



Pacing

for people with M.E.



Transforming the world of M.E.



Foreword

Myalgic Encephalomyelitis (M.E.) is a chronic fluctuating illness. It is commonly also known as Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is diagnosed as Post Viral Fatigue Syndrome (PVFS).

‘Pacing’ is about balancing activity and rest to help manage M.E. and work towards recovery. Patients and many professionals recognise its value.

Pacing yourself when you’re ill might sound like common sense, but that doesn’t mean that embarking on an effective pacing programme is second nature, or easy. It requires a good understanding of the principles of pacing, combined with commitment to making them work for you.

Pacing can help you to take control of your condition and enable you to become an expert in managing your illness.

This booklet has been produced with the help of health professionals and people with M.E. to give you a step-by-step guide. Whether you are following this at home or you are working with a healthcare professional we hope it will help you to pace successfully.

We are particularly grateful to Peter Gladwell, Clinical Specialist Physiotherapist, Frenchay Hospital, for his guidance on updating this booklet and to our Principal Medical Adviser, Dr Alastair Miller.



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NHS guidelines

In 2007, the National Institute for Health and Care Excellence (NICE) published a clinical guideline on the diagnosis and management of CFS/M.E. for NHS healthcare professionals in England and Wales. It is available via links on our website www.actionforme.org.uk or directly from NICE by visiting www.nice.org.uk or by calling 0845 003 7783.

NICE defined pacing as: “energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion.” It says, “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.

“In practice, the term pacing is used in different ways. One understanding of its meaning is as adaptive pacing therapy, facilitated by healthcare professionals (see p 11). Another understanding is that pacing is a self-management strategy, without intervention from a healthcare professional.”

In Scotland, NHS Scotland has produced a Good Practice Statement for healthcare professionals, Quick Reference Guide for GPs and leaflet for patients, facilitated by Action for M.E. The Guide emphasises that “All treatment should be collaborative and tailored to the needs of the individual patient.” These documents are available on the NHS Scotland website, www.show.scot.nhs.uk and via links on our website, www.actionforme.org.uk Or call us on 0117 927 9551.



What is M.E.?

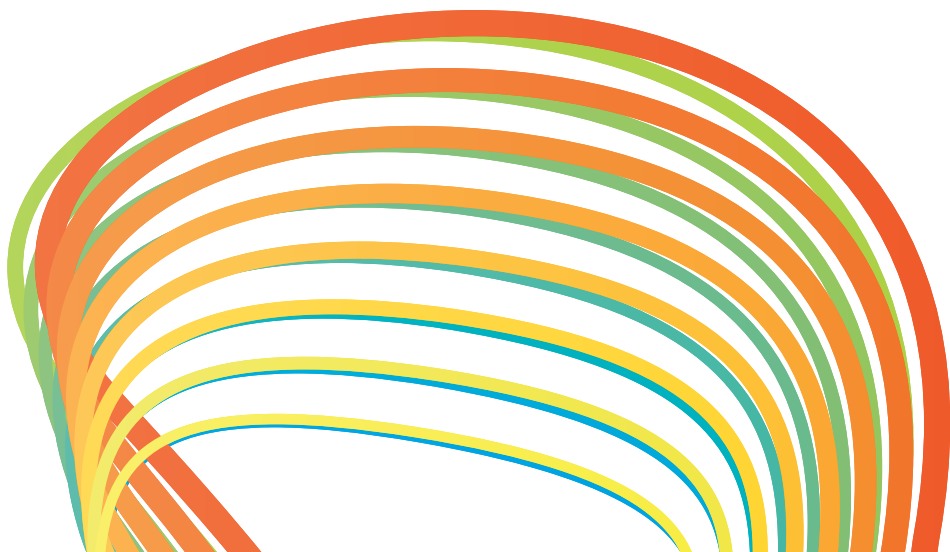
M.E. is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. Many people will seek medical advice at some time because they experience persistent fatigue or pain.

Feeling extremely tired most, or all of the time is one of the main symptoms of M.E. This feels very different from ordinary tiredness. Simple mental or physical tasks can leave you feeling exhausted or struggling to function. You may feel the impact straight away but it can typically take a day or two to kick in. This worsening of symptoms after exertion is a key feature of the way that M.E. affects people and is often referred to as 'payback.'

Additional symptoms may include muscle and/or joint pain, sleep disturbance, 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration.

Treatment of M.E. rests largely on managing the consequences of the illness and maximising the opportunity for improvement. This is where pacing has an important part to play.

To find out more about M.E. and how it affects people read our introductory booklet *All about M.E.* or visit our website at www.actionforme.org.uk



What is pacing?

Pacing is all about balancing activity and rest to bring about improvements in the way you feel. It also offers the person with M.E. an opportunity to control the affects of their illness and, while pacing does take a lot of self-control and patience, in time you should be able to do more than you would otherwise.

The word 'activity' is used in a broad sense, to include mental and emotional activity, as well as the more obvious physical sort. Taking a balanced, steady approach to activity counteracts the common tendency to overdo things. It avoids the inevitable ill effects that follow.

Pacing gives you awareness of your own limitations which enables you positively to plan the way that you use your energy, maximising what you can do with it. Over time, when your condition stabilises, you can very gradually increase your activities to work towards recovery.

"I make a conscious effort to balance work, rest and play within the limitations of my M.E. It is now a lifestyle and requires a huge amount of discipline. The benefits of pacing have had a massive impact on my life."



Recharge your batteries

To understand pacing it can help to think of your available energy as being like a mobile phone battery. If you completely drain the battery you have to wait to recharge it before you can use the phone again. If you use some of the battery and make regular top ups, then your phone will always be ready for use.

