some people find it helpful to talk about how they feel, with a non-judgemental friend, or trained counselling professional.

NB. Frustration, anxiety, low mood and depression are sometimes experienced by people with M.E. as a consequence of having to cope with the impact of the condition and its symptoms. This does not mean that M.E. is a mental health condition, and it should not be treated as such.

What is pacing?

Pacing is a self-management technique.

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. There are a number of elements to self-management, and this booklet introduces some of the main ones that relate to M.E.

“It is very personal and every individual will need their own version of pacing in my opinion. It’s very relative to ‘life before’ – and we were all different then, too! Lots of different factors to consider, it’s a simple concept but application is tricky. Lots of trial and error.”

Pacing as self-management should not be seen as a treatment, but more as a way of coping with the impact of M.E. Taking a balanced, steady approach to activity counteracts any tendency to overdo things. Keeping your activity levels within sensible limits avoids overly aggravating your symptoms and prolonging the recovery phase after the increased activity.

You also know that if the activity is within your limits, you have a realistic chance of achieving the activity as planned. Understanding and accepting what your current abilities are helps you to plan ahead with more confidence.

Over time, if your condition stabilises, you can choose to try, if you feel able, to very gradually increase your activities to work towards improvement (see p 43).

A word about terminology

Balancing out activity and rest is sometimes called “energy management,” “activity management” or simply “pacing,” which is the term Action for M.E. – and the people we support – most often use.

“Energy management” is a term more often used by health professionals, as it includes more than just pacing, such as planning and prioritising (see p 31) and sleep management (see p 28).

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. You may also hear references to the “energy envelope” theory, which is about keeping the activities you undertake within your available energy levels. The majority of this booklet focuses on this sort of pacing.

The 2007 NICE guideline for M.E. (a reviewed and updated edition is expected October 2020) says: *“In this guideline, pacing is defined as energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion. The keys to pacing are knowing when to stop and rest by listening to and understanding one’s own body, taking a flexible approach and staying within one’s limits; different people use different techniques to do this.”*

Other clinicians consider pacing a way to first stabilise then gradually build up increases in activity, sometimes called “pacing up” – see p 43.

Post-exertional malaise

A good starting point is to understand the way in which the symptoms can be worse up to a day or two after a significant increase in physical, mental or emotional demands.

The medical term for this is “post-exertional malaise,” and it is one of the key features that define M.E. This means that somebody might increase their activity levels on a Monday, but may not feel worse until Tuesday and/or Wednesday.

Pacing means taking control of the balance of activity and rest to prevent post-exertional malaise; and learning how to communicate to other people about the balance that usually works best for you (see p 48).

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

Mental 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 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 over-stimulation) may also affect symptoms.

"Acceptance is key, and learning to pace the physical things means being strict with routine until you learn to adapt. But you also need to pace your mental activity, be it watching TV, using an iPad or smartphone and, most importantly, stressful thoughts and situations. Bad news can be as debilitating."

For some, 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 contact Action for M.E. for information and support.

Summary What is pacing?

- Pacing is a self-management technique, and should not be seen as a treatment but more as a way of coping with the impact of M.E.
- Keeping your activity levels within sensible limits avoids overly aggravating your symptoms.
- Pacing means balancing of activity and rest to prevent post-exertional malaise.
- Activity means physical, mental and emotional activity.
- For some, activity may be very minimal (especially for those who are severely affected) yet still have a considerable impact on energy and symptoms.

Is pacing right for you?

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.

“Pacing has been the single most useful thing I have done. I was told early on by an Occupational Health doctor that symptoms can hit a few days later. Very useful to know. I pushed myself far too hard the first year – it was difficult to change the mindset of pushing through, which is what I had always done before if I felt unwell. Just meeting others going through the same thing was far more beneficial than I had anticipated: it is a fluctuating illness and we cannot always control it. Knowing this took a lot of pressure off me, and I am doing better at not blaming myself every time I crash, or feel a bit better.”

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

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.

“The illness sometimes appears to fluctuate/worsen independently of activity and a rigid pacing plan or diary would not work for me, I have to listen to my body and adjust on a day by day basis. I suspect my energy capacity is still only 15% of normal but I can reach a functional capacity of 30-40% of a normal day because of pacing.”

Summary Is pacing right for you?

- Make sure you fully understand what any management approach involves before you decide to try it or not.
- M.E. affects different people in different ways and all management approaches must reflect this.

Pacing as part of your toolkit

Pacing is one tool in a toolkit of strategies that can help to manage M.E. Other measures to help manage your symptoms, and reduce their impact on your life, might include:

- medication for individual symptoms (see below)
- support from a specialist M.E. service (see p 11)
- diet and nutrition (see p 11)
- relaxation and/or meditation (see p 15)
- delegation and/or asking for help (see p 37)
- sleep management (see p 28)
- planning (see p 31)
- having a setback plan (see p 56).

See more at www.actionforme.org.uk/treatment-and-management

“Pacing like any tool has to be used at appropriate times. If I’m at my worst then it won’t work. But at other times is helpful to establish a baseline and ensure I don’t push myself to breaking point (ie. in bed unable to do anything).”

Medication for individual symptoms

While there is no single pharmacological cure for M.E., there are a number of medications that your doctor can prescribe that may help with individual symptoms. In some cases, this may include those licensed primarily for other health conditions. Action for M.E.’s 2019 Big Survey of more than 4,000 people found that 68% used medication for individual symptoms.

Different drugs have different effects on symptoms and also differ in their side effects. If you find that a drug is ineffective or cannot be tolerated, it may be worth systematically trying others, in partnership with your GP. People with M.E. often have a limited tolerance to drugs, so starting lower doses than usual may be needed, then slowly increasing if appropriate, and only with support from your health professional.

Specialist M.E. services

Depending on where you live, your GP may be able to refer you to an NHS service in your area. Some NHS services offer people with M.E. a specialist service that builds on the key elements of pacing and other approaches, such as cognitive behaviour therapy (CBT), graded exercise therapy (GET – see p 43), and managing diet and nutrition.

NB. A significant number of patients, scientists and charities, including Action for M.E., do not support the NICE guideline's current view that CBT and GET "are the interventions for which there is the clearest research evidence of benefit" for people with mild to moderate M.E., given legitimate questions being raised about safety and effectiveness.

Diet and nutrition

Eating balanced and healthy meals is important during your illness, to provide you with the energy and nourishment you need for better health. Maintaining a good intake of fluids is important too, as well as reducing your consumption of stimulants such as caffeine and depressants like alcohol.

The effort required to buy food and prepare nutritious meals can mean that some people with M.E. find it difficult to maintain a healthy diet. This can be made harder by loss of appetite or food intolerance, which may mean that you consider taking vitamin/mineral supplements.

If you are experiencing significant problems with your diet and struggling to maintain an adequate food intake, discuss the possibility of a referral to a dietician with your GP or specialist. Dietitians are qualified and regulated health professionals that assess, diagnose and treat dietary and nutritional problems.

Summary Pacing as part of your toolkit

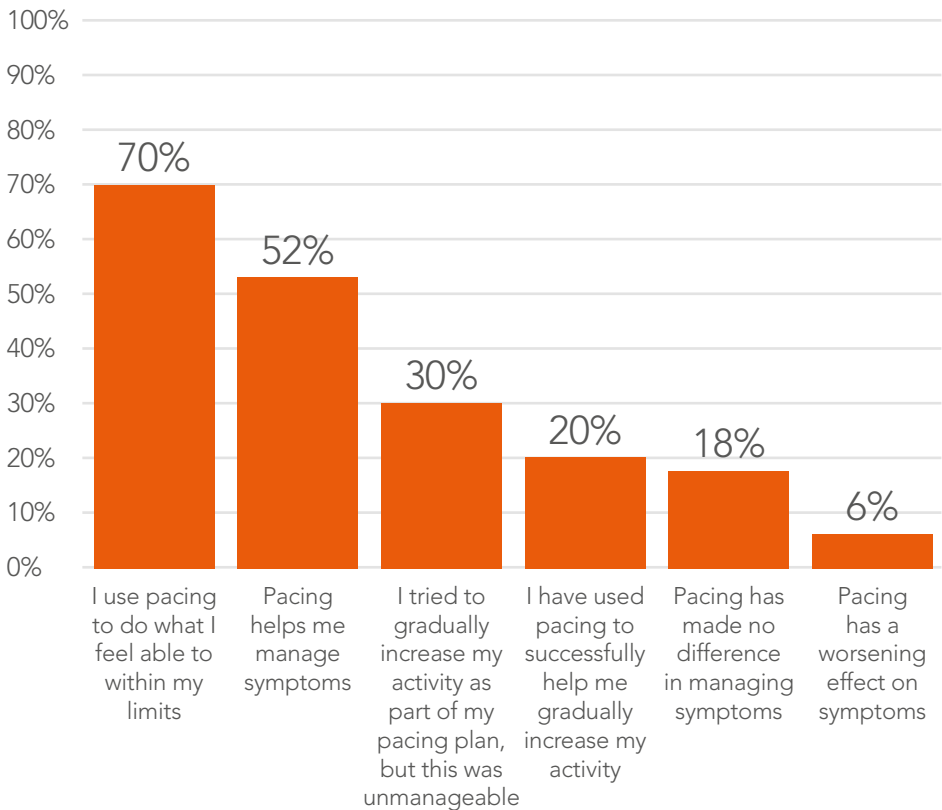
- Pacing is one tool in a toolkit of strategies that can help to manage M.E.
- Your doctor can prescribe medication that may help with individual symptoms.
- Depending on where you live, your GP may be able to refer you to an NHS service in your area.
- If you are struggling to eat balanced and healthy meals, discuss the possibility of a referral to a dietician with your GP or specialist.

How can pacing help?

So far, pacing may not seem very appealing. You have gathered that it requires planning and discipline, which probably doesn't sound easy when you're ill. It may also seem restrictive – the last thing you need when you are already coping with the limitations imposed by your illness.

