

Fatigue Management in Long Term Conditions

Strategies to improve wellbeing and manage chronic fatigue



Hello everyone, and thank you for joining us today.

Today's session is an introduction to managing fatigue when you're living with a long-term condition.

Fatigue can affect people in lots of different ways, and what helps one person won't necessarily be right for somebody else. So the aim today isn't to give you a set of rules to follow. It's to help you understand fatigue a little better and introduce some practical strategies that you can try and adapt to your own situation.

Over the next 30 minutes, we'll look at what we mean by fatigue, the different ways we use energy, how to recognise your own patterns and warning signs, and some approaches to pacing and rest.

Hopefully, by the end of the session, you'll have a better understanding of your own energy and one or two ideas that feel realistic for you to try.

You'll also see a QR code on the screen. This takes you to our My Health Living Well with Long-Term Conditions website, where you'll find information and resources that you can come back to after the session.

So we'll start by looking at what we actually mean when we talk about fatigue.

Fatigue

Fatigue can affect every aspect of daily life and may not improve with ordinary rest.

**Body**
Illness, pain, symptoms

**Sleep**
Poor or disrupted sleep

**Mind & Emotions**
Thinking demands, worry, stress

**Everyday Life**
Activity, work, caring, social demands



An illustration of a person in a red shirt and blue pants, bent over and looking exhausted, standing next to a large white battery with a yellow lightning bolt symbol. The battery has a red bar at the bottom indicating low energy. The background is a light yellow with faint blue circles.

**Fatigue is individual and can fluctuate, what affects it will be different for everyone.**

We'll start by thinking about what we actually mean by fatigue.

Fatigue is more than ordinary tiredness. It can feel like physical exhaustion, mental exhaustion, or a mixture of both, and it may not improve as we'd expect after sleep or rest.

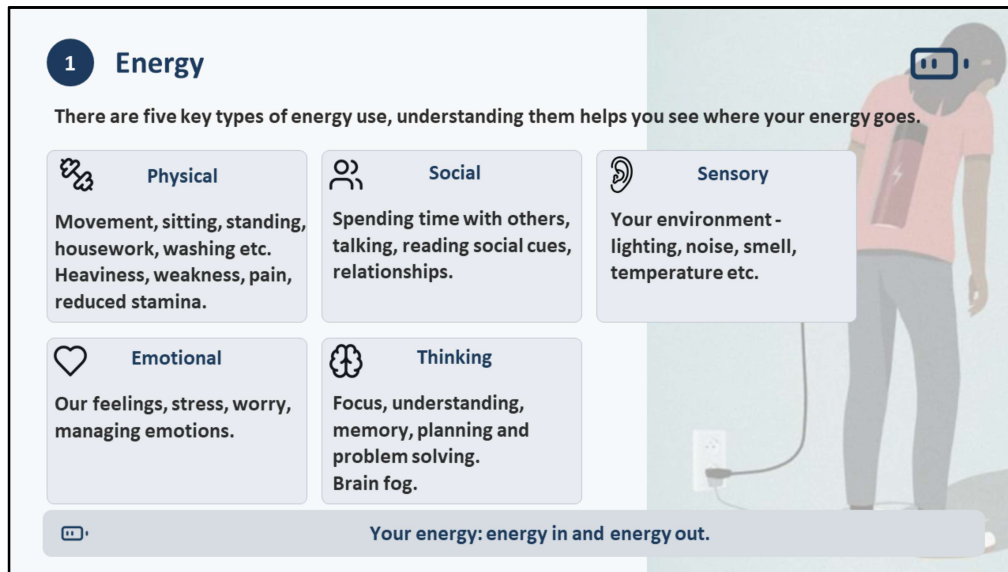
There are lots of things that can contribute to fatigue. These might include illness, pain, disrupted sleep, difficulties with concentration and memory, or emotional demands such as worry and stress.

Everyday activities, including work, caring responsibilities and socialising, can also affect our energy.

The important thing to remember is that fatigue is different for everyone. What contributes to it, how it feels and how much it changes can vary from person to person.

So today, we're going to look beyond physical activity and think about the different things that use our energy and how we might manage them.