Managing your energy through planned periods of activity and rest will mean that you are more likely to be able to do the activities that you want to do.

It can be as important to understand early on what pacing is *not* about. It does not give you a free hand to push through activities, banking on rest and recuperation afterwards. Pacing takes an altogether smoother approach.

If you are prone to trying to cram in as much activity as you can in the morning, and have to sleep during the afternoon or the next day to recover, pacing helps you to break this habit. Similarly it discourages you from gathering energy through the day and then attempting a burst of activity later in the afternoon or evening.

The principles behind pacing are not set in stone and there are different interpretations of how they can be applied. This booklet is based on the clinical practice of some of our key medical advisers and the feedback Action for M.E. has received from people with M.E.

We will look at all the key elements of pacing in more detail later in the booklet.

"I look at my daily activities and break them down into achievable chunks, sometimes resting during a task and completing it later."



Pacing as part of your treatment package

Pacing is one part of the package that can help to manage your M.E. It's important that you and your doctor take other measures to treat and prevent symptoms. Your doctor can prescribe medication and suggest other strategies for managing pain, sleep difficulties and mood problems, for example.

Some NHS services offer people with M.E./CFS a treatment package that draws on the key elements of pacing, cognitive behavioural therapy (CBT) and graded exercise therapy (GET) or graded activity, although the clinicians may not use these terms. They may use a phrase like 'fatigue management' instead.

Depending on where you live, your GP may be able to refer you to a structured NHS programme in your area.

Pacing can also be an ideal self-help strategy if it is seen as one piece of the jigsaw in the management of your illness.

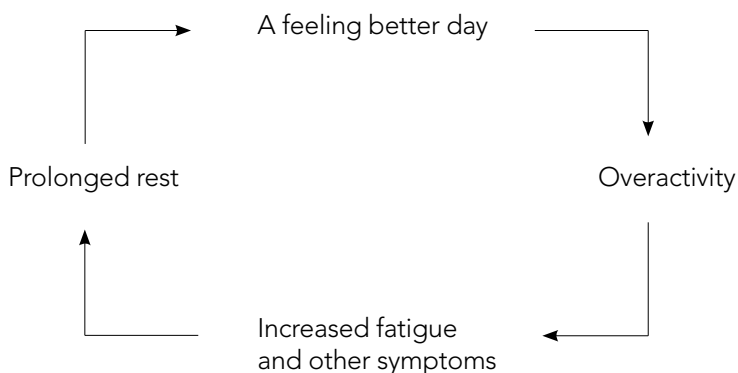


How can pacing help?

So far, pacing may not seem very appealing. You've 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 that it is. The long term benefits include: stability, control, better coping and a focus on recovery.

Stability v the 'boom and bust' cycle

A key frustration for many people with M.E. is the way that the illness fluctuates. Some days you can feel slightly better and at other times you can feel a lot worse, perhaps for no obvious reason. When illness reduces your activity levels it's very easy to try to make up for lost time on better days. But cramming in too much activity on a day when you are feeling better often leads to a setback in your symptoms. It becomes a vicious circle that is damaging to the recovery process and frustrating and unpleasant to live with. This is sometimes called 'boom and bust' or 'activity cycling' and it's easy to fall into this cycle:



Pacing helps you to take a more even path through your illness. You can achieve a stable level of activity that is realistic to your health and that you can sustain without facing harmful consequences.

Control

When you're ill with M.E. it can feel like you're on a roller coaster that's running out of control. Life can be turned upside down. Pacing helps you to take charge of your health, increasing your confidence and reducing the unpredictability.

Understanding and accepting where your limits lie, allows you to plan ahead with more confidence. Keeping your activity levels within sensible limits avoids overly aggravating your symptoms and so prolonging your recovery period. You also know that if the activity is within your limits, you have a realistic chance of achieving the activity as planned.

Better coping

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

A focus on recovery

Pacing is not a cure for M.E. but by balancing activity and rest in a measured way you are supporting the body's natural recovery process, stepping up your rate of recovery. Many people find that they begin to improve once they accept their illness, understand how it works, and follow a realistic and achievable approach to getting better.

"I now plan my days and weeks. Before, when my energy was good, I ended up using it all, thinking I would do things just because I was able – and then suffering with days in bed."

What is the evidence?

A form of pacing known as adaptive pacing therapy was one of four therapies – together with cognitive behaviour therapy (CBT), graded exercise therapy (GET) and standardised medical care – studied by the PACE trial (www.pacetrial.org) in 2011.

- Adaptive pacing therapy (APT) is a version of pacing that has been found to be helpful in chronic pain disorders. It is usually administered by an occupational therapist.
- CBT is a form of psychotherapy, often administered by a psychologist, which may offer help in finding new ways of coping with the illness.
- GET, which is usually administered by a physiotherapist, is about gradually increasing physical activity from a sustainable baseline level.
- Standardised specialist medical care (SSMC) is a standardised version of the treatment to which M.E. patients are referred by their GPs in those areas of the UK where specialists are available to offer advice and medicine and to refer patients on for supplementary therapies such as CBT, GET and pacing therapy.

While the trial found all four approaches to be moderately effective, it found this particular form of pacing (adaptive pacing) to be less effective than CBT and GET at improving function.

All participants in the PACE Trial were assessed at hospital and the trial did not include house/bed bound patients, ie. those more severely affected.

Action for M.E. was surprised that the PACE trial did not indicate that APT was an effective strategy for managing the condition alongside SMC. Surveys by Action for M.E., such as those undertaken in 2001 and 2008 (see overleaf), and other M.E. charities have consistently shown that the majority of people with M.E. find that pacing helps them to manage their illness.