So is it worth it? The overwhelming answer from most people with M.E. who contact Action for M.E. is yes. The long-term benefits can include stability, control, better coping and, for some, establishing a starting point for improvement or recovery.

Action for M.E.'s 2019 Big Survey of more than 4,000 people with M.E. asked them questions about a number of symptom management approaches, including pacing. We found that most respondents (88%) had tried pacing in the past five years. See the graph below for key pacing results.



Dealing with any long-term illness is a challenge. Pacing can give you a greater understanding of your health and its combined benefits can make coping easier. It helps you to rethink your approach to tasks so that you resist any natural tendency to keep going until you are forced to stop by fatigue or other symptoms.

“Pacing has been life-changing for me. It was first suggested to me, a few months after my diagnosis, by an M.E specialist. It was extremely difficult at first, as it felt so strict! Only half an hour of ‘red’ time a day (aka high energy), which included brushing my hair, and watching TV. It was shocking how much high energy I had been using without realising. Pacing has stopped me from having those extreme boom and bust days.”

A physiotherapist’s view

Pete Gladwell, Clinical Specialist Physiotherapist, says: “Pacing is about balancing physical and mental activities with rest. Effective pacing can provide more stability, control and sustainable levels of activity. This can also offer, if you choose, a firm foundation for ‘pacing up’ (see p 43), which involves a considered plan to try and nudge up the level of an activity or exercise.

“Those who do not improve in terms of function may still find pacing and baseline setting to be helpful strategies to:

- improve control over a challenging illness
- reduce the frequency and severity of setbacks
- provide some ability to plan and problem-solve around limited capacity
- communicate clearly to other people what you can usually manage.”

Summary How can pacing help?

- Most people who contact Action for M.E. say the effort, planning and discipline of pacing are worth it.
- Long-term benefits can include stability, control, better coping and, for some, establishing a starting point for improvement or recovery.
- Nearly three-quarters (70%) of Action for M.E.’s Big Survey respondents said they use pacing to do what they are able to within their limits.
- Pacing can give you a greater understanding of your health and make coping with a long-term condition easier.

Understanding the basics

This is an introduction to each of the key areas before we look at them in more depth. The three key elements of pacing are:

- activity analysis
- establishing a sustainable baseline
- using rest and relaxation.

Activity analysis

Learning pacing means learning how demanding each activity is for you at present: in other words, activity analysis. This means assessing what is involved in a particular activity, and the skills and energy required to undertake it.

If you only associate activity with physical pastimes, pacing requires you to take a fresh look. In pacing terms, activity incorporates any action that uses energy, whether this is a physical, mental or emotional demand.

Everyday activities might range from sitting up in bed or having a shower, to watching television, to worrying or feeling angry. Some people with M.E. tell us that emotional activity is the most draining, and the hardest to measure and control.

Establishing a sustainable baseline

A baseline is a level of activity that you can sustain on a regular basis. In other words, you should be able to do the same baseline amount of activity day after day. Your baseline level will be below your “personal best” that you can manage on a better day.

If you know what your baseline level is, you can choose to stop an activity at a point where you are less likely to experience post-exertional malaise and/or a worsening in symptoms.

Once a sustainable baseline has been established and stuck to, you may find that your symptoms ease and your energy levels increase, or that you have the same level of symptoms but with fewer setbacks.

“The first consultant I saw about M.E. told me to only ever do a maximum of 70% of what I felt capable of; the 30% you kept in reserve made sure you didn’t overdo it. I have applied this ever since, to activities where I have complete control (ie. hobbies, sports, housework, gardening etc.) both in terms of the duration and intensity of the activity. Over a period of time I found I could cope with and enjoy more activity without ill effect.”

Using rest and relaxation

Short, regular rest periods throughout the day help to give you time to recuperate, and can stop you becoming overwhelmed by symptoms. Rest and relaxation are as central to pacing as activity, although the amount of rest that you need will vary at different stages of the illness.

“I use pacing as part of my daily routine. I try to rest mid-morning and mid-afternoon. If I am trying to do something more strenuous, eg. a bit of light weeding, I have to rest every 15 minutes. If I pace myself it does make a difference to how much I can and can't do. It also reduces the dips in energy.”

For your mind and body to get more benefit, it helps to learn how to fully relax and properly rest your brain. This may call for a new perspective on what you consider to be relaxation. Before you became ill, you might have used mental activities to relax, like reading or watching television, or you might have enjoyed physical exercise. For recuperative rest, you may now find that it is better to be quiet and still, both physically and mentally.

In general, it is better to avoid sleeping during the day, as this may disrupt your night-time sleep cycle (see p 28). Try to use rest rather than sleep if at all possible.

“My balance between activity, rest and relaxation varies from day to day according to my symptoms and my choices. I try to ‘go with the flow’ and accept whatever each day brings.”

Summary Understanding the basics

- The three key elements of pacing are activity analysis; establishing a sustainable baseline; and using rest and relaxation.
- Activity analysis means learning how demanding each physical, mental and emotional activity is for you.
- A sustainable baseline is a level of an activity that you can sustain on a regular basis.
- Rest and relaxation are as central to pacing as activity; this may call for a new perspective on what you consider to be relaxation.

Pacing in practice: activity analysis

In pacing terms, activity incorporates anything that uses energy, whether it is a physical, mental or emotional demand. As well as being able to analyse activity as physical, mental or emotional, you can also rate an activity according to how much energy it uses. Activities will be low, medium or high consumers of energy. You need to consider the balance of different types of activity and the level of energy they use when you are planning your day.

Completing an activity diary can help you to better understand your situation. An activity diary provides an overview of your week, allowing you to “zoom out” from the detail to look at patterns of activity and rest. This can help you understand what is going on and enable you to reflect on your own particular circumstances. The effects of overdoing it may not show up for a day or two so your diary could help you to identify what triggered your symptoms.

“I have kept a pacing diary in the past at times, though I find it too tiring to do on an ongoing basis. It helped me to realise I needed to rest more frequently and break up daily activities more. It has enabled me to do more activity up to a certain point within my limits.”

Action for M.E.’s 2019 Big Survey of more than 4,000 people with M.E. found that, on the whole, respondents who kept a diary reported more successful outcomes when it came to managing their energy. Do bear in mind, though, that it may take some time to find a way to do this in way that works for you. Keeping a diary is a task in itself.

“Initially I used a very detailed diary which I hated and it increased my anxiety and depression. A more informal method works better for me. It is almost instinctive for me to spread out activities over the day/week.”

A sample of the kind used by the specialist M.E. Service at North Bristol NHS Trust can be found on the page 18.

Of course, symptoms vary for other reasons than activity levels, for example poor sleep. An activity diary can help you to monitor your sleep (see p 28), so that you can work out where the problem areas are and make appropriate changes.

It helps to keep your activity diary until you are able to spot patterns or apply the pacing principles in your head, or build them into your routines and plans (see p 31). An activity diary can offer clues about where there might be room for new activities in the day, and it can also be helpful when attempting to start a significant activity change, for example a phased return to work or study, or starting to drive a car again.

A diary may need to be temporarily restarted during a setback (see p 50).

“Pacing is absolutely essential to be able to manage everyday life. When I was first diagnosed, I did keep a diary, establish baselines etc. and this was very helpful in reducing the severity of my symptoms, and help me maintain some social contact as well. I live by myself so it’s necessary I keep well enough to wash and feed myself, do everyday tasks etc.”

How to complete an activity diary

1. Look at the key at the bottom of the diary on p 18: it has a box for sleep, one for rest, and three for different levels of activity. Choose a contrasting colour or pattern for each box, and fill it in.
2. Now look at the first line of the diary: it starts at midnight on the first day, and each box represents an hour. Use your colour or pattern to fill in the boxes, showing what you’re doing at different times of day.
3. It is possible to fill in only part of the box if an activity lasts for part of an hour. Complete the rest of the box with other colours or patterns, depending on what you did next. If you have a few different activities in any hour, it might be a sign you are doing too much.
4. It is up to you to decide which activities are high, medium, low demand or restful. Think about how much energy (physical, mental or emotional) each activity usually demands from you on a “middling” day. In this way, you’ll be able to make the diary suit your own current situation.
5. If your sleep is broken, make a rough estimate of how long you were awake for, and fill in the diary with the colour for rest or high, medium or low demand activity, depending on what you did whilst you were awake.

Activity diary analysis

When you have filled in your activity diary for a week or more, you can start to look for patterns.

- Is there a pattern within a day?
(eg. busy in the morning, needing to rest for the rest of the day)
- Is there a pattern happening over several days?
(eg. busy during the week, crashing at weekends)
- Do you rest only when you are exhausted or, do you rest before activities?
This is known as pre-emptive rest, and is planned in
- Are you doing mostly physical, or mostly mental activities? Is there a balance?
- Are you doing any activities that you enjoy, as well as “chores”?
- Can you identify any blocks of activity which could be broken down into smaller chunks? If so, you may benefit from setting sustainable baselines – see p 14.

“I used to keep a pacing diary – it is an activity in itself and requires energy. I used an online M.E. diary to look for patterns, which was helpful, and highlighted the problems that lead to keeping a food diary and a mast cell disorder being uncovered. In the beginning, pacing meant as little as a couple of minutes of activity followed by 15-20 minutes of rest, which was a surprise. I found pacing mental activity difficult, as anxiety was a big part of my symptoms and depleted my energy quickly. Family expectations and their desire for our old selves to return can be counter-productive when trying to pace activity.”

Summary Pacing in practice: activity analysis

- In pacing terms, activity incorporates anything that uses energy, whether it is a physical, mental or emotional demand.
- An activity diary can help you understand what is going on and enable you to reflect on your own particular circumstances.
- Completing an activity diary is a systematic process, and it may take some time to find a way that works for you.
- When you have filled in your activity diary for a week or more, you can start to look for patterns, and use these to help you make decision about how you manage your activity and rest.