It can be useful to start thinking about what might be contributing to your fatigue personally. There may not be one obvious cause, and often several things are interacting with each other.



When we think about managing fatigue, it can be helpful to think about where our energy is going.

We often automatically think about physical activity, things like walking the dog, standing, washing, housework or going out. But physical activity is only one way that we use energy.

Thinking ability/cognitive meaning using our brain, uses energy too, concentrating, remembering, making decisions, planning or problem-solving. Such as completing forms or dealing with emails.

Social activity also takes energy. Having a conversation, listening, being around other people or going somewhere busy can all add to the overall demand. An example could be attending a wedding or a family visit.

And for some people, sensory demands such as noise, bright lights, smells, temperature, clothing such as new shoes or busy environments can be tiring as well. Examples could be road works or DIY.

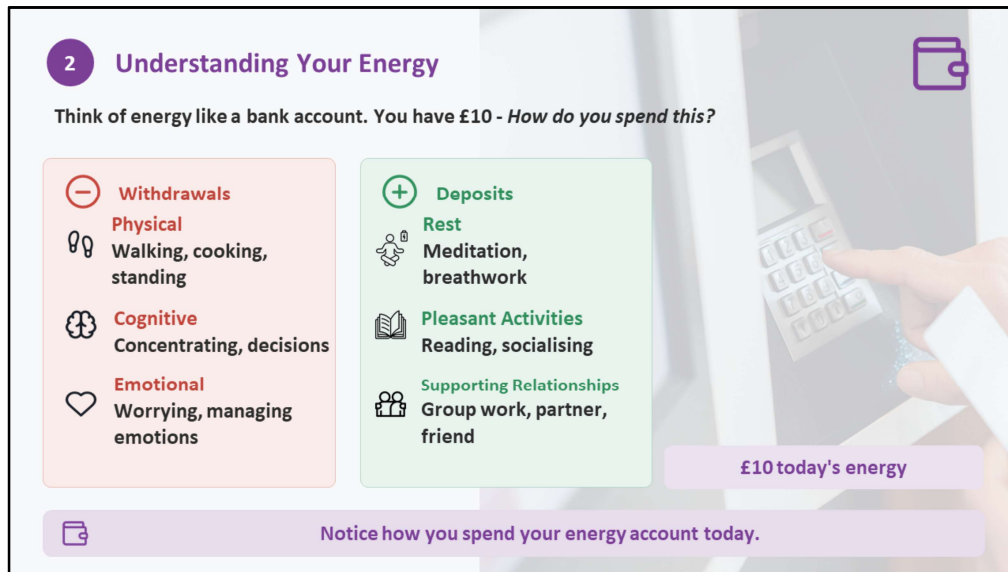
Emotional demands can use energy, this might include dealing with worry, stress, anger, managing difficult feelings or coping with uncertainty. Even positive emotions such as

excitement can be tiring, although some experiences can also help us feel better or more energised.

Most activities actually involve more than one of these at the same time. For example, going for a coffee might involve physically getting there, following a conversation, being in a noisy environment and perhaps managing how you're feeling that day.

None of these activities are necessarily things we want to avoid. Some may be really important or enjoyable. The aim is to start noticing what uses your energy, what helps restore or recharge it, and what is manageable for you. We all have different thresholds of what we can manage. It can be useful to think about what you liked or found difficult before your symptoms began.

That awareness is what helps us begin to work out our own baseline, which we'll come to later in the session



Another way of thinking about energy is a bit like having a bank account, or an envelope of money that you have available to spend.

So, just for an example, imagine you wake up in the morning and you have £10 worth of energy available for that day.

Everything you do takes a little bit from that £10.

Some things are quite obvious, getting washed and dressed, making food, walking your dog or doing housework. But from what we've just talked about, we know it's not only physical things that use energy.

Concentrating, making decisions, worrying, managing emotions, having conversations, **sensory elements like light, smells, noise** or being somewhere busy can all take something from that £10 as well.

And the amount things 'cost' can be different from person to person. Something that uses £1 of my energy might use £3 of yours, and it might even cost you a different amount on different days.

The difficult bit with fatigue is that we don't necessarily wake up with £10 every day.

One day you might have £10. Another day you might wake up and feel as though you've

only got £5.