Action for M.E.'s survey results on treatments in 2008 (compared to 2001)

Treatment	Helpful 2008 (2001)	No change 2008 (2001)	Made worse 2008 (2001)
Pacing	82% (89%)	15% (9%)	3% (2%)
CBT	50% (7%)	38% (67%)	12% (26%)
GET	45% (34%)	21% (16%)	34% (50%)
Pain medication	74% (61%)	22% (28%)	4% (11%)
Sleep medication	76% (67%)	17% (17%)	7% (16%)
Medication to help mood	64% (n/a)	22% (n/a)	14% (n/a)
Other medication eg. for nausea)	71% (n/a)	23% (n/a)	6% (n/a)

While our surveys are not scientific studies and we cannot guarantee the results are representative of all people with M.E. (only those who were able and have chosen to participate in a survey), we think they are significant.

Action for M.E.'s policy in promoting pacing is that:

- pacing has been consistently rated as helpful and safe by the thousands of people with M.E. who have participated in our surveys
- adaptive pacing as defined and applied in the PACE trial has now been proven to be safe for all and effective for at least one in three people
- pacing in one form or another remains one of the key approaches used by therapists in specialist NHS M.E./CFS clinics*
- pacing is a valuable self-management technique that is free and accessible to all, including the considerable number of people who do not have access to a specialist NHS clinic.

*A limited form of pacing (setting baseline) is the starting point for graded exercise therapy.

What do the professionals say?

Dr Alastair Miller, Action for M.E.'s medical adviser, says: "I know from long experience that some patients think, 'I can overcome this illness by sheer mental effort or go to the gym and blast it out of my system' while others have a diametrically opposed viewpoint that says, 'the cure for M.E. is rest' and therefore, 'I am going to rest until I get better.'

"The expression boom and bust characterises the excessive energy expenditure that occurs when people feel well, followed by the major flare up of post-exertional malaise that is one of the cardinal features of M.E. It is an attempt to minimise over- or under-activity that forms the basis of pacing as a potential therapeutic approach in M.E."

Physiotherapist's view

Peter Gladwell, Clinical Specialist Physiotherapist, says: "Pacing can mean different things to different people. To me, pacing is about balancing physical and mental activities with rest. Effective pacing avoids the boom and bust trap, and provides more stability, control and sustainable levels of activity.

"Effective pacing can also offer a firm foundation for pacing up, which involves a considered plan to try and nudge up the level of an activity or exercise.

"The PACE trial indicated that pacing up slowly, under specialist supervision, can lead to a modest increase in function, compared to pacing alone. Both of the treatment approaches which did best (CBT and GET) incorporated pacing, as they started out by setting sustainable baselines for activities."

Continued overleaf



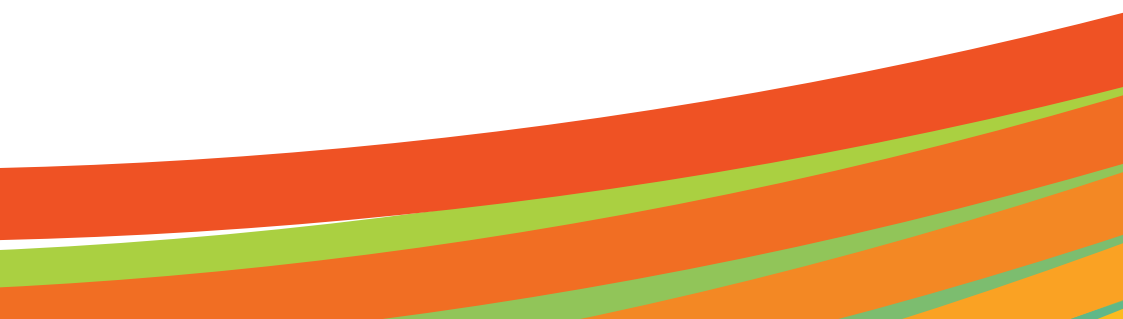
"We need to recognise that pacing up did not lead to increased function for a significant proportion of the research participants. Those who did not improve in terms of function may still find pacing and baseline setting to be helpful strategies to:

- improve control over a challenging illness
- reduce the frequency and severity of setbacks
- provide some ability to plan and problem-solve around limited capacity.

"These benefits of pacing are subtle and qualitative and are not usually measured during a randomised controlled trial.

"It is possible to take a paced approach to exercise, as well as activity. I often meet patients with CFS/M.E. who have worked out for themselves that underdoing exercise (or activity) is more helpful than overdoing exercise (or activity). Underdoing it allows sustainability, and in due course can lead to opportunities to experiment: to nudge (not push) the levels upwards.

"A testing, gentle nudge upwards will not always be successful and this needs to be recognised from the outset."



Who can pace?