Pacing in practice: establishing a sustainable baseline

The activity diary allows you to “zoom out” to look at patterns of activity and rest. Baseline setting means “zooming in” to look at the detail of what you do, and how long you do it for, using the principle of a stop rule. There are four stop rules, and these are explored below.

You’ll see from below that using time- and activity-based stop rules are the most helpful to use when learning pacing.

“Fighting it” as a stop rule (not ideal)

Think about somebody starting out with an activity, eg. walking. They may be aware that it is getting harder and harder to keep walking due to an increase in symptoms, and there is likely to come a point when they have to stop because the symptoms have increased so much. It is as if they were trying to fight their symptoms to carry on for as long as possible.

That person’s stop rule is having severe, intrusive symptoms, and they don’t stop until they are forced to. They are pushing on through to do the most they can in the short term, but there is likely to be a price to pay later on: it might take them the rest of the day to recover, or the next day as well, or longer still. It’s also likely to trigger post-exertional malaise (see p 7). Using this stop rule is not what this booklet calls pacing.

“Listening to your body” as a stop rule (better)

Somebody else might be using a system where they’re saying: “I’ve spent too many days recovering from pushing myself too hard, so I’ve learnt to watch out for warning signs.” If they get warning signs as their symptoms build up, they may decide to stop sooner. The hope is that they’ll recover sooner than someone who is pushing through, and can start again doing the next activity before too long.

These people may have to rely on reading their personal warning signs all the time, such as slowness, exhaustion or an increase in pain. This type of pacing is what people would typically describe as “listening to their body,” and the stop rule is the increase in or change in their symptoms.

Sample activity diary

Week
 / /

Midnight to midday

	12	1	2	3	4	5	6	7	8	9	10	11
Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												

Week
 / /

Midnight to midday

	12	1	2	3	4	5	6	7	8	9	10	11
Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												

Sleep
 Rest
 Low demand
 Medium demand

Midday to midnight

12 1 2 3 4 5 6 7 8 9 10 11

Midday to midnight

12 1 2 3 4 5 6 7 8 9 10 11

 High demand

This is a more subtle way to manage activity than the “fighting it” stop rule, but it’s impossible to use for people that only get delayed warning signs, for example a day or two after an increase in activity. The warning signs come too late.

It’s also a difficult stop rule for people with M.E. who have been coping with pain, fatigue and other symptoms by trying to distract themselves, to block the symptoms out. For some people with constant symptoms, sometimes the only way to cope is not to focus on them, but of course “listening to their body” means the opposite of this.

“I use a Fitbit to monitor how much walking I can manage without symptoms and how much is too much.”

Using time as a stop rule (most helpful)

The third way to know when to stop an activity is based on past experience and using time as a stop rule. Somebody might say: “I know from experiences that, if I go for a five-minute walk, then have a 10-minute break, I’m OK for another five minutes.”

“I use a minute timer, not a diary. It is extremely difficult to know when to stop performing an activity; overdoing it causes a crash and can set me back months at a time. This can be as simple as exposing eyes to text, listening to a book being read to me, sitting up, or using my iPad. My timer is set at very modest levels, starting at three minutes and very slowly building up.”

Using activity as a stop rule (most helpful)

The fourth way is a similar system, again based on past experience but using the amount of activity as a stop rule, rather than time. Using this form of pacing, somebody might say: “I’ve worked out that if I’m preparing food, I’ll prepare one type of vegetable and then I’ll stop and have a break. Then I’ll start again on my next stage of preparing a meal, and then I’ll stop.”

This is about breaking things down into manageable chunks of activity, and stopping because a chunk of activity has been finished, even if you feel that they could carry on for longer.

“Pacing has helped me to find out my limits and I can recognise when I need to stop an activity. My baseline is very low, but my specialist recognises this and uses pacing to help me prevent flares rather than to try and increase my activity.”

Starting to set a sustainable baseline

- If you know that you overdo an activity a lot, you might want to set your initial baseline at about 50% of what you think you can do. This is known as “the 50% rule.” It is a rule of thumb, but it can help some people in the early days of baseline setting.
- If you think you are pushing yourself just a bit too much with an activity, try using the 75% rule. For example, if you carry out a particular activity for 20 minutes but suspect it’s a bit too much, try reducing your activity time by five minutes to 15 minutes (ie. 75% of 20 minutes). The aim would then be to maintain a 15-minute block of that type of activity each day. Some people find they can repeat the baseline level after a rest/relaxation period.
- Another method is to think about how much of an activity you could do if you wanted to do the same amount, day after day. This method relies on “gut feeling” and intuition to start with, but you will learn by keeping a record of your activities (see p 16) whether you have found a sustainable level. You could use a confidence scale like the one below.



- Ask yourself how confident you feel about managing the activity at that specific level, day after day. If your confidence level is high, you are probably close to your baseline.
- The golden rule is: remember that all activities must be set at a level that should be sustainable. It can be very disappointing to find that your baseline is lower than you expected but remember that you are taking a step back in order to go forward, in the way that best suits you and your circumstances. The first aim is to gain a stable pattern of activity.

Stabilising your activity

When you have set your baseline, you need to give your whole system time to settle into this level. How long this takes will vary from person to person; it can frequently take weeks, and sometimes longer.

Balance is the key not only in the activities that you choose, but also their type. Your day should include a balanced mix of physical and mental activity and you can choose to deliberately alternate or “switch” between the two.

“One thing I have found helpful is switching activities, so that no one group of muscles gets too tired, eg. read or look at computer, then do some housework or cooking or play the piano.”

Heart-rate monitors

A number of respondents to Action for M.E.’s 2019 Big Survey said they used heart-rate monitors. Specialist physiotherapist Pete Gladwell says: “I’m aware of the practice and I think there are some pros and some significant cons. Heart rate can increase for a lot of reasons, including autonomic disturbance. People can also overdo it by carrying on at a less demanding level that doesn’t spike heart rate. Plus, heart-rate monitoring doesn’t help with cognitive or emotional demand.”

Because of the complexities around heart-rate monitoring, we strongly recommend that you seek specialist advice if you are considering using one.

Summary Establishing a sustainable baseline

- Baseline setting means looking at the detail of what you do, and how long you do it for, using the principle of a stop rule.
- There are four types of stop rules: fighting it (not ideal); listening to your body (better); using time (most helpful) and using activity (most helpful).
- Setting a baseline can include starting at 50% or 75% rule of what you think you can manage, to help you stop overdoing an activity.
- Try not to be discouraged if your baseline is lower than you’d hoped: remember you are taking a step back in order to go forward, in the way that best suits you.
- When you have set your baseline, you need to give yourself time to get used to this.
- Balance is the key not only in the activities that you choose, but also their type, ie. a mix of different mental, physical and emotional demand.

Pacing in practice: using rest and relaxation

Good quality rest and relaxation is an essential part of a successful pacing programme and you need to build this into your day. Action for M.E.'s 2019 Big Survey of more than 4,000 people found that 92% use rest/bed rest as a way of managing the condition.

The amount of rest needed varies from person to person. Some people need a lot of rest while others find that, if they are getting good-quality rest, they can cope with short, frequent mini-rests, lasting as little as five to 10 minutes.

Relaxation is about achieving complete rest of the body and mind. If you feel that your brain or body is being stimulated, you are not achieving true relaxation. It can take some time to learn to "switch off" physically and mentally. Some people find it very difficult to relax properly and feel guilty if they're not busy or doing something "useful."

There are several techniques or skills that you can learn to help achieve a state of relaxation. It helps to:

- make room for relaxation (see below)
- learn good breathing (see below)
- tackle tension (see p 26)
- unwind (see p 27).

Make room for relaxation

Set aside a time and place to relax. Where you choose will depend on your circumstances but you need to find a place where you won't be disturbed. Switch off the phone and let those around you know that you don't want to be interrupted. Get yourself as comfortable as possible, either lying down or sitting with your neck, feet and arms well supported. Make sure you are warm enough.

Good breathing

Learning techniques for good breathing, and remembering to put them into practice, is important. When you are feeling stressed, anxious or worried, your breathing can be shallow and quick. This is called hyperventilation. When you hyperventilate, you use only the upper part of your chest, whereas good breathing uses your whole chest and lung area.

A lot of people are unaware that they are hyperventilating and it can become a habit. It alters the blood chemistry and causes symptoms such as pins and needles, dizziness, palpitations, breathlessness and chest pain, and heightens anxiety and panic. Naturally these symptoms can cause further worry and anxiety and a vicious circle is created.

It's helpful to practice good breathing on a regular basis.

- 1 Place one hand on the top of your chest and the other hand at the bottom of your rib cage/abdominal area.
- 2 Breathe in slowly through your nose and into the 'bottom' of your lungs. You should feel your abdominal area rise while your chest should only move slightly.
- 3 When you take a breath in, pause for a moment and then breathe out slowly either through your nose or mouth. Make sure you breathe out fully.
- 4 Repeat this process slowly. You might need to build up the number of slow, calm abdominal breaths gradually until you get used to doing them.

Tackle tension

There are a number of different techniques to help tackle tension so you will need to find what works best for you. Some people find that focusing on a pleasant or relaxing image can help to calm the mind and body.

Another method is to consciously relax any unnecessary tension in your muscles. Your aim is to recognise when your muscles are tense, then to relax them in response to this. One way of doing this is to clench a fist for a few moments and then unclench. Note how tense and uncomfortable it felt when clenched and how good it feels when fully relaxed.

Try this with other muscles in the body, for example your neck, shoulders, and back. Focus on whichever area you think might be tense. Clench for a few moments and then unclench. Some people find it helpful to systematically work their way around the body from head to toe.

As you get better at the technique, it's possible to bypass the clenching and just "let go" of each muscle group in turn. This can also be used alongside deep, slow breathing as a "first aid" measure in stressful situations. There are many body scan meditations available free online and in mindfulness meditation apps, which can help you focus on your breathing.

