



MANAGING MY ENERGY LEVELS

*A helpful resource and practical
advice to support people
diagnosed with a long-term
health condition to live well with
fatigue*

Always there to care

Lindsey Lodge Hospice and Healthcare
Burringham Road
Scunthorpe
DN17 2AA

Tel: 01724 270835
Email: llh.enquiries@nhs.net

Introduction

This resource has been written by occupational therapists with professional expertise and lived experience of fatigue management with input from patients and the public who are living with fatigue as a symptom. It is designed for people who have fatigue due to a long-term condition and aims to help people manage their energy as best as they can, so they can do more with their time more easily.

Everyone's experience of fatigue is unique. That's why it's difficult to define. Fatigue involves a lack of physical and/or mental energy that affects usual and desired activities.

It's common to have low energy and feel more tired than usual when you're managing a long-term condition. Even simple tasks, such as putting on shoes, can be hard work, which can lead to feelings of frustration, isolation and anger that then contribute to fatigue. It's useful to understand these things so you can seek medical advice if needed.



Monitoring your energy levels

When starting to think about managing your fatigue, it is important to understand fatigue as a symptom and how it affects you.

In order to help understand how fatigue affects you, it can be helpful to keep a record of how you feel throughout the day and what activities you've been doing, including when you're resting. By completing a record, you may see patterns of when you have the most or least energy and what activities take the most energy and you can use this information when planning your day.

To do this you can:

- Write your records in a standard diary, or search online for 'fatigue diary' for specific examples you can use (fatigue diary templates are also available within the in-patient unit and/or wellbeing centre)
- Use your own words to describe how you feel, or you might find it useful to give your energy levels a score out of 10 each time, so you can compare how you're feeling throughout the day and week
- Use a colour coding system if it's too tiring to write down every individual activity. Red can be used to show activities that are most demanding, green for activities that are least demanding and amber for those in between

Completing a record does not have to be onerous. Often keeping a record over a period of 3 – 7 days is all that is required to help understand what may help your fatigue and what may trigger your fatigue.

'I felt completely overwhelmed with fatigue, like walking through treacle most days. Keeping a diary helped me to understand my fatigue and regain some control' – patient quote

Once these patterns are established, you can then begin to think about applying the following principles:

The 3 P's principles (Pace, Plan, Prioritise)

Learning to pace, plan and prioritise your daily activities can help you to save energy. Using this approach with every activity that you do, can help you to adapt and adopt new ways of doing familiar everyday activities without unnecessary exacerbation of symptoms.

PACE

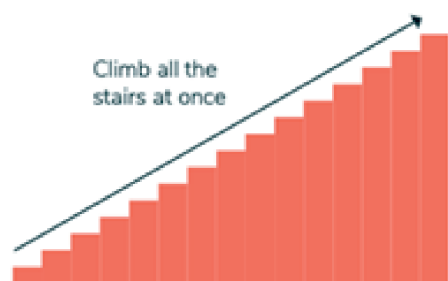
Evidence suggests that pacing helps people with long-term fatiguing conditions manage their energy and maintain activities.

Pacing top tips include:

- Break activities up into smaller tasks and spread them throughout the day
- Try adjusting different parts of an activity to reduce the energy demands
- 'Build rests into your activities; they're key to recharging your energy' – patient quote
- Stop, pause and rest between activities where possible
- Sit and rest wherever possible.

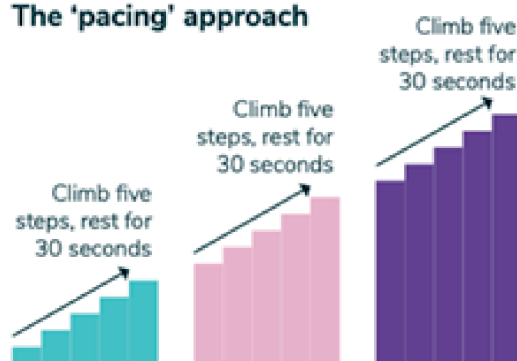
Pacing involves thinking about how you can break activities up into smaller tasks or separate parts. The diagram below demonstrates how pacing can be used when climbing the stairs:

The 'big push' approach



Result: You have to rest for 10 minutes at the top and feel achy and tired the next day.

The 'pacing' approach



Result: You don't need a long rest at the top and don't feel so tired the next day.

It's best to stop for a break before you reach exhaustion. This will be at different times for different people – you may feel it during the activity, later that day, or even the next day. Using a diary, as explained previously, can help you to record how you cope with each activity and any effects that you notice. It may take some experimenting to figure this out!

PLAN

A weekly planner can help you to manage your energy, not just your time. However planning ahead can be both helpful and demanding, therefore it may be helpful to find a quiet moment at the start or end of your week to think about how you can plan for a few days ahead (particularly if you are undergoing specific treatment such as chemotherapy, radiotherapy or an infusion).