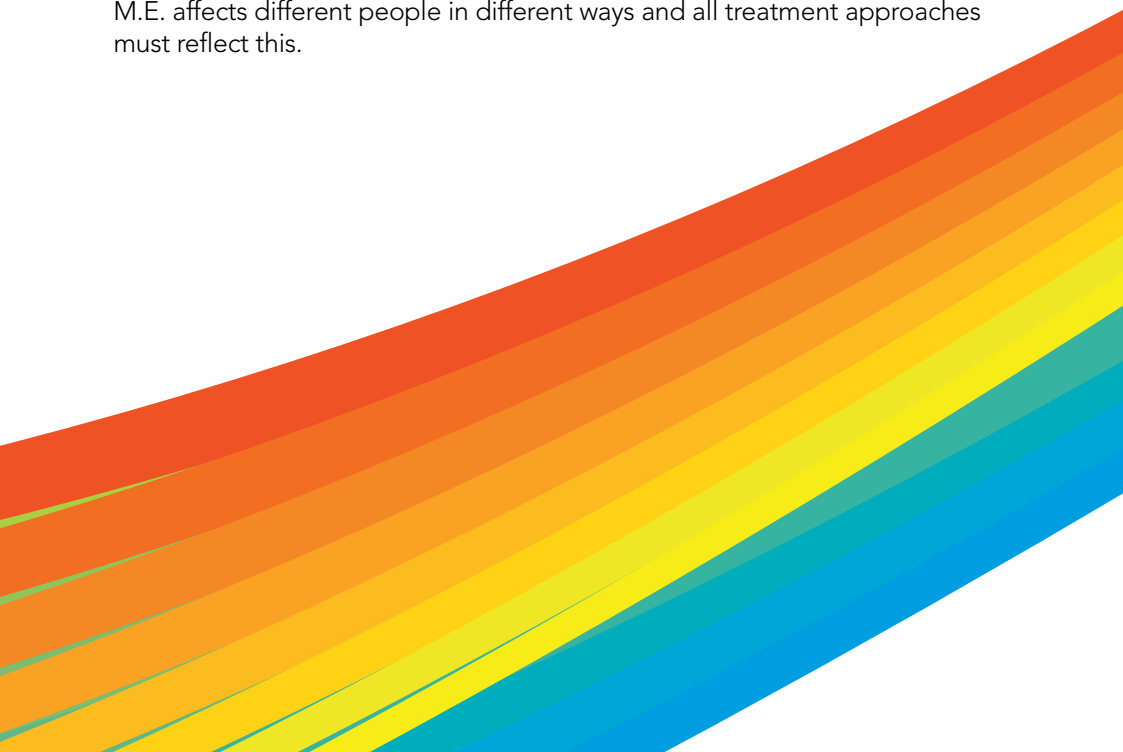
The nature of pacing, as an approach entirely tailored to your individual situation, makes it suitable for most people with M.E. Whether you are newly diagnosed or have been ill for a long time, pacing has something to offer you. The same can be said whether you are mildly affected, or have more severe M.E.

If you are severely affected, an example of pacing might be the *gradual** introduction of daylight or everyday noise 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.

*Words like 'gradual' and 'slowly' are vital in pacing. It is important to establish your baseline (the level at which you can maintain a particular activity on both a good and a bad day) and, once that sustainable baseline has been established, to increase that activity by no more than 10% – see pp 18-27 for details.

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.

M.E. affects different people in different ways and all treatment approaches must reflect this.



Understanding the basics

The four key elements of pacing are: activity, rest and relaxation, establishing a sustainable baseline and increasing your activity as you are able.

This is an introduction to each of the key areas before we look at them again in more depth in the next section, from p 18.

Activity

If you only associate activity with quite physical, active pastimes then 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. So everyday activities might range from getting up or having a shower, to watching television, to worrying or feeling angry. In fact, many people with M.E. find that it is emotional activity that is the most draining, and also the hardest to measure and control.

The types of activities that you will be pacing will depend on how the illness affects you, your circumstances and preferences. For some people it will be the basic tasks of daily living; for others it will be physical exercise or brain activities, or work and family activities.

"For me, activity means listening, talking, laughing, concentrating, making eye contact, watching TV, coping with light and noise, lifting a magazine..."



Rest and relaxation

Short, regular rest periods throughout the day are essential to give you time to recharge your batteries. 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.

For your mind and body to get real benefit you need to be fully relaxed and properly resting 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 healing rest, you may now find you have to be quiet and still, both physically and mentally – but don't feel guilty if you do still find TV relaxing. It is highly individual!

In general, it is better to avoid sleeping during the day, as this may disrupt your night time sleep cycle. However, sometimes, it may be a necessary and useful way of 'recharging the batteries.'

"I build in rest periods after each activity to ensure I don't get drained. I plan a rest between visitors, use the answer phone when I'm too tired to take a call and recognise my limitations."

Establishing sustainable baselines

A baseline is a level of activity that you can sustain on a regular basis. In other words, you must be able to do the same amount of activity whether you are having a good or a bad day. In this way you won't be tempted to do more on a good day, or forced to do less on a bad day. Once a sustainable baseline has been established you can find that your symptoms ease and your energy levels increase.

People usually find that their starting baseline is considerably lower than their current level of activity. Your illness has probably forced you to give up lots of things but you may still be trying to hang on to doing too much.

'Increasing as able'

As natural recovery occurs you should find that you are able to increase your activity. Any increases should be very gradual and the process should be initiated and controlled by you.

"Pacing my activities means that my fatigue and other symptoms don't increase after doing an activity."

Pacing in practice

1. Activity

Now that you've had an introduction to the basics of pacing we can look again at each area in more depth.

One thing at a time

When you are doing a specific task, such as preparing a meal, it's very tempting to try to complete it in one burst of activity. Instead, split the activity into a series of small stages, with periods of rest and relaxation in between. Only attempt one activity at a time.

"I prioritise some energetic activities, giving up others or accepting help to achieve those I have prioritised."

Energy use

We have already explained that in pacing terms, 'activity' incorporates anything that uses energy, whether it is a physical, mental or emotional demand.

As well as being able to class 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 this when you are planning your day. An activity diary may help (see p 35).

Be energy wise

Look at whether there is anything you can do to make an activity easier and less taxing. For example, if you are washing up, can you sit rather than stand? Try soaking dishes first so that they are easier to clean, then leave them to dry on the draining board. In this way you might be able to modify a high-energy activity into a medium-energy activity.