Unwind

Deep relaxation takes practice, and relaxation or mindfulness apps or CDs can be a good guide. Some people benefit from practising meditation and yoga. The important thing is to find a way of resting that works for you. Gentle music can be helpful for some, but others find that listening to music counts as activity.

If you are having difficulties learning to rest or relax effectively, please seek further advice. Your doctor should be able to help, or recommend another health professional who can support you with this.

Summary Using rest and relaxation

- Good quality rest and relaxation is an essential part of successful pacing programme
- Set aside a time and place to relax; try and save your bed for night-time sleep.
- Find a way of tackling tension that works for you: your aim is to recognise when your muscles are tense, then relax them in response. This can also be used alongside deep, slow breathing as a "first aid" measure in stressful situations.
- Deep relaxation takes practice; find a way that works for you.
- If you are having trouble learning to rest or relax effectively, please seek further advice; your doctor should be able to help.

Managing sleep

Most people with M.E. experience sleep difficulties. Some people will have difficulty falling asleep, or have broken sleep. Some people will have the opposite problem, and will sleep more than usual: this is known as hypersomnia. This can reduce the quality of sleep, and leaves fewer hours awake to function. A sleep problem can exacerbate symptoms such as exhaustion and poor concentration.

Research shows that there are a number of “sleep phenotypes” in M.E. – which means that the type of sleep problem encountered varies from person to person, and can change over the course of the illness.

It also means that what helps one person manage their sleep difficulties may not work for another. Nevertheless, some basic sleep advice can be useful for some people.

What is the nature of the problem?

It is important to work out what kind of disruption is taking place. You can use an activity diary (see p 16) to record your sleep pattern, and gain more insight into the nature of the problems you are having. This helps you to decide what changes might help.

- Do you have a problem getting off to sleep?
- Is it that you keep waking up throughout the night?
- Is it that you wake early and cannot get back to sleep again?
- Is it that, despite having slept, you don't feel well-rested?
- Do you feel the need to sleep longer in the morning, go to bed early, or sleep in the daytime?

Where do you sleep?

Make your bedroom “sleep-friendly.” Advice is that the bedroom should be a relaxing environment, associated with sleeping (as opposed to having company, watching TV, etc). There can be increased difficulties sleeping after using screens that emit blue light, such as TVs, laptops and mobile phones. Switching them off two hours before bedtime can be beneficial in getting off to sleep. Bedrooms for sleep at night should be dark, quiet, tidy and ideally kept between 18° and 24°C. Also make sure you have a supportive, comfortable mattress and pillows.

- Give some thought to how comfortable your bed is.
- Temperature is important: it's hard to sleep when it's too warm or too cold.
- What is the ventilation like? Some prefer a window open but others find it too cold or a distraction.
- Are there any noises disturbing you that you could do something about? Some people are better able to sleep when there is a little noise going on in the background, and can't sleep when it's too quiet.

How do you prepare for sleep?

Hot drinks can be soothing for some people, and we often associate hot milk with bedtime, so that can be a useful association to draw on. However, drinks with stimulants in them are not a good idea. Caffeine – in tea and coffee – is a stimulant and is known to disturb sleep. This effect will last for several hours after drinking it. The more caffeine you have in the day, the more likely it is to affect your sleep.

It can help simply to avoid caffeine six hours before bedtime. Some people need to avoid caffeine in the afternoon and evening altogether. While alcohol can help some people to fall asleep, many people find that it causes disruption later in the night so might be best avoided.

Emotions and sleep

Although you might say that there's nothing you can do when you're in bed to sort your anxieties out, it's sometimes hard not to worry anyway. If you want time to think things through on your own, it can be better to do this earlier in the day; writing things down can be useful.

Just before bedtime, it can help to have a regular set of activities that help you to wind down. Some find it helpful to write lists for the following day, do relaxation exercises, read a book or listen to relaxing music or talk radio. The important thing is to do something that helps you wind down, so you are not feeling stressed at bedtime.

Remember, the key to self-management is learning what is helpful for you as an individual, and taking charge of any gradual changes you make.

Medications and sleep

Different medications do have important effects on sleep. If pain is disrupting your sleep, it might be worth discussing the pros and cons of different pain medication with your GP or a pharmacist. Simple painkillers can help, but some people benefit from medications like Amitriptyline or Nortriptyline taken in very low doses, about two hours before bedtime.

NB. Note that some people experience side effects and find it difficult to stop taking these medications. You should consider all the implications carefully with your doctor first.

“I noticed right at the beginning of my illness that pacing made a difference to my functional ability, especially cognitive activities, but no matter how much I rested I did not improve until years later when I was allowed to give up work and saw an M.E. specialist. I was given medication for sleep and, so long as I stuck to the pacing, my sleep improved and my cognitive function improved. If I did more than my pacing allowed I deteriorated and experienced worse symptoms than I’d ever had before.”

Summary Managing sleep

- Good sleep is about quality, not quantity. Establishing a regular sleep pattern is important.
- What works for someone else may not work for you. The key is self-management: learning what is helpful for you, making changes gradually.
- You can use an activity diary (see p 16) to record and gain insight into your sleep pattern.
- Is your bedroom “sleep-friendly”? Give thought to how comfortable your bed, duvet and pillows are and the temperature, light and noise levels.
- It can help to have a regular set of activities that help you to wind down, including avoiding caffeine six hours before bedtime.
- Speak to your doctor if you are considering medication for sleep.

Daily and weekly planning

Planning can be a powerful self-management skill. It can be a very simple process, which you can use to make sure that there is a balance in your day, and in your week. It can allow you to look “at a glance” to see if your planned activities have a sustainable balance of activity and rest. You can also share your plan with other people, to help them understand how you need to manage your activities in a sustainable way.

“Some days pacing works and helps me lessen my fatigue; other days it doesn’t make any or very little difference to my energy levels. Generally speaking, I have found it quite useful in managing my M.E. alongside the planning and prioritising of tasks.”

A useful planning system should make it easier for your brain to function despite “brain fog” as it involves “offloading” lots of information from your brain into your planning system. Your brain will function better if you only give it one main task at a time. If you have already planned your day or week in advance, you can use your plan as a reminder system rather than trying to hold all the information in your brain, and also expecting it to cope well with the task in hand.

It is important to understand that a plan does not always fall into place as you might have hoped it would. Life events might intervene, circumstances might change, and the plan will need to be adjusted. So be flexible with your plan: use it as a guide, don’t expect it to be set in stone. It helps to think that a wise plan increases the odds of managing what you want to achieve, but it doesn’t guarantee it.

“Pacing is important to me as I cannot manage ‘big activities’ without it. I have to space out medical appointments, and plan resting and recovery days. I have a ‘leaving the house checklist’ so I don’t forget anything important. I am mostly bedbound so leaving the house is a big deal. If I didn’t pace, I would be totally reliant on other people to help me turn over in bed/go to the toilet etc. I found this out after having two consecutive appointments one day after the other and I want to avoid being that situation again if I possibly can.”

How to plan

There are many different ways to plan, including paper or electronic diaries and calendars. Electronic systems have the added value of being able to set a reminder, to help you remember the planned activity. This section suggests some simple methods that can be done with a sheet of paper, or a simple online spreadsheet if you prefer.

A daily planner can be quite detailed, or it can be a “broad brush” approach that puts the main activities that you want to achieve into some kind of order but allows you lots of flexibility.

A fairly detailed example for mild/moderate M.E. is shown on p 34, with a column down the left-hand side for the time of day. Activities have then been broken up into two columns, one showing more physically demanding activities, and a second showing more mentally demanding activities. There is a fourth column on the right hand side showing activities that fall into the “rest and relaxation” category.

This kind of diary helps people to “switch” from physical activities, to mental activities, and then to rest. It is also possible to add up the length of time doing each type of activity, to create a total for physical, mental and restful time spent. This can be useful to help keep an eye on the balance between these activity types.

It's also possible to colour-code each section by shading it with the same colours that you've used for high, medium and low demand activities in the weekly recording diary (see below). It can help to plan in some enjoyable activities as well as “chores.”

A sample **weekly planner** is shown on p 36. It has a column for each day of the week, broken down into morning, afternoon and evening. You can use a diary like this to plan the main activities for the week, and make sure that none of the days are overloaded. It's also helpful to look for gaps in the week when you might want to add in new activities gradually.

“I find that pacing is the only way I can get things done. I plan the week ahead rather than the day so I know not to do too much for a couple of days before something important.”

Using a planner for planned rest

Pacing involves trying to balance different types of activity with useful amounts of rest and relaxation. Using a planner allows you to plan in periods of rest, and to think about when it is best to use it.

Some people use planned rest periods before an activity, to increase the odds of managing the activity successfully. Planned rest can even be helpful if something unexpected happens: if you managed to fit planned rest into your routine before the unexpected event, you are better placed to cope with it.

“Pacing allows me some quality of life, and to participate in some major family events. I had an extremely important event which I managed to take part in by resting all day, then spending one hour on my scooter at the event, then 20 minutes lying down in the back of the car, then another hour at the event, then another 20 minutes lying in the car. I got through it and enjoyed it because of pacing.”

Using a planner to help with communication

It can be difficult for other people to understand the complexities of living with and self-managing M.E. You can use a daily or weekly planner as a tool to show people how you need to spread activities out.

It can also help you to negotiate with people when you plan to do something with them. If they have seen your planning diary, they have a better chance of understanding your self-management strategies, and then work alongside you to help your plans to succeed.

The unexpected

Life is unpredictable, so however thoroughly you plan you can still be caught out by the unexpected. So it's important not to work right up to the margins of what you can sustain – leave a bit of a cushion so that you can deal with things that come out of the blue. If you are caught out, you will need to compensate by removing some activity from your plan.

“I definitely consider that pacing works and improves my condition. The improvements are easily undone again, by challenging things that happen. Emotional drains and shocks knock me backwards again the most. I am trying to learn the most skillful ways of navigating these, including how best to recover. There is plenty to learn from these situations.”