Planning top tips include:

- Plan ahead as much as possible
- Create routines
- Spread activities out
- Keep items you need together and in easy reach
- Look for equipment to reduce effort



It may be helpful to consider the below when planning:

- List your normal daily and weekly activities
- Think about how demanding they are and in what way
- Look back at your record or diary if you've kept one
- Spread out the activities that you find most tiring and give yourself time to rest before and afterwards. Where possible, do heavier/harder weekly activities on different days with rest days in between
- Remember that due to pacing, activities may be split up and need to be given more time.
- Notice your patterns – if you find your energy is lower, or concentrating is harder, at certain times of day, plan to avoid more demanding activities then. For example, instead of showering in the morning, when you're busy or more tired, do it in the evening
- Don't try and do activities all in one go – plan breaks or changes to your activity. For example, plan to have a break from cooking or gardening by sitting down and doing a mental/thinking activity like using your phone
- Communicate – tell others about your plans so they know you need to plan your time this way. **You can plan individual activities too**
- Think about ways you can do activities differently to use your energy differently. For example, instead of lifting and carrying items when cooking, try pushing and sliding them across the work surface
- Try to group activities or tasks that are local to each other. For example, if the library is close to the pharmacy, can you plan to do both on the same trip, remembering to take a rest break in between?

Look for assistive equipment that will reduce the demands on your energy. The **occupational therapist, physiotherapist or advanced assistants** will be able to provide advice and support with this if you need.



PRIORITISE

If you experience limitations with your energy it is important to choose carefully how you use it. This means making clear decisions about what your priorities are (and trying not to feel guilty about it!)

“Think about having a balance between what you NEED to do and the things you WANT to do” – patient quote

Top tips to help you to prioritise including asking yourself:

- What do I need to do today?
- What do I want to do today?
- What can be put off until another day?
- What can I ask someone else to do for me?
- What activities are going to help me feel energised?

It can be difficult to manage the pressure to be active, whether from others or yourself. It's important to set boundaries so you can prioritise your health – to do this, sometimes you need to say no. This can be hard if you don't want to let someone down or miss out but is an important part of managing your energy levels.

During these situations, it may be worth considering:

- What's important to you and acknowledge what's less important.
- If you know where you want to focus your time and energy, you can identify when to say no
- Be confident when saying no and appreciative – if people ask you to do something, they're doing so because they trust and believe in your abilities or want to spend time with you
- Say no to the request, not the person asking, and explain why. You may want to explain about managing your energy and why you need to say no

You may find it hard to say no because you don't want to miss an opportunity. However, please try to remember that by saying no to one thing, you are saying yes to something else that you may value more (and that is ok).



Resting your body and mind

Rest can be tricky to include into your daily routine. What we often find 'relaxing' isn't always 'restful' and therefore it is important to think about how we can truly rest both our body and mind in order to optimise our energy.

When you add good quality rest to your daily routine, it can support your health and help with recovery from activities.

Typically when we rest, this may include seated activities like watching TV, using your phone or socialising, but these activities actually continue to use energy and concentration. To rest fully, sometimes you'll need to change what you're doing.

Resting your mind is as important as resting your body, because the brain uses a lot of energy. When thinking about quality rest, look at approaches that also relax the mind.

There are lots of resources available around rest. You may need to learn new techniques – look for approaches that suit you. Techniques include:

- breathing exercises
- mindfulness
- muscular relaxation
- calming sensations such as heat or cold, gentle movement or music.

If you can learn to practice rest, this can be a very positive action to help improve your energy. To help pace yourself, you can also plan rest into the day and make it a priority before and after activities.

"I find resting little and often tends to be the best approach"

– patient quote



To help you to start to think about how the 3 P approach applies to daily life, the following practical tips for different activities of daily living may be helpful for you to consider:

Washing and grooming		
Pace	Plan	Prioritise
<ul style="list-style-type: none"> • Sit to wash your face, brush your teeth and dry your hair. Have rests after each. • Pat yourself dry rather than rubbing. 	<ul style="list-style-type: none"> • Keep all the things you need in the same place. • Put a mirror at face level when sitting. • Use liquid soap instead of a bar. • Use long-handled equipment, such as a long-handled sponge. 	<ul style="list-style-type: none"> • Try dry shampoo. • Use electrical items, such as a toothbrush, razor, etc.
Bathing and showering		
Pace	Plan	Prioritise
<ul style="list-style-type: none"> • Allow plenty of time and take rests. • Sit in the shower if possible. • Rest in a dressing gown or large towel rather than drying. 	<ul style="list-style-type: none"> • Open an inside door to allow good ventilation. • Use long-handled equipment. • Use equipment to help you get in and out of the bath or shower, such as a rail or chair. 	<ul style="list-style-type: none"> • Is bathing an activity you enjoy and are willing to spend a lot of energy on? • Is a daily bath or shower necessary? • Can you have a strip wash at the sink instead?
Dressing		
Pace	Plan	Prioritise
<ul style="list-style-type: none"> • Sit to dress. • Break up tiring tasks with easy ones and take breaks. • Dress your lower half first when you have the most energy. 	<ul style="list-style-type: none"> • Rearrange your bedroom so the items you use most are easy to reach. • Collect all your clothes before you start. • Wear clothes that fasten at the front and are loose. • Put underwear and trousers on at the same time and then pull them up together. • Put skirts on over your head. • Sit down to put on socks and shoes. Lift and cross one leg onto your knee to bring your foot closer. 	<ul style="list-style-type: none"> • Rearrange your wardrobe and drawers so that all your clothes are close together. • Put clothing in groups of colour to make them easier to find. • Get your clothes out the night before. • If you have someone who can help, could they get your clothes out and help you get dressed?

