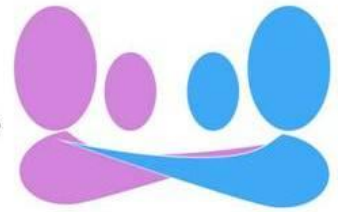


# Hampshire Friends With M.E.



[www.friendswithme.org.uk](http://www.friendswithme.org.uk)

Registered Charity No. 1101610

## **Information Sheet 2: Pacing for ME/CFS**

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### **What is pacing?**

Pacing is a strategy that helps you manage the limited energy you have when living with chronic illness, and gives you back some control by focussing on what you *can* do. It encourages a balance of activity and rest and can result in fewer symptoms. You can adapt it to your own needs and is a key tool underpinning other approaches you may try. Many people with ME/CFS report positive benefits from pacing, including the ability to do more overall and a better quality of life.

### **Aims of pacing**

Pacing activity helps you to stay within the limits of your stamina, stopping before you start 'running on adrenaline' or 'overdo' it. This then reduces the negative impact of activity - the post-exertional malaise (PEM) - that is characteristic of ME/CFS. People living with limited energy are often in a boom and bust cycle which can actually increase symptoms and mean a gradual decline in functioning.

For example: doing a lot one day, then being unable to get out of bed the next, or trying to cram more activities in when you feel better, then 'paying for it' with a crash. It is important to remember that 'activity' includes mental and emotional tasks as well as physical ones, anything that uses up energy. Pacing is about improving your balance of activity and rest so that you can have a steadier amount of energy across the week and so experience less 'crashes'.

### **Basic principles:**

#### Have an 'energy measure':

Find an image that reflects how your energy levels and stamina feel to you: are they like a battery running down or is it easier to think of a container of liquid that gradually drains? Maybe you prefer 'Spoon Theory'<sup>1</sup> that explains chronic illness as having limited units of energy that get used up with every activity you do.

Some people with ME/CFS use wearable activity trackers or heart rate monitors to help with pacing. However you understand your energy levels, it's useful to gauge them regularly to help make decisions about what to do and when to rest. You could share this with people supporting you to help them understand your choices and needs.

#### Know your baselines:

Notice how long you can do everyday activities such as: walking, talking, shopping, driving, and using the internet, etc., before you experience a noticeable increase in fatigue/pain/cognitive difficulty. You could make a note of how you feel after each over a week then work out your average, with ME/CFS your baseline needs to be what you can manage on a 'bad' as well as a 'good' day. This can be upsetting as you are measuring your limitations, so allowing time to feel the emotions that come up when you do this. Remind yourself why this task is important: it is the basis of learning to pace yourself and doesn't mean you will always be this restricted.

#### Stop before you need to:

Getting into the habit of stopping to rest *before* you begin to notice an increase in symptoms will enable you to do more overall as you will suffer less for what you do. Planning to do no more than 75% of what you think you can keeps something in reserve and gives a 'cushion'. This helps because activities are not always under your control, especially when you are out of your home environment, or other people are involved.

#### Break tasks up into smaller chunks:

For example, if you do an activity like washing up, or hoovering a room and feel awful, try doing it in two sections, with 15-30 minute rests in between. While this may sound silly and feel frustrating initially, if you can do a whole task without feeling more ill afterwards this change is well worth it. Notice what's running through your mind as you try this technique: 'this is ridiculous, I should be able to do this, I am pathetic, I wish I was normal...' and try to replace these with more compassionate thoughts such as 'if I pace myself I won't feel so bad, I am ill and doing the best I can.'

#### Rest before and after an activity:

Getting into the habit of resting both before and after you do anything is helpful for many reasons: you haven't drained your energy before you start; it allows a recovery period between activities; you have the opportunity to check your symptoms and energy levels through the day - ask yourself 'how am I feeling now?'; it encourages a balance of activity and rest that will start to feel like a natural part of your routine; and it provides structure.

What feels truly restful for you? Try to find a quiet, comfortable place and really switch off - going online is not resting! See the 'Living Well with ME/CFS' information sheet for more on this.

#### Plan ahead:

Taking a few minutes to think about the detail of an activity can really help with pacing. For example, if you want to go shopping but know that it really takes its toll on you, consider where you are going carefully: Is it far to walk from the bus stop or carpark? Are there benches or a café where you can rest? Will you be able to get what you need all in one place? What else have you got to do that day? Are you being realistic about what you want to achieve?