If your symptoms suddenly get worse, don't push on with your plan regardless. Listen to your body and prioritise rest and relaxation.

Sample daily planner for mild/moderate M.E.

Start time (approx.)	Physical activity (mostly on feet)	Mental activity (mostly sitting)	Rest and relaxation (sitting or lying)
8:00 AM			wake up, rest
8:30 AM	Get up, have a wash		
8:45 AM	Make cup of tea		
8:50 AM		Drink tea, watch TV	
9:20 AM	Make breakfast		
9:30 AM		Eat breakfast, TV	
9:50 AM			Meditation practice
10:10 AM	Wash up, tidy kitchen		
10:30 AM		Make phone call	
10:40 AM		Check email	
11:00 AM			Rest lying down
11:30 AM	Weed the garden		
11:40 AM			Sit in the garden
11:50 AM	Plant out new plants		
12:00 AM			Sit in the garden
12:30 AM	Prepare lunch		
12:40 AM		Eat lunch	
1:00 PM		Read	
1:20 PM			Rest lying down
2:30 PM	Make drink		
2:40 PM		Drink, read	

Start time (approx.)	Physical activity (mostly on feet)	Mental activity (mostly sitting)	Rest and relaxation (sitting or lying)
3:00 PM	10 minute walk		
3:10 PM			Rest lying down
3:50 PM	Prepare for shower		
4:00 PM			Short rest sitting
4:15 PM	Shower then dry hair		
4:45 PM			Relaxation practice
5:15 PM	Prepare vegetables		
5:30 PM		Watch TV	
6:00 PM	Cook simple meal		
6:30 PM		Eat meal	
6:50 PM			Short rest sitting
7:00 PM	Wash up, tidy kitchen		
7:20 PM		Friend visits	
8:30 PM		Watch TV with friend	
9:00 PM			Rest lying down
9:30 PM	Make hot drink		
9:40 PM		Drink, listen to music	
10:00 PM	Prepare for bed		
10:20 PM			Relaxation in bed

Sample weekly planner

	MON	TUE	WED	THU	FRI	SAT	SUN
MORNING	Sam visits (helps with laundry)	GP appointment	Quiet morning	Remedial Yoga class	Quiet morning	Family visit	Flexible time
AFTERNOON	Listen to afternoon play	Quiet afternoon	Spend time in garden	Quiet afternoon	Go to supermarket with Jo	Quiet afternoon	Spend time in garden
EVENING	Quiet evening (prepare for tomorrow)	Jo visits (bringing a meal with her)	TV evening	Mum visits (bringing a meal with her)	Quiet evening	TV evening	Reading

Summary Daily and weekly planning

- Simple planning can be a powerful skill, making sure there is a balance in your day or week, and helping you offload information from your brain into the plan.
- You can share your plan with others, to help them understand how you need to manage your activities in a sustainable way.
- Plans don't always fall into place as you might hope, so flexibility is key.
- There are many different ways to plan, including paper or electronic diaries and calendars. We have shared simple daily and weekly planners here.

Pacing versus real life

“Pacing assisted in the really bad flare-ups but is not realistic for me, trying to balance the demands of raising young children and trying to work. This often leads to using days off to recover, rather than enjoy/socialise, therefore mostly leading a life which has very little me time, time with friends, relaxing activities etc. I feel my quality of life is affected greatly by this.”

The step-by-step guide laid out in this booklet isn't easy, especially when you have other responsibilities and commitments you cannot easily adjust or take a break from.

Below are practical suggestions from people with M.E. for pacing at home, at work, and when looking after others. We very often hear that people feel guilty for missing out on activities as part of their pacing plan, or that they feel left out and left behind. It's really important to have support in place to cope with the emotional impact, not just of M.E., but also of the management strategy you use to cope with it.

Pacing at home

“My standards for housework have dropped. Mostly family and close friends visit and they know you are ill, so don't worry. If you cannot do it, let it go. I do everything I can sitting down. I cook and prepare meals sitting down on a bar seat. If I want to bake or make anything slightly complicated, I collect the ingredients together the day before. I shower sitting. Iron the minimum, always sitting. Supermarket shopping online. Cook in advance and freeze if someone is visiting. Don't try to shower on the same day as going out; a freshen-up works fine. When out, after an hour, go have a lie down in the car for 20 minutes. Use a mobility scooter. Mostly be kind to yourself, and have as much fun as you can.”

Some people with M.E. are entitled to help at home, including meals-on-wheels or personal care such as help with getting up, washing, dressing, feeding or going to the toilet.

If your M.E. has left you unable to do these things easily for yourself, the first thing you should do is contact your local social services department to ask for an assessment of your care and support needs.

Some local authorities may screen people before agreeing to an assessment so it is worth thinking about your care needs before you make the call.

Practical tips from people with M.E.

- Plan a weekly menu and shop online for home delivery. Thinking what to cook when you come home from work can be a cognitive load too far. While it takes some time on the weekend to think of a week's meals, it makes the weekday evenings much easier to cope with. Create a list of meals you cook regularly to choose from to make creating the plan easier. Supermarket websites make it easy to create shopping lists which you can store for later use. These make it easy to order regular staples you buy every week.
- If you are using weekly activity scheduling (see p 36) as part of pacing, this makes it easier to see in advance the evenings you are likely to be most fatigued. You can then schedule a quick and easy meal like a stir fry or something from the freezer.
- Easy breakfasts include: oats soaked overnight in yogurt with some berries added in the morning; hard boiled eggs which you can cook on the weekends; instant porridge; and chia pots. Try to avoid sugary breakfast cereals which may not give you enough energy to keep you going until lunch.
- When it comes to cooking, standing up can be too exhausting so consider using a perching stool. Consider breaking up the preparation into short manageable chunks with rests in between – see stop rules on p 19.
- Inexpensive devices can take the effort out of some meals. For example, soup makers cut up and cook the ingredients all in one bowl. You could use this to prepare the bases for other meals and then continue cooking on the stove. Slow cookers also take a lot of effort out of cooking.
- Make the freezer your friend. Cook in large quantities and freeze portions for later use. Good examples include curries, pasta sauces such as bolognese, casseroles, soups and chilli.
- Ask friends and families to cook extra portions for you when they are cooking similar meals.

Pacing at work

Nine out of ten respondents to our Big Survey had stopped or reduced work as a result of M.E. For those in work, employers have a legal duty under the Equality Act 2010 to make reasonable adjustments to the workplace or working practices so that employees with M.E. are not placed at a disadvantage. These can apply to:

- where, when and how much you work, such as providing a quiet area for rest breaks, adjusting hours to avoid rush-hour travel, working flexible hours and working from home
- your workplace environment, such as allocated parking and improving the lighting or location within your workplace
- support or equipment to enable you to carry out your job, such as an ergonomic chair and assistive technology, eg. speech recognition software.
- your duties, how you carry them out and how your colleagues work with you. You and your employer may be used to doing things in certain ways just because they have always been so. Could you work together to find alternative, more effective ways of working?

“Make sure your desk or workspace is right for you and not causing you additional pain. You might need additional back and neck support or arm rests. Also ensure the lighting is not causing you additional problems. You might also need a heater or fan if you are experiencing problems with temperature regulation.”

Keeping an activity diary (see p 16) at work can help you better understand what you are spending your energy on, and what reasonable adjustments might be most helpful.

Advice and financial help may be available. You or your employer may wish to seek further advice from relevant experts in workplace health and reasonable adjustments, such as occupational health or Access to Work (see p 59).

Practical tips from people with M.E.

- Don't be afraid to use assistance for non-visible disabilities where they are available when commuting. For instance, Transport for London offers a “Please offer me a seat” badge.
- Learn to say no – keep your workload manageable and don't be tempted to take on more work than you can realistically complete.

- Police your own boundaries. Employers and colleagues might be tempted to assume that you can still work at full capacity and will ask you to work beyond what you can manage. Be firm the first time this happens so they learn that you are serious.
- Make it clear that you can't be interrupted when working – cognitive disturbances make concentration difficult so you might find being constantly interrupted difficult to manage. Take lunchtime breaks outside your place of work – take a short walk (if possible); sit in a quiet place like a church; sign up for lunchtime meditation classes close to your work.
- Consider wearing noise-cancelling headphones and setting times throughout the day when you are available to speak to others.
- You could ask for a space to be set aside at work for you to rest, take a pillow, ear plugs and/or eye mask, and/or listen to a guided mediation.
- There is obviously a large range of sandwiches, soups and salads available from high street stores, staff canteens and supermarkets. However, if you find tackling the lunchtime rush too overwhelming, you might find it easier to bring simple lunches from home which don't require too much energy.
 - Sliced vegetables (eg. carrots, celery, baby tomatoes, cucumber, sugar snap peas) with a pot of houmous. Supermarkets sell pre-cut vegetables in small bags which makes this easy. And/or you could add precooked chicken, sliced meat or fish.
 - Soups are also easy – you can preheat at home and take to work in a thermos if you don't have access to a microwave.
 - Leftovers from evening meals make easy lunches.

Pacing when looking after others

Caring responsibilities, either for children or elderly family members, who may or may not live in your home, make pacing extremely challenging.

Local authorities have a duty to provide an assessment of needs and provide support to carers, defined by UK charity Carers Trust (see p 59) as "anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support."

If you are a carer, you can request an assessment by contacting your local council's social services department. You could also ask your GP to make a referral.

Practical tips from people with M.E.