It's particularly important to take this approach with demanding activities that may be taxing in a number of different ways. For example, shopping will include travelling, sitting, walking, carrying, and coping with a busy environment with bright lights and noise.

Don't just do things the way you have always done them. Only stick to old routines if they are manageable. For example, if you get up in the morning and have breakfast, build in a rest before you get dressed. Activities that you may have previously carried out automatically, such as showering, drying your hair etc. now need to be included in your plan.

It can help to think of your available energy as being like money in a bank account. You have a certain amount to spend, and when you exceed that you go into debt. To manage your money wisely you have to budget your spending and aim to stop spending that you can't afford. Economising will help your budget to go further.

Review your priorities

Look at each activity and judge how essential it is. You may need to adjust your usual thinking, as you won't be able to do everything that you did before you became ill. Can you put off the activity to a later date? Can you ask friends or family to help you? Perhaps you can drop it altogether?

This can free up time and energy, allowing you to choose an activity that you really enjoy. When you are ill and your activities are limited, it's very easy for the boring things in life to take over. You may feel guilty if you let them go, or you might think that's where your focus should lie. In fact, it's very important for your well-being that you allow yourself time for enjoyable activities, so make sure you have a balanced mix of those that you have to do, and those that you want to do. Don't feel guilty!

"I break down daily activities into units so that I don't do too many high energy tasks at the same time."

Balance

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 should deliberately alternate or 'switch' between the two.

"I try and plan my day to have quiet periods where I sit down, followed by more active periods."

2. 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. The amount of rest that is 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 frequent but short 'mini-rests,' perhaps lasting as little as five to ten 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' both 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, learn good breathing, tackle tension and unwind.

Make room for relaxation

Set aside a time and place to relax. You don't need to go to bed to relax and in fact it can be best to save your bed for night time sleep. Where you choose will depend on your home 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 really comfortable, either lying down on a mat, or sitting in a chair 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.

Become aware of your breathing

- Place one hand on the top of your chest and the other hand at the bottom of your rib cage/abdominal area. 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.
- 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. Repeat this slowly 10 times. You might need to build up to this number.

It's a good idea to practice breathing like this on a regular basis.

Tackle tension

There are a number of different techniques to help tackle tension so you will need to find out 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 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.

Unwind

Deep relaxation takes practice, and relaxation tapes or CDs can be a good guide. Gentle music can be helpful if you find that your mind starts to race. Some people benefit from practising meditation and yoga. Complementary therapies such as reflexology, aromatherapy and massage can also help. The important thing is to find a way of resting that works for you.

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

3. Finding a sustainable baseline and stabilising activity

To find the amount of activity that you can confidently manage on a day to day basis, you first need to have a good awareness of your current activity patterns and their impact on your symptoms and how you feel. How do your symptoms change and fluctuate in relation to what you have been doing? Remember to consider not just physical activity but also mental and emotional activities.

Keep a diary

It can help to keep a simple diary of activity and rest. A sample of the kind used at Frenchay Hospital, Bristol, can be found on pp 35-37.

A diary will help you to 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 but your diary may help you to identify what triggered your symptoms.

Sometimes, diaries are more helpful to identify peaks and troughs in activity, than symptom responses, because of the delay. Also, of course, symptoms vary for other reasons than activity levels.

You will need to keep your diary until you are able to spot patterns or apply the pacing and planning principles in your head, or build them into your routines. A diary may need to be temporarily restarted during a setback or relapse and can also be helpful when attempting to start a significant activity change, for example returning to work or study, or starting to drive a car again.

Calculate your baseline

There are several ways to work out the length of time you can do a particular activity, and you may need to experiment to find the best one to suit your situation. This can take some time.

You will need to work out a baseline for each different activity you undertake.

Techniques include:

- The 75% rule. If you think that you can carry out an activity for 20 minutes, try reducing your activity time by five minutes to 15 minutes (75% of 20 minutes). The aim would then be to maintain 15-minute blocks of activity interspersed with rest/relaxation periods throughout the day.
- An even simpler way is to set your baseline at about 50% of what you think you can do on an average day.
- Split each activity up with 5-10 minute rest breaks.

When you're setting a baseline, the golden rule is to remember that all activities must be set at a level that can be maintained on both a good and a bad day.

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!

"It took six months to stabilise me. My routine is still very strict. Slowly, very slowly, things have increased. There is a long way to go."

"I'm learning to read the signals of my body that tell me I am tiring. I stop any physical, mental or emotional effort long before I actually feel exhausted. I stay resting even when I feel the energy return."

Stabilising your activity

When you have set your baseline you need to give your body time to settle into the level. How long this takes will vary from person to person but it can take weeks. You will be ready to gradually increase your activities when you feel your body has acclimatised to the level and you can confidently sustain it.

"Know your limits. Set a small target for the day and if you complete it, congratulate yourself. Don't think, 'I've done this so I can do more,' there's always tomorrow. You should be pleased with the smallest of tasks. Keep positive."

"I always arrange slots in a day where I can lie down and relax to classical music. By doing relaxation breathing exercises at the same time I find it revitalises me."

4. 'Increasing as able'

As natural recovery occurs and you have found a sustainable baseline, you should find that you are able to gradually increase your activity. You could do this by adding one small extra task or by lengthening an existing activity. Any increases should be very gradual and the process should be initiated and controlled by you.

If you decide to extend an activity, do this by 10% and no more. For example, if you can currently carry out housework for 10 minutes, try increasing it to 11 minutes. Or you could break this up into two five and a half minute activity periods with a rest/relaxation period in between.