Making the bed		
Pace	Plan	Prioritise
<ul style="list-style-type: none"> • Put on the sheet, stop for a rest, then the pillowcase, then rest again. • Sit for some of the tasks, such as doing the pillows. • If you can, get help with the duvet cover. 	<ul style="list-style-type: none"> • Have your bed positioned so that you can walk all around it. • Start and finish one side, then move to the other so you only circle the bed once. 	<ul style="list-style-type: none"> • Could someone help you by making the bed? • Can you do different parts on different days?
Cooking		
Pace	Plan	Prioritise
<ul style="list-style-type: none"> • Spread the preparation throughout the day. Peel vegetables in the morning, cook in the afternoon and reheat in the evening. • Sit regularly for short periods whilst preparing or stirring food. • Take rests during and after cooking. • Use a trolley to move cooking equipment or cutlery to the table. 	<ul style="list-style-type: none"> • Cook large amounts and refrigerate or freeze extra portions. • Get everything you need ready before you start. • Keep things that are used together/most often in the same part of the kitchen and near waist height, so you aren't bending and reaching. • Cook simple meals without too much preparation or cooking time. 	<ul style="list-style-type: none"> • Buy pre-prepared vegetables. • Buy frozen ready meals. • If able, could family or a friend prepare some meals? • Prepare and eat your main meal at lunchtime
Shopping		
Pace	Plan	Prioritise
<ul style="list-style-type: none"> • Have a rest when you get to the shop. • Take your time collecting your items. • Put heavy items in different bags. • Use a trolley to push your shopping home rather than carrying a bag. • Spread heavy items across shopping bags. 	<ul style="list-style-type: none"> • Make a list with similar items together, such as milk and yoghurt together, so that you walk around the supermarket less. • Shop at quieter times. • Avoid large/deep trolleys to reduce bending when putting in and removing items. • Pack items together that go in the fridge/freezer or the same cupboard so it's easier to unpack. 	<ul style="list-style-type: none"> • Can family or a friend help you with the shopping? • Can you do online shopping? • Can you shop on a day when you don't have other heavy tasks to do?

Laundry		
Pace	Plan	Prioritise
<ul style="list-style-type: none">• Spread the tasks throughout the day. Load the machine in the morning, empty it in the afternoon.• Sit down to iron.• Use a low clothes horse and sit to hang out washing.• Take rests during and afterwards.	<ul style="list-style-type: none">• Wear clothes that wash, dry and iron easily.• Do several smaller loads each week, rather than one large wash.• Store everything you need, such as powder and pegs, in one place.• Use a laundry basket on wheels.• If possible, have your dryer at chest height.	<ul style="list-style-type: none">• Is it necessary to iron all your clothes?• Do you need to fold all your towels and sheets?• Consider the use of products such as crease releaser sprays.
Housework		
Pace	Plan	Prioritise
<ul style="list-style-type: none">• Spread heavy activities throughout the week. For example, vacuum a different room, or part of a room, each day.• Do a mix of heavy and light activities in a day.• Have a rest during and between activities.• Sit down for tasks like polishing or washing up.	<ul style="list-style-type: none">• Collect all the items you need before you start.• Use long-handled equipment where possible.• Use a mop to clean floor spills rather than bending over.• Allow washing up to air dry.• Use small rubbish bags so you don't have to lift one heavy bag.	<ul style="list-style-type: none">• Can you ask a friend or family member to help you or pay for someone to do this for you?• Prioritise the main rooms which are used and clean others less frequently.• Clean one room, or part of a room, at a time and not the whole house at once.

If you feel you would benefit from further advice and support in relation to managing your fatigue, please either liaise with a member of your support team within the hospice or contact the wellbeing centre at Lindsey Lodge Hospice and Healthcare on 01724 270835 to request a referral to the occupational therapist.

References

- DeLuca J, Genova HM, Capili EJ, Wylie GR (2009) Functional neuroimaging of fatigue. Physical Medicine and Rehabilitation Clinics of North America. 20(2):325-37. doi: 10.1016/j.pmr.2008.12.007
- Action for M.E. (2020) Pacing for people with M.E. Action for M.E.'s Big Survey: two-page explainer. Keynsham, UK: Action for M.E. Available at: <https://www.actionforme.org.uk/uploads/images/2020/02/Big-Survey-Pacing-for-people-with-ME.pdf> (Accessed 20.03.23) Royal College of Occupational Therapists: How to manage your energy: practical advice for people recovering from illness or managing long-term health conditions

Date of issue: January 2024
Revision: January 2027
Review period: 3 years
Author: Sarah Hodge