- Employ help if at all possible; the cost will pay untold dividends whether you can afford an hour a day or several days a week.
- When times are busy you need to find five or 10 minutes to sit quietly. Every minute counts.
- Delegating is essential; the whole family works as a team. My children could cook from 12 years old, as pre-M.E., we used to cook together. Being more relaxed about the housework helps. Essential hygiene stuff is done but everything else can be done in time. With M.E. it's hard to be a perfectionist, so I let that go. Good enough is enough.
- I struggled with balancing my children and my symptoms. Possibly I erred towards the former as, over a decade on, I am mostly bedbound, but have three adults who are doing well in the world and who make me incredibly proud. The one upside was that they all learned basic self-sufficiency. I would make the same choices over again.
- With children some advance planning helps where possible. For example, have a few objects/toys for them to either retrieve or find while you get yourself sorted. On your return, they have to put them back or hide them again, depending on age, so you get a breather.
- We have three small people and I'm awful at pacing because I'm one of their carers, whilst needing a certain amount of care myself. Lesson number one: scoop up guilt for cancelling/missing/flopping on sofa, it gets you nowhere. I'm still learning that one myself.
- It is really difficult. With my toddler I have found I must remember to factor in fatigue caused by emotional things, too. If he has a tantrum or is very noisy, that impacts me. I've tried getting more toys that allow me to sit and play with him gently: sticker books, jigsaws etc. We rely on family for a lot of help. I've also hired a babysitter to play with him while I sleep.
- When my children were younger we would make the most of my rest times by using them as a chance to watch a movie or having a "pamper party." That way I was using as little energy as possible but still spending time with them. It also helps to explain why you need to rest eg. I'm charging my batteries, as it will help them understand your condition more.

Other barriers to pacing

It can be challenging to balance the strategy you are developing for pacing with the needs of other physical and/or mental health conditions. Experiencing anxiety, depression or other mental health issues is not unusual for those who live with a long-term condition, given the demands made on your coping skills.

Advice about managing mental health conditions often includes eating well – which can be challenging with M.E. – and exercising, which is obviously problematic. It's important that any health professional giving you advice understands the impact of each of the conditions you are living with.

The NICE guideline for multimorbidity – ie. living with more than one condition – says that care should involve a “personalised assessment and the development of an individualised management plan. The aim is to improve quality of life by reducing treatment burden, adverse events, and unplanned or uncoordinated care. The approach takes account of a person's individual needs, preferences for treatments, health priorities and lifestyle.”

Summary Pacing versus real life

- Pacing isn't easy, especially when you have other responsibilities. It's really important to have support in place to cope with the emotional impact, not just of M.E., but also of the strategy you use to manage symptoms.
- Planning, preparation, inexpensive devices and asking for help can make cooking and housework easier.
- Employers have a legal duty under the Equality Act 2010 to make reasonable adjustments so that employees with M.E. are not placed at a disadvantage. These can apply to where, when and how much you work; your workplace environment; your duties, how you carry them out and how your colleagues work with you; and support or equipment.
- Local authorities have a duty to provide an assessment of needs and provide support to carers. You can request an assessment by contacting your local council's social services department, or ask your GP.
- Experiencing anxiety, depression or other mental health issues is common for people living with a long-term condition, like M.E. It's important that any health professional giving you advice understands the impact of each of the condition you are living with.

Exploring increases: “pacing up”

We know that some clinicians consider pacing to be about carefully managing activity and other stressors to avoid post-exertional malaise. Others would consider it a way to first stabilise then gradually build up increases in activity, sometimes called pacing up.

For example, a 2019 survey of more than 90 NHS professionals working in pain/fatigue management (not necessarily specialist M.E. services) found that 87% considered “gradually increasing activities” to be part of pacing.¹

These gradual increases, or “pacing up” following the establishment of a sustainable baseline, might incorrectly be referred to as graded exercise therapy (GET). GET is built on a deconditioning model but pacing up is pragmatic; it doesn’t depend on a theory. Pacing up can apply to all sorts of activities, not just physical, so it’s not correct to call it GET.

Pacing up, or not, is your choice. Action for M.E.’s 2019 Big Survey of more than 4,000 people with M.E. found that only around one in five respondents successfully increased activity, with one in three saying that they tried gradually to do this, but found it unmanageable.

“I have found careful pacing beneficial, with experience of my own illness, and with careful gradual increases in activity, taking into account my illness state at every point in time, and not overriding symptom feedback outside what I am confident will recover well within the daily cycle. I find it is best for any aggravation of symptoms (post-exertional malaise) to be minimal.”

People who are experiencing a phase of improved symptoms and who have found a sustainable baseline might find that they are able to very gradually increase their activity. They could do this by adding one small extra task or by lengthening an existing activity, even by as little as one minute.

Other people try increases when they have been on a plateau for some time: they want to see if they can add another activity, or increase the amount of activity. They are using an increase to learn more about what they can manage, and they accept that not every increase will be successful. Pacing up is not necessarily a route to recovery but instead a way to establish a new baseline.

“I used an app, MECFS Diary, at the beginning, which was very useful. Pacing has allowed me to increase my activity levels, but up to a certain point. When I tried going beyond, I got worse.”

Gradual increases

Increases should be very gradual, initiated and controlled by you. It is essential to establish your sustainable baseline first – see p 14.

If you decide to extend an activity, do this by up to 10% and no more. For example, if you can currently manage walking for 10 minutes, try increasing it to 11 minutes. Increasing from five to 10 minutes would not be advisable as this is a 100% increase!

Be sure to wait a good period of time to be certain that the activity increase hasn't caused a worsening of your symptoms. Over time, repeat this process so that your activity periods are gradually lengthened and your rest periods shortened.

Whichever approach you choose, do not be too ambitious and only increase activities little by little. At each stage, be sure that you have established a new, secure and sustainable baseline before any further increase. You might not achieve a goal you originally set out, but any improvement will be beneficial to your health and quality of life.

If you are severely affected, an example might be the gradual introduction of daylight to the home environment. A realistic way to ensure the gradual introduction of daylight could be to start the process when it's dark outside, with the moon as the only light source. You could then build up slowly to dusk exposure.

"I use pacing to increase my 'activity' by which I mean standing up and moving around, not 'exercise.' Pacing is really hard, as no day or activity is the same, but I'm getting much better at listening to my body's early warning signs (that took ages to learn!). I used to walk really fast and charge about. Now I try to minimise walking, eg. by parking the car as near to the exit as possible, and walking slowly. It's hard to take breaks with a toddler though, even if I have clocked that I need one. Without having learned pacing I would be bedridden a lot of the time, I think. It's been a gift of a skill to learn."

Action for M.E.'s 2019 Big Survey of more than 4,000 people with M.E. found that less than one in ten (9%) severely affected respondents said they used pacing to increase their activity.

Don't push too hard

No self-management approach should involve pushing you harder than you feel able or willing to manage, and you should always raise any concerns you have with the professional supporting you. You could also speak to their manager or practice leader if you are concerned about their response.

You will need to learn to distinguish between the normal effects of increasing activities and the negative effects of having over-done it. For example, you are likely to notice a temporary increase in stiffness or fatigue when gradually increasing your physical activity levels. This is normal and your body will need a few days to adjust and adapt. Stretching after activity can help to reduce muscle soreness, though please remember that stretching is, in itself, an activity.

Increased levels of fatigue and other symptoms continuing for a week or longer, especially if they increase as the days go by, probably indicate that you have increased the activity too quickly, or by too much.

The signals that your body gives out can be quite subtle and are not necessarily physical, such as pain or fatigue. Feeling irritated, stressed or starting to lose concentration can equally be an indication that you are doing too much. Some people benefit from learning to recognise these early-warning signs – but for many others, these signals are post-exertional. In other words, they only happen after they have already overdone things.

You are not your illness

Some people with M.E. will, from time to time, decide consciously to overdo it in order to achieve important activities, but they will then pace their activity to make sure they bounce back more quickly. This is not pacing, but pacing can help realistically anticipate what the impact of doing this sort of thing might be, so people can make an informed choice. You're not living in a lab environment, and you know what you can handle. Being compassionate to yourself if you slip, or choose to pause your pacing plan, and deciding to live with the impact of this, is important. You are not your illness.

Goal setting

Because everyone's manageable level of activity is different, it's essential that any health professional who may be supporting you to set goals understands M.E., and that many people with M.E. are not able to work towards agreed goals, however carefully and gradually they try.

To help you manage your activities, it can be very helpful to set clear, achievable goals against which you can measure your progress. Thinking about your goals in advance allows you to make sure that the goal is likely to be achievable, rewarding and sustainable.

For example, if concentration and memory problems make reading difficult, you might set yourself a specific reading goal. Choose a book that is enjoyable and not too taxing, then read it in small stages – tackle a paragraph at a time at a time, and build in quality rest periods.

To help with your memory, try writing a short note to remind you of any key points you have read: this helps when you start reading again as you can look at your brief notes before you start. Similarly, you could choose a newspaper or magazine and take the same approach.

If you want to explore building up a physical activity, such as walking to your local shop, consider your current capacity or baseline and then set yourself a realistic and measurable goal. If your baseline is currently set at walking regularly around your home, build in several small stages before the end goal of getting to your local shop. These stages are often called “action plans” (see opposite).

Your first stage may be to walk outside to the garden or to the pavement. You might then have several more stages of increase along the way. Don't be tempted to make big jumps or increases, however well you may be feeling. In the end, a slow and steady approach will help you to reach your goal more successfully.

“Pacing became a negative tool for me as keeping such in-depth records highlighted more of what I couldn't do, rather than celebrating what I could do. It did, however, show me how to manage my energy better, by being honest with myself about realistic goal setting for each day, each week and each month.”

Action planning

Action planning is a frequently used tool in the self-management toolkit. It helps to focus your efforts, and could help you develop plans with greater odds of success. Action planning involves five elements, which add up to a SMART action plan, that you can set out on paper.

- **S for specific** – be clear about your aim, such as reading a specific book
- **M is for measurable** – how much will you aim to read before you stop?
- **A is for achievable** – rate your confidence about managing this from zero to 10. If its below seven, it might be worth rethinking your action plan: can you make it easier in some way, or aim to do less of the activity?
- **R is for rewarding** – this should be something that you'll be pleased to have achieved. It's easy to end up doing things that you feel you "should" or "ought" to do: make sure that it is important to you.
- **T is for time factor:** when do you aim to carry out your action plan? Morning, afternoon or evening? Once a week, twice a week, or every day? You can link this with your planning (see p 33).