#### Admit what drains your energy:

A sad fact of ME/CFS is that pleasurable activities can be just as much of a drain on your energy as chores. Talking on the phone, going to events, chatting with a friend, shopping, watching films - which do you find difficult? Be honest with yourself and others about the things that make you feel worse.

You are more likely to be able to work out ways to pace leisure activities rather than carrying on until you drop, and suffering for days as a result. You are then more likely to get a good balance of rest, productive activity and pleasure in your life. Trying to 'multitask' is also draining, so try to do one thing at a time.

### Regular Review:

- Using the calendar on your phone, a paper diary or weekly activity sheet<sup>2</sup> to record activity and rest, rating how you felt, can help you to learn to pace.
- Spend a few minutes at the end of the week reviewing: is there anything you notice: What went well? What was a problem? What have you learned?
- At another time, consider the week ahead: what is your planned balance of activity and rest? Are there enough blank spaces for rest and unexpected tasks? Are there pleasurable activities scheduled? Are physical and mental activities balanced?
- This doesn't have to be rigidly controlled, aim for general balance.
- You could rate activities 'low,' 'medium,' or 'high' energy. Are these spread out as evenly as possible across the week?
- Get someone you spend time with day to day to help you with this process, they may notice something useful.

### Make choices in everything:

Managing your energy means making decisions and choices that are in your own best interests, which some people find hard to do. Get into the habit of asking yourself 'what is right for me?' before any decision you make. When you are asked to do something, buy yourself time to decide by saying 'can I have a think and get back to you?' Automatic responses are not usually in your best interests as they often come from old habits and don't take enough account of your needs as a person with ME/CFS. Finding new ways to do things can also help, for example: you can sit down to chop vegetables, or reduce the amount of time you spend talking to a loved one on the phone by telling them how long a conversation is manageable for you.

### **Useful skills & support:**

#### Acceptance:

Ironically it is only when we accept the current reality of life with ME/CFS that we can begin to move forward. If you are continually fighting against your body and pushing its limits, trying to keep up with the levels of activity you did before you became ill, you will find it hard to 'go with' your body and pace yourself. Acceptance does not mean resignation, or 'giving in,' to the illness, it means being realistic about your current circumstances.

This is important when developing pacing skills – being honest with yourself helps you to set achievable goals and realistic limits. It also reduces the time spent anxiously thinking about how things used to be and how they might be in the future - while this is a natural response to illness it drains energy further, lowers mood and reduces opportunities to engage in enjoyable activities.

#### Self-awareness:

Awareness of how we feel physically and emotionally is an important part of pacing. Getting to know the warning signs that you are moving into 'overdoing' is important for this: palpitations,

aching legs, increased brain fog, shaking, irritability - what are yours? If you get an infection or experience an emotional difficulty it is also important to adjust activity levels to allow for this – self-awareness is important as it can help you to take care of yourself when you're particularly vulnerable.

However, being aware of symptoms can be very distressing. An over-focus on how you feel can add to anxiety and tension, increasing your ME/CFS symptoms. A delicate balance needs to be struck: a noticing rather than constant monitoring. Mindfulness is helpful for this:

### Mindfulness

You can develop self-awareness and acceptance using mindfulness meditation to increase awareness of your body and thought patterns. Mindfulness is the process of bringing your attention to what is happening now, moment by moment, without judgement or getting lost in thoughts or worries. As well as helping with pacing it is a wonderful way to cope with chronic illness, improving quality of life, mood and outlook. See sheet 'Living Well with ME/CFS' for more information.

### Find a pacing 'buddy' or supportive friend:

If you can, involve a trusted person, ideally someone you see regularly, in your pacing. This might be a friend, partner, or even someone online who you often chat to. Other people sometimes notice patterns that we don't see in ourselves, or they may have useful ideas on how you might do an activity differently.

Having another person who understands what you are trying to do, keeps an eye on how you are doing and can also give you feedback on your progress, especially on down days, can be really helpful.

### Workplace Support:

If you are employed, getting the support of Occupational Health, your union representative, supervisor or a mentor can help you make mutually agreed changes that assist you to sustain work. This is beneficial for employer and employee, and a regularly reviewed written agreement can be a useful way to get your needs supported.

This can be a difficult process so you may need advice from the Citizens Advice Bureau, an ME/CFS charity or a disability rights organisation. Some of the strategies discussed in this sheet fall under the legal definition of 'reasonable adjustments' under The Equality Act 2010<sup>3</sup> which employers have a legal obligation to consider for employees with a diagnosis of ME/CFS.