Increasing from 5 to 10 minutes would not be advisable as this is a 100% increase! Remember: only increase by 10%.

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.

Side effects and listening to your body

Learning to pick up on the signals that your body gives you and making sense of them is an important part of pacing. 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 increasing your activity levels. This is normal and your body will need a few days to adjust and adapt. Stretching after exercise can help to reduce muscle soreness.

However if your fatigue and other symptoms continue for a week or longer this might indicate that you have increased the activity too quickly.

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 others, these signs are post-exertional. In other words, they only happen some time after they have already overdone things.

If you find that your 'early warning signs' do not come early enough, your best option may be to rely on your pacing plan.

It can be helpful to think again about the mobile phone analogy, given on p 7. Using up some battery power may actually aggravate some symptoms to some extent, but the key focus is to ensure a quick enough recovery period. Some successful pacers feel that they cannot achieve anything if they don't aggravate their symptoms somewhat, but pace their activity to make sure they 'bounce back' and recharge quickly.

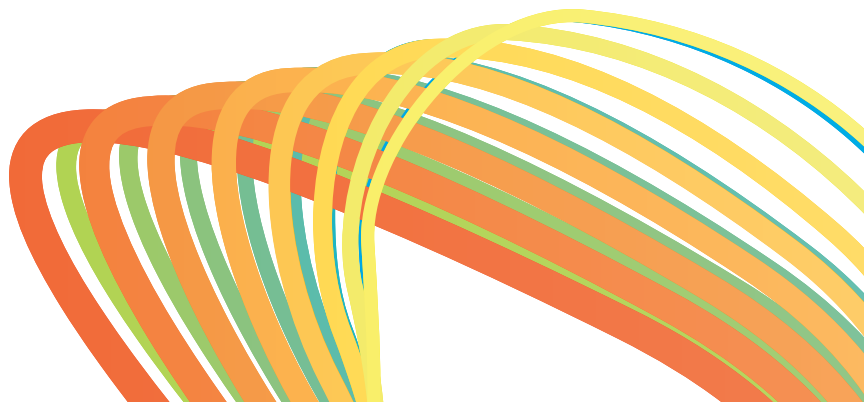
Goal setting

To help you increase your activities, set targets against which you can measure your progress. These goals must be realistic, achievable 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 build in small stages – tackle a couple of pages at a time, or a chapter, and build in quality rest periods. Similarly, you could choose a newspaper or magazine.

If you want to build up a physical activity, such as walking to the shops, 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. Your first stage may be to walk outside to the garden or to the pavement. You might then have several stopping points 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 goals more quickly.



5. Stumbling blocks

Now that you understand how pacing works, you can probably imagine how hard it can be 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 pacing 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 pacing 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 pacing you will need to adapt and change them. 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.

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 pace. If you are struggling with delegating, saying "no" or dealing with other people's reactions and attitudes, counselling or CBT may be useful.

The unexpected

Life is unpredictable, so however thoroughly you might plan your time you can still be caught out by the unexpected.

Because of this it's important not to work right up to the margins of what you can sustain – leave a bit of a gap or cushion so that you can deal with any activities that come out of the blue.

If you are caught out, you will need to compensate by removing a similar activity from your plan.

Setbacks

Because M.E. is a fluctuating illness 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. If you think you may be heading for a setback, take some time to review why this is happening. It's sensible to drop back to a really secure level of activity while you recover, even if this means dropping several levels, or going back to where you started, before building up again. It's not a good idea to cut activity out altogether because too much rest and too little activity can exacerbate the setback rather than improve matters.

Dropping to a lower activity level can be demoralising, but the good news is that people usually find it's easier to build up through the levels after the first time. If you are having regular setbacks/relapses it's likely 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 attempted to increase my activity too quickly?
- Have I been pushing myself too hard?
- Have I taken into account all my activities – emotional as well as physical and mental? Am I resting properly?
- Am I getting enough good quality sleep? Or sleeping too much?
- Are my goals realistic?

If you are finding it difficult to return to normal activity levels after a setback, it's advisable to talk to your doctor or other health professionals involved in your care.

Learn from your experiences. Develop a personal strategy for preventing the same thing from happening again.

Common questions

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

A 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 tiring for you to carry out. This is essential to enable your condition to stabilise. You'll then be able to move forward and 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 is a critical stage in the pacing process and will enable you to work towards recovery. It will be easier if those around you have an understanding of what you are trying to do, so suggest they take a look at this booklet.

Q How do I plan for a big event or occasion, while pacing?

A It is important not to give up all pleasurable social activities when you have M.E. Decide what is realistic for you and learn to manage situations differently. 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.

Q When I increase my activities I often feel worse – why is this?

A When you first start to increase your activities you may find that you experience a small increase in your symptoms, such as fatigue or muscle stiffness. This is normal and your body will adjust in a few days. If however 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. Ask yourself the following questions: Have I set an appropriate baseline? Have I stabilised at a level long enough before attempting to increase my activities? Am I attempting too much at a time? Remember that increases must be very 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 pacing.

Q Why does trying to relax make me feel wound up and anxious?

- A** 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 (yoga and meditation), from self-help books, or from relaxation and self-hypnosis tapes 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.

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

- A** How you resume your pacing plan 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 baseline.

However, if your pacing programme has been going well and you feel that your relapse is due to another illness, such as the flu or a virus, you may be able to pick up from where you left off. 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 weakness and stiffness of the muscles after a setback or relapse. 10% of muscle strength is lost after one week of resting in bed. Whatever the cause of your relapse – and sometimes there may be no obvious cause – you should aim for a gradual and careful return to your previous activity levels.