It's important to recognise that not every action plan is successful. However, it can still be an important part of learning more about your self-management: if the action plan didn't work, why not? Can anything be done about the reason that it didn't work? You might need to look at managing stumbling blocks on p 50.

Summary Exploring increases: "pacing up"

- Pacing up means stabilising, then gradually building up increases in activity.
- Pacing up, or not, is your choice. No self-management approach should involve pushing you harder than you feel able or willing to manage.
- Action for M.E.'s 2019 Big Survey found that one in five people successfully increased activity; one in three tried gradually to do this, but found it unmanageable. Some people find they are not able to increase their activity, no matter how carefully they try.
- If you decide to extend an activity, do this by up to 10% and no more. Be sure to wait a good period of time to be certain that the activity increase hasn't caused a worsening of your symptoms.
- To help you manage your activities, it can be helpful to set SMART (specific, measurable, achievable, rewarding, time-factored) goals.
- Even if your action plan is not successful, it can still be an important part of learning more about your self-management, and help you problem-solve.

Explaining M.E. and pacing to others

M.E. is a “non-visible” condition, so other people won’t necessarily be able to tell how you are feeling, or what you can manage. It is also a condition that has been poorly understood in the past, so you may need to communicate about your condition to another person who isn’t well educated about M.E. This means that good communication skills are a very important part of self-management.

There are three important areas of communication, and it can help to keep them separate, so that any messages you are trying to communicate are as clear as possible.

What is M.E.?

It can be simpler to offer a quick explanation of what M.E. is, rather than trying to get into the complexity of the research findings. It can help to have a simple, one-line answer that you have prepared, when people ask you what it is. For example, some people say:

- *“It’s like having terrible flu that doesn’t go away.”*
- *“It’s a neurological condition that causes extreme fatigue and pain.”*

Another good alternative is to share a link to Action for M.E.’s website, or social media (see p 59). That way, people who have a real interest can read more, and you can save your energy for other conversations.

What does it feel like to live with M.E.?

Some people also want to know how you feel, and what your symptoms are. However, the symptoms can be difficult for other people to understand, particularly because there can be so many.

The Spoon Theory might be a useful tool here (you may have seen references to spoonies online). Christine Miserandino, an American woman living with lupus, wrote it to convey what it’s like to live with a chronic health condition. You can find it at www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory

It is even harder to explain how you feel to somebody who has never had a significant health problem. To complicate matters further, even if other people are able to understand a little of how you feel, that won’t tell them anything about what you can manage, or how you go about living your life. To do that, you need to talk to them about your self-management approach.

How do you manage M.E. and its symptoms?

This third kind of conversation can sometimes be more straightforward, as it is practical, and matter-of-fact. For example, if somebody doesn't understand the medical explanation of M.E., or how you are feeling today, they may understand it if you explain how long you might be able to walk for before needing to rest.

A good understanding of baselines and planning can help with this kind of conversation. If you know that your baseline for using a computer is 20 minutes, then you can tell somebody else what you can typically manage. If you know that you need to rest for three half-hour periods of the day, then you can explain your needs if you have a visitor, or if you go away somewhere. Other people are more likely to understand if you are able to communicate clearly.

You may need to be more assertive. Assertiveness is a clear style of communication, which expresses your own needs, while acknowledging the needs of others. It is a midway between being passive (just giving in, for an easy life) and being aggressive (being pushy, to get your own way at all costs). There are many books and online resources about assertiveness.

Writing in Action for M.E.'s membership magazine, *InterAction*, counselling psychologist Joan Crawford says: *"Being assertive is about being able to communicate how we are feeling confidently and non-aggressively, and reasserting the boundaries with those around us – boundaries which may have been violated by someone else's disbelief or misunderstanding. It may well be necessary to express ourselves assertively because not doing so may lead to increased anxiety due to our own needs not being met."*

Summary Explaining M.E. and pacing to others

- Other people are unlikely to be able to tell how you are feeling, or what you can manage, so good communication skills are important.
- It can be simpler to offer a quick explanation of what M.E. is, rather than trying to get into the complexity of the research findings.
- Talking to people about your self-management approach, including your baseline and planning, can be easier than explaining how you feel and what your symptoms are.
- You may need to develop assertiveness skills, to help you say "no" more easily if you are being asked to do things which are above your sustainable baseline.

Managing stumbling blocks

Now that you understand how self-management works, you can see that it might well be challenging to put into practice. There is likely to be pressure from everyday life, and from yourself or others, to deviate from your plans. If your lifestyle makes self-management extra difficult, you will need to take some time to stand back and reflect. Think about whether everything you are attempting to do is essential.

Taking on too much

It can be hard to let go of things that might be preventing you from self-managing effectively. There are likely to be demands and pressures from other people and you may also be battling with your own expectations. If you have standards that are getting in the way of self-managing, you will need to adapt and change them.

We know that making the necessary changes in your life in order to achieve successful pacing can be very difficult to do. You may have to let go of the habits of a lifetime, and ways of thinking, that are second nature to you. This requires time and patience and you may well benefit from working with a health professional experienced in supporting people with M.E. to help you make changes.

It's all too easy to push yourself to finish a task you have started, or to feel bad about "letting somebody down." It's important to learn to let go and to make fewer demands on yourself. It just isn't possible to do all the things you did before you were ill, and this is not your fault.

"Be compassionate to yourself and acknowledge that what you are doing is very difficult, possibly the most difficult thing you have ever sought to achieve in life. Many people with M.E. may have been used to just working harder when overcoming obstacles in their work or life. Working harder is the very worst thing you can do when it comes to pacing."

You may have people in your life who drain you emotionally, or you may be the sort of person who is always available in a crisis. Do you always put other people first, regardless of how you are feeling? Remember that emotions are far harder to account for when learning to self-manage M.E. If you are struggling with delegating, saying "no" or dealing with other people's reactions and attitudes, some counselling may be useful.

Also remember to include self-nurturing activities that bring you pleasure. Just because you have a chronic illness does not mean that you don't deserve to treat yourself well and take pleasure in life. We hear from many people with M.E. who feel a sense of guilt if they are not working, but are seen by their family and friends to be taking part in enjoyable activities. You will know that you may pay a price for having done so, but that can be hard to communicate (see p 48).

“You deserve to include some fun in your life and in the long run this is more likely to help you to achieve better health and wellbeing. You might find the work of Dr Kristen Neff on self compassion helpful.”

Setbacks

M.E. is a fluctuating illness: it's likely that you will tend to experience good and bad patches. Setbacks or relapses can happen for all sorts of reasons but often they are caused by trying to do too much.

“Keeping a daily M.E. diary to record everything related to my health has been invaluable. I've done this since 2007, it only takes five minutes at the end of the day, but it's a good resource when relapses occur. I also record medication, GP and hospital visits, which helps with poor memory and brain fog.”

If you think you may be heading for a setback, take some time to review why this is happening. It's often sensible to drop back to a lower level of activity while you recover, before building up again. That said, some people learn that it's not a good idea to cut activity out altogether because too much rest and too little activity can make the setback worse, rather than improve matters.

Pete Gladwell, Clinical Specialist Physiotherapist, Bristol NHS M.E./CFS Service, says: “We don't know why this is the case – it's clear it's not deconditioning – but it is regularly reported by patients in our clinic. It seems to increase lethargy, brain fog, pain and stiffness, and risks low mood. Reduced exposure to natural daylight and contact with nature can also have a negative impact.”

This is all about self-management: learning what is the most useful approach for you, at the present time.

Dropping to a lower activity level can feel demoralising, but the good news is that people usually find it's easier to build up through the levels back to their previous baseline if they have learnt how to make “baby steps” when they were learning pacing.

If you are having regular setbacks/relapses it is possible that you are attempting to do too much when you are going through a good phase, then suffering payback.

Think about the following:

- Did I set my baseline correctly?
- Have I been pushing myself too hard?
- Have I taken into account all activities – emotional, physical and mental?
- Am I resting properly?
- Am I getting enough good quality sleep?

If you are finding it difficult to return to normal activity levels after a setback, it's advisable to talk to the health professionals involved in your care. Learn from your experiences. Develop a personal strategy for preventing the same thing from happening again.

"I pace in my head daily, mentally working out broadly what social things I can say yes to given my other commitments etc. But when I've had bad relapses I've used it much more specifically, keeping detailed records day to day of tiredness, brain fog, pain, sleep and activities etc."

Summary Managing stumbling blocks

- Making the necessary changes to achieve successful pacing can be difficult. You need time and patience to let go of your previous routine, habits, and ways of thinking.
- It just isn't possible to do all the things you did before you were ill, and this is not your fault.
- If you are struggling with delegating or dealing with other people's attitudes, some counselling may be useful.
- Remember to include self-nurturing activities that bring you pleasure. Having a chronic illness does not mean you don't deserve to treat yourself well.
- M.E. is a fluctuating illness. Setbacks or relapses can happen for all sorts of reasons but often they are caused by trying to do too much.
- If you think you may be heading for a setback, take some time to review why this is happening. If you are having them regularly, you may be attempting to do too much when you are going through a good phase.
- Try and learn from your experiences, and develop a personal strategy for preventing the same thing from happening again.

Common questions

How do I balance effective pacing with other people's demands on my time?

First of all, recognise that being ill will change your role and impact on relationships with those around you. Give yourself permission to be ill and let go of the things that are currently too physically, mentally or emotionally exhausting for you to carry out. This is essential to enable your condition to stabilise. This should help you move forward and, hopefully, very gradually restart some of the activities you would like to be doing.

It may seem impossible to let go of activities where other people depend on you but this can be a critical stage in the self-management process. It will be easier if those around you have an understanding of what you are trying to do, so you could suggest they take a look at this booklet.

How do I plan for a big event or occasion?

Decide what is realistic for you and learn to manage situations differently, using the approach set out in this booklet. If you want to attend a social event, such as a family get-together or a wedding, you will need to decide what you can realistically manage. Once you have done this you can start to plan.