### Professionals specialising in the self-management of chronic illness:

Professional support with pacing and self-managing chronic conditions can be found at specialist NHS ME/CFS or fatigue services in some parts of the UK, or from therapists who work privately<sup>4</sup>. Practitioners might be Occupational Therapists, Integrative Counsellors, physiotherapists, holistic or CBT therapists but it is important that you feel comfortable about their experience helping people with chronic illness, and most importantly their understanding of and beliefs about ME/CFS. See 'Alternative Approaches to ME/CFS' information sheet for more on this.

### **Dealing with blocks to pacing:**

### Your self-image and values:

Old patterns of thought from before you became ill about how you 'should' be and what you 'should' be doing can get in the way of developing new habits. For example if you believe that if you're not constantly busy 'doing' then you are worthless you may need to talk this over with someone. Frustration, guilt, and resistance to how you feel are a drain on energy. The reality is that having ME/CFS changes almost every aspect of life and this means you have to adapt. The illness is not your fault and is nothing to be ashamed of, on the other hand learning to pace takes courage and ingenuity. Remember to acknowledge each day's small victories.

### Society's expectations:

You may struggle with how you see yourself compared to other people at your stage of life, be deeply affected by how the media negatively portrays people with disabilities, or believe that certain things you can no longer do are required for you to be a valued member of society. You may be acutely aware of how much your health problems force you to live differently to the 'norm', and how much you need help. Be aware of these possibilities, talk them over with someone you trust and be kind to yourself. The reality is that you are living with a complex illness and doing the best you can.

### A different level of functioning:

You may be asking yourself 'Why would I accept how little I can do?' Living more slowly is essential to pacing well and living with ME/CFS in general. Stopping activities while you are enjoying them and not suffering too much is hard, so focussing on why you are doing this is vital: 'If I stop now I won't feel so bad later,' 'If I keep pacing myself it will pay off.' If you have a setback for any reason, be kind to yourself and try to stabilise your routine at a slightly lower level of activity. Be careful though, too little activity can actually make a setback worse.

### Other peoples' agendas:

There may be people around you who can't accept your illness or ignore it; some who push you to do more than is good for you; there may be people who are used to your support and struggle to see you as ill. Be aware of other people trying to influence or override the decisions you make about your activity levels - you know yourself best. If challenged you could say: 'I am doing this to help myself, it is something a lot of people with ME/CFS find useful, it would be really good if you could support me.'

### Emotional difficulties:

If you feel overwhelmed by the losses you are experiencing due to your diagnosis, anger that this is happening to you, sadness at the changes in your life, anxiety about your future or any other natural emotional response to having ME/CFS, you may need to address these before you are able to fully engage in pacing. Talking to a trusted friend or even a counsellor<sup>5</sup> can really help.

### **How will I know I'm pacing well?**

- When your energy levels and symptoms are more consistent - less 'boom and bust.'
- When you get less post-exertional malaise or 'payback' from most activities.
- When you are having to think less about how you do things
- When you are automatically allowing yourself time to rest.
- When there are more 'good' days than before.

- Once you have established a more sustainable balanced level of activity you may feel you want to begin to increase what you do. If this is the case take it gently: a good rule is to only increase by 10% of current activity levels each week, for example if you can walk for 10 minutes without any payback, next week's walks will be 11 minutes.

### Conclusion:

Learning to pace takes patience but the effort is worth it for improved quality of life. It may take a few weeks to see changes and gain confidence in your strategies. Take it easy: being too rigid or getting anxious that you are 'getting it wrong' is not helpful as this can increase stress, which in turn adds to fatigue and other symptoms. It is best to pace in a relaxed and mindful way, and keep focussed on the fact that it is something you can actively do to help yourself.

### Resources:

- 1) Christine Miserandino's Spoon Theory  
<https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>
- 2) Activity record sheet: <http://www.getselfhelp.co.uk/docs/ActivityRestDiary.pdf>
- 3) Equality Act 2010 information about reasonable workplace adjustments from Citizens Advice Bureau <https://www.citizensadvice.org.uk/work/discrimination-at-work/what-are-the-different-types-of-discrimination/duty-to-make-reasonable-adjustments-at-work-what-must-employers-do/>
- 4) Contact Vicki Mould for details of local counsellors who have completed her training 'Working with ME/CFS in Counselling'.  
<http://www.azaleacounselling.net/phdi/p1.nsf/supppages/6756?opendocument&part=5>

British Association for Counselling & Psychotherapy (BACP) online directory for local counsellors 'It's Good to Talk' <http://www.itsgoodtotalk.org.uk/>

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