Q I'm scared to increase my activities as I may overdo things and relapse. How can I deal with this?

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

When people run into difficulties with increasing their activities it is usually because they haven't found a sustainable baseline and have attempted to do too much too quickly. Read this booklet carefully and take on board the advice. Don't be too hard on yourself if pacing 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.

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

- A** It depends what they mean by exercise! Definitions of exercise vary, but most people tend to think of exercise as being the same as physical exertion: pushing the body to the maximum, in order to build fitness.


A more helpful definition is to think about exercise as 'any movement which is performed with the aim of improving your health.' Using this definition, many gentle movements can count as exercise. Even sitting up in bed can be thought of as an exercise.

Sometimes, a gentle stretching programme can be worth exploring, 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, or walking, or Tai Chi, depending on how severely they are affected and where their interests lie.

The critical thing is to treat 'exercise' or 'movement for health' like any other activity: see p 16. 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 Ss' – strength, stamina, suppleness and stability. Focusing on improving even one of these can help.



People with M.E. discuss pacing

Mary Stow, who has M.E., says: “With this illness your body just doesn’t respond to things the way it used to. You need to ‘unlearn’ all that stuff about pushing yourself to gain more energy – it doesn’t work any more. And you have to learn to say ‘no,’ to spend more time passively listening rather than talking, resting rather than doing, watching rather than participating and accepting things rather than trying to change the world.

“It’s difficult always wanting to do more. I want to join in the fun, I want to play sport again, I want to work hard and achieve things and I want to party with my friends. Most of all I think I have a deep-rooted desire to please people by making an effort, whether that’s socially, at work or at play. Saying ‘no’ can be very hard!

“Boom and bust has always been a big issue for me. It’s considered a virtue in our society to overcome a disability by refusing to accept the limits it imposes, as wheelchair athletes demonstrate. Accepting that our pacing heroism may be misunderstood and will almost certainly go unnoticed is difficult to take, but key. To me it’s about ‘staying within my limits’.

“I try to think of it as doing a little bit less than I can every day. Pacing isn’t easy but as time has gone on I think I’ve got better at it, helped by the fact that I’m seeing the benefits and finding that I can do more and more. I feel now I’m really starting, slowly, to get better.”



Not what *can't* I do but what *can* I do

Teresa says: "The road to recovery from M.E. is very long and slow. However I do believe that pacing is a strategy which is helping and equipping me to move forward. Before I learned about pacing I was just trying desperately to hold onto my old life – and failing to do so! Pacing has changed my focus from what I can't do to what I can do and is helping me to build from there.

"Pacing hasn't always been straightforward and setbacks have and do occur. Learning that the dips and setbacks are part of the process is hard, but each time it has taught me more about how to adjust my pacing and move forward, and over the months they have been less frequent. Pacing requires repetition, consistency and discipline.

"After pacing for a year and a half I am just beginning to see more small changes happening. My days have become more consistently good in the past couple of months. I have seen my confidence start to grow again and I feel more equipped and prepared to try a little bit more. I am living a life again even if it's within small boundaries. I do believe these boundaries will expand as I continue to live a paced lifestyle."

Conserve your energy

Jeannie Le Mesurier says: "I found trying to rest for 20 minutes, five times a day and incorporating regular gentle activity all took up a surprising amount of time. I also found pacing was very difficult to carry out when my brain worked too fast, when I was exhausted and over-tired and when I had pain and aching in my body.

"I have learnt to conserve my energy where possible, for example by taking lifts and escalators when shopping in town and booking a mobility scooter. When life becomes more stressful I have learnt to negotiate those things that really merit my thoughts and energies. I have also learnt to avoid people who make unreasonable demands on me.

"I would advise anyone learning to pace to listen carefully to their body and not to ignore the signals it gives out. I have become more spiritual – regularly doing meditation and gentle yoga when my body allows. It's important to believe and trust that you will recover and allow yourself little windows of joy in the form of 'nice' things to do or look forward to. As my body slowly recovers I can feel the sunshine coming back into my life again."

Returning to work

Mike Carr says: "My return to work was very gradual. I started at four hours a week, after discussing my plans and requirements with the personnel section at work. Initially they liaised with my line manager for me, until I gained more confidence. I then increased my working week to eight hours but relapsed when my duties became more complex. Because of this I went back down to four hours.

"My role now is mainly computer and telephone work with occasional meetings.

"I work from home when possible and have a TFT (flat) screen on my computer to cut down on glare, along with a copyholder to help reduce eye movement. The more demanding the work, the quicker I get tired. Also the more demanding life is, the less energy I have for work!

"If you're thinking about going back to work and you've got enough support, inside and outside work, do it. To one degree or another, your working role is part of your identity. To succeed, even in a modest way, can contribute to your self-esteem and make you feel better about yourself."

Other comments

"I consider my own needs first. Pre-M.E. I was a people pleaser, always saying 'yes' and then suffering the consequences. Now I do what I can, in my own time, without overspending precious energy."

Tips from people with M.E.

Action for M.E. asked readers of its membership magazine, *InterAction* and fans of its facebook page, www.facebook.com/actionforme, what techniques they used to help them to pace themselves. Here are some of their responses:

Gill Bridgestock

"I try to imagine I'm plastering a wall, keeping all activities even and smooth. I alternate mental tasks with physical and have a set time to go to bed and wake. Most helpful is to learn to meditate. I do it for 1 hour at lunchtime every day, it really works!"

Sandy Zundel

"I rest as much as I do activities in the day. Another way to do it is to put a limit on activity time. Give yourself a two to four hour limit for the day."