For example, if you have decided that you can manage to participate for some of the event, as long as you build in rest periods, you can plan for these. If the travelling is a problem, consider making the journey the day before, or set out early so that you can have a rest period before the event. Let people know your limits and explain your needs. If you need a quiet space to rest, let them know. Most people will want to be accommodating where possible.

“Pacing has been the single best thing I have found. Best bits are planning ahead, including learning to say no or postpone things in advance, and feeling empowered to explain reasons for this to others; changing my mindset so I do not feel task-oriented (ie. I can break task up into smaller steps, and not have to finish it); and monitoring what I have done against symptoms, so over time have worked out what I am capable of. Negatives are that I put too much burden/responsibility on myself, struggling with balance of degree of symptoms to put up with against maximising how much I get done.”

Why do I often feel worse when I increase my activities?

If you decide to increase your activities – gradually, and only if you feel you are able to (see p 43) – you may find that you experience a small increase in your symptoms, such as fatigue or muscle stiffness. This is a common experience and your body may well adjust to the new level of activity in a few days.

However, if these symptoms don't start to feel easier then it is likely that this attempt to increase isn't working this time. Part of self-management is learning when a small increase in symptoms is an acceptable response during an increase, or if the increase isn't manageable this time around. It is important to be gentle when exploring the edges of an ability, and to be prepared to step back again if needed.

If you attempt to increase your activities too quickly, or from an unsuitable or unstable baseline, you will run into problems. Take time to review your situation.

- Have you set an appropriate baseline?
- Have you stabilised at a level long enough before attempting to increase activities?
- Are you attempting too much at a time? Remember that increases work best if they are small – no more than 10%.

Give yourself time to adjust to the level and make sure that you build in plenty of rest and relaxation periods. If you have difficulties with sleeping, pain, low mood or anxiety, address these problems before they take over and get in the way of self-management.

If I increase my activities, I may overdo things and relapse. How can I deal with this?

Feeling concerned and worried about increasing activity levels is understandable, particularly if you have tried this before without success.

Increasing activity really isn't for everyone, and it may be that you only use pacing to stay within the limits of your available energy (see p 14). For some who feel willing and able to try an increase, they run into difficulties usually because they haven't found a sustainable baseline (see p 19) and have attempted to do too much too quickly (see p 44).

Don't be too hard on yourself if self-management doesn't always go to plan. You are bound to make mistakes and the important thing is to try and learn from your experiences so that you have more chance of success in the future.

My doctor thinks I should get more exercise. What do you think?

For most people, exercise means physical exertion: pushing the body to the maximum with activities like running and cycling, in order to build fitness. In this context, the 2007 NICE guideline for M.E. (a reviewed and updated edition is expected December 2020) warns that “advice to undertake unsupervised, or unstructured, vigorous exercise (such as simply ‘go to the gym’ or ‘exercise more’)” should not be given, because this will very likely worsen symptoms.

For some health professionals, the definition of exercise can be quite different, i.e. any movement which is performed with the aim of improving your health. Using this definition, many gentle movements can count as exercise. Even turning over in bed, sitting up in bed or sitting out in a chair can be thought of as exercise if they are done to maintain and improve a person’s health.

So, if are confident your doctor has a good understanding of your baseline and current activity levels, and how M.E. and affects you, and if you understand why they want you to increase your activity, it may be worth considering, if it feels right to you to do so.

A gentle stretching programme can be worth exploring for some, because it is low-energy, relaxing to do and can help with suppleness, balance and coordination. These forms of movement can help some people to maintain the equilibrium between recuperative rest and movement on a quieter day. Other people might start with a few minutes of yoga, pilates, walking or Tai Chi, depending on how severely they are affected and where their interests lie. It can be helpful to undertake these activities under the instruction of a physiotherapist who really understands the impact of M.E. on your body

Someone living with M.E. who has learnt about self-management will understand their baseline level of physical activity (see p 14). If they feel in control of their self-management, then they will be able to work out for themselves what their goals around physical activity are, and this booklet can help people to take self-management decisions about this.

The critical thing is to treat ‘exercise’ or ‘movement for health’ like any other activity (see p 8). Try a tiny amount slowly until you find a sustainable baseline and increase the activity by no more than 10%, until a new sustainable baseline is reached. Movement for health is likely to be more helpful if you think about your needs in terms of the four S’s – strength, stamina, suppleness and stability. Focusing on improving even one of these can help.

Why does trying to relax make me feel anxious?

Taking time to relax may sound easy but for most people it's a skill they need to learn and it can be quite a challenge! You can learn relaxation techniques from classes (gentle yoga and meditation), online, from self-help books, or from relaxation and self-hypnosis apps and CDs.

If you are finding that worries or anxieties keep intruding into your relaxation and rest periods, try setting aside a few minutes each day to write down your concerns. You can then add ideas on how to resolve them. If you feel that anxiety is taking over, it's important to seek out further professional help – talk to your GP.

I've had a relapse: how do I restart my pacing?

It depends on the nature of the relapse. If you can attribute the relapse to doing too much too quickly, it's important to learn from the experience and drop back to a level that is more realistic, or review your sustainable baseline (see p 15).

If your pacing programme has been going well and you feel that your relapse is due to another illness, you may be able to build up to where you left off. Be gentle with yourself, and listen to what your body is telling you.

If it is due to the impact of an ongoing issue, such as the effect of a bereavement, you may need to adjust your schedule to make space for this inevitable and necessary drain on emotional energy.

It's normal to feel some muscle weakness and/or stiffness after a setback or relapse. Whatever the cause of your relapse – and sometimes there may be no obvious cause – aim for a gradual, careful return to your previous activity.

“Here is what I have learned along my 12-year journey. You should only do around half of what you think you can manage in any task. If you do get carried away and go too far (which we all do) it's OK to lie down and rest for a while. Rest helps. Don't worry about what other people think of you: you are ill, they are not. They are going to think what they like, no matter how hard you work to try and please them. Plan, if you can. It gives you piece of mind and some control. Get gadgets for everything. Electric toothbrush, remote controlled plug sockets, shower seat, timer for kitchen, video doorbell, caller protect and ID. They help a lot. Remember you are not alone. There are 250,000 people with M.E in the UK. We are all there with you.”

Glossary

Activity

Physical, mental and emotional exertion counts as activity, even in small amounts. Examples include walking, reading a book or having a difficult conversation with a friend or family member. For those more severely affected, an activity might be sitting up in bed – see p 10.

Activity analysis

Recording the type and duration of activities in a diary and then analysing the patterns that emerge – see p 16.

Activity diary

An activity diary provides an overview of your week, allowing you to “zoom out” from the detail to look at patterns of activity and rest – see p 16.

Baseline

A baseline is a level of an activity that you can sustain on a regular basis. In other words, you should be able to do the same baseline amount of activity day after day, all things being equal – see p 14.

Energy management

Balancing out activity and rest is sometimes called “energy management,” “activity management” or simply “pacing,” the term used by Action for M.E. – see p 6.

Exercise

For most people, exercise means physical exertion: pushing the body to the maximum with activities like running and cycling, in order to build fitness. For some health professionals, the definition of exercise can be quite different, ie. any movement which is performed with the aim of improving your health. Using this definition, many gentle movements can count as exercise. Even turning over in bed, sitting up in bed or sitting out in a chair can be thought of as exercise if they are done to maintain and improve a person’s health – see p 55.

Pacing

Pacing is a self-management technique, focused on gaining control and improving quality of life. It should not be seen as a treatment but more as a way of coping with the impact of M.E. – see p 6.

Pacing up

Once someone has established a sustainable baseline for an activity, a gradual increase in activity is known as “pacing up”. Alternatively, they may have established a sustainable routine and pacing up can be about adding in a new activity into the routine – see p 43.

Post-exertional malaise

Post-exertional malaise is an increase in symptoms after using even small amounts of energy; this may be delayed by up to a day or two after the increase – see p 5.

Relapse

A setback or relapse is when your symptoms get worse for a period of time – see p 50.

Rest

Short, regular rest periods throughout the day help to give you time to recuperate, and stop you becoming overwhelmed by symptoms. Rest and relaxation are as central to pacing as activity, although the amount of rest that you need will vary at different stages of the illness – see p 25.

Self-management

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 – see p 6.

Setback

See “relapse” above.

Sleep management

Most people with M.E. experience sleep difficulties. Sleep management is an approach that aims to address these – see p 28.

Stop rule

A stop rule describes the ways in which someone knows when to stop an activity. Some types of stop rule are more helpful for pacing as they can offer a way of measuring where your baseline is. Stop rules help you to look at the detail of what you do, and how long you do it for – see p 19.

Reference

- 1 Antcliff, D. et al. (2019) Survey of activity pacing across healthcare professionals informs a new activity pacing framework for chronic pain/fatigue. *Musculoskeletal Care*. 1–11. <https://doi.org/10.1002/msc.1421>

Useful contacts

Action for M.E. offers information and support on its website, in its membership magazine *InterAction*, and via its Information and Support Officers, by phone/email.

Information, support and welfare: 0117 927 9551

Email: questions@actionforme.org.uk

www.actionforme.org.uk

Local M.E. support groups can be a valuable source of support, information and friendship. Some are very small, some cover large areas, usually offering regular meetings and sometimes a newsletter and/or other resources, plus organised events too.

www.actionforme.org.uk/find-local-services

Our friendly peer-support forums for people living with M.E. are free to join.

www.actionforme.org.uk/forum

Access to Work

Government support for disabled people at work

Tel: 0800 121 7479

www.gov.uk/access-to-work

Carers Trust

Look up your local carers centre for support and advice for carers

www.carers.org/search/network-partners

If you have found this resource helpful, please consider making a donation to help us reach more people living with M.E.

Visit www.actionforme.org.uk or call 0117 927 9551 to donate now.

Thank you.

“Pacing is simply the way I work with my body, rather than against it, to give myself as much functioning as my body, mind and emotions allow.”



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