Pete

"Kate, my wife, worked out a coloured pin system to help her to pace herself in the early days. She allocated so many pins for each kind of activity, and used a pin for approximately half an hour of each. That way, as the day went by she could monitor whether she had used up too much of one or another sort of pin, and try and redress the balance."

Anna Cooksey

"I keep a daily diary. I keep a note of how many hours' sleep I have had, how many times I wake up in the night and how long for, dreams I've had, (I often have very strange or frightening dreams during a bad period of health), daily activity and symptoms. This really helps me to take more rest during the day as I know I have to write it down and someone could read it and say, 'I told you so!' It also helps me to find patterns and cut down certain activities that have caused symptoms."

See more people's thoughts on activity diaries on p 38.

Joss Wanton

"If I start to feel more than averagely ***** I go and lie down."

Appendix I:

Activity, rest and sleep diary (Frenchay Hospital)

Please find overleaf a version of the activity diary sheet used by staff at Frenchay Hospital, Bristol, when helping patients with M.E. to manage their illness. This is how they use it:

1. Look at the Key at the bottom of the diary: it has five boxes, one for sleep, one for rest, three for different levels of activity. Choose a colour or a pattern for each of these boxes, and fill it in. Select colours or patterns which will contrast well, eg. sleep=green, rest=blue, low energy demand = yellow, medium energy demand=orange, high energy demand=red.
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. It is OK to fill in only part of the box if an activity lasts for part of an hour.
3. Complete the rest of the box with other colours or patterns, depending on what you did next.
4. It is up to each individual to decide which activities are high, medium, low demand or restful. Think about how much energy (physical, mental or emotional) each activity might demand from you. 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, high, medium or low demand activity depending on what you did whilst you were awake.

If you wish to use this diary, please take photocopies before you fill it in.

If you forget and need another copy, contact Action for M.E. or download one from www.actionforme.org.uk

NHS/Frenchay Hospital diary –

Week _____
____/____/____

Midnight to midday

121234567891011

Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												

Week _____
____/____/____

Midnight to midday

121234567891011

Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												

activity, rest and sleep

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

What do people with M.E. say about activity diaries?

Josephine Elms

"I found activity charts really helpful to make me see just how much I was doing when I thought I was resting – colour coding mental exertion (eg. concentrating on a book/TV), light and moderate physical exertion, actual rest and sleep. Years on I still go back to it when I'm struggling.

"Start just recording what you're doing for a few days to a week, then have a good look – it's surprising how little rest time there is, even though you think you're not doing anything.

"Schedule in proper rest times, then focus your energy on the important things for you – whether that's half an hour doing crafts, a phone call, or watching a favourite TV programme."

Michelle Wright

"Like Josephine, I found a weekly 'activity log' really useful early on (I've been ill for five years now). I no longer keep a detailed activity log, but do jot a few lines into my diary every night before I go to sleep. Then, if I am feeling low or worn out, I can usually see why – especially by referring back through the previous days. (I'd not remember otherwise!)

"The other thing I did, which is more dramatic and not always feasible for everyone, is to move away from family and friends. Hard, but it means I can stay focused on making steps to aid my recovery, pace properly, and not try constantly to 'get back' to pre-M.E. me."

Jacqui Adams

"I gave up keeping records years ago. I often had forgotten what I was going to write down before I found the post-it notes. I tend to carry a cheap mp3 player in my pocket that can record and I then transfer the recording to the computer after a few days. If I go to the specialist's or doctor's I take a Dictaphone and ask them if I can use it as my memory is poor. Most of the time they say 'yes'."

Laura Whitby

"I find that as I have such a long list of symptoms that are constant and very severe all recording does is cause me to reflect on them. I find just getting on with it and treating them as normal is a much better coping strategy."

Yvonne Leach

"As my M.E. symptoms are random, variable and fluctuating, keeping an activity chart is just a snap-shot of a point in time. If it makes you feel better all good and well... It may be useful to show your doctor – but remember keeping an activity chart is an activity in itself."

Pauline McLeod

"I have kept an activity and relaxation diary for four years now. Initially I noted whether my activities were low, medium or high, also mental or physical to make sure that I alternated as advised at the CFS clinic. Now it has become so much second nature that I just know what I need to do without noting everything down.

"I now just write my relaxations as I go to make sure I fit them all in, and note my activities at the end of the day and how I feel each day. This helps me to plan important activities and manage my energy. It is really useful to check back when I feel unwell to tweak something or to see where I have used too much energy."

Kay Smillie

"The best thing I ever did was keep a chart of things I did, my mental thoughts, and how I physically felt daily for six weeks. It was very hard to do at the time, but I persevered and I'm glad I did.

"I highlighted when I felt really bad in red, not so bad in amber, and 'good' in green (that's 'M.E. good,' not 'normal good'). The chart highlighted certain patterns that I hadn't been aware of previously, so I had a rethink. I altered what I was doing and the way I was doing things.

"I now get up and go to bed at the same time every day. This makes things easier for my husband too, as I am showered, dressed and fed before he leaves for work. He doesn't have to worry so much about me falling in the shower, etc while he is away.

"Routine and structure seem to help – for me anyway. I have an A5 diary which has everything in it. This way I can see what I am doing in any one day, and what is coming up in the future. However, there is still an element of flexibility as life happens.

"I still maintain that being positive and accepting the illness, not fighting it, is key to being able to live with an M.E. body. Oh, and I meditate for 10 minutes every day as this is the only way that I feel my body can 'rest'."

"Before I learned about pacing I was just trying desperately to hold onto my old life – and failing to do so! Pacing has changed my focus from what I can't do to what I can do and is helping me to build from there." Teresa



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