If you planned your day expecting to have £10, but actually only have £5 available, you can see how easy it would be to end up using more energy than you have.

And sometimes we do choose to spend more energy. You might have a wedding, see a friend, go out with your family, or do something that's really important to you. We're not saying don't do those things.

What we're trying to get better at is recognising: What have I got available today? What do I need or want to spend it on? And where can I create opportunities to rest or restore some energy?

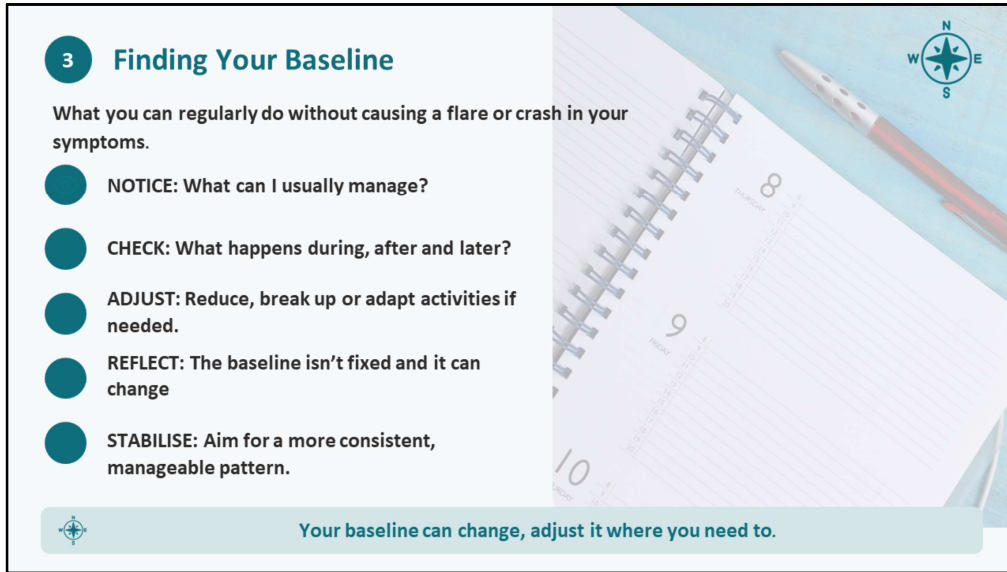
And just like with money, unexpected things happen. If you've already used most of your energy for the day, an unexpected phone call, appointment, visitor or something going wrong can have a much bigger impact. That's another reason it can be helpful, where possible, not to plan right up to the limit of what you think you can manage.

So this isn't about saving all of your energy and doing nothing. It's about finding a balance between the things you need to do, the things you want to do, and opportunities to restore.

And that balance won't look exactly the same for everybody.

To start working that out, we first need to get an idea of what level of activity is manageable for you, what we call your baseline. And that's what we're going to look at next.

Notice how you spend your energy account today. At this stage, I'm not asking you to change anything. Just starting to notice where your energy goes can be really useful.



3 Finding Your Baseline

What you can regularly do without causing a flare or crash in your symptoms.

- NOTICE: What can I usually manage?
- CHECK: What happens during, after and later?
- ADJUST: Reduce, break up or adapt activities if needed.
- REFLECT: The baseline isn't fixed and it can change
- STABILISE: Aim for a more consistent, manageable pattern.

 Your baseline can change, adjust it where you need to.

So, we've talked about where our energy goes. The next step is starting to get an idea of what is manageable for you, and this is what we mean when we talk about finding your baseline.

Your baseline is the amount of activity you can manage fairly consistently without significantly worsening your symptoms or contributing to a flare or crash.

And we're not looking at what you can manage on your very best day. We're looking for something that feels more reliably manageable.

A good starting point is simply to notice.

What can I usually manage? How do I feel while I'm doing it? How do I feel afterwards? And importantly, how do I feel later that day or even the following day?

That's important because sometimes the effects of activity aren't immediate. You might manage something at the time and think, 'That was fine,' but notice later that your symptoms have increased or that you need much longer to recover.

If you're noticing that happening regularly after a particular activity, that's useful information. It might mean looking at whether you could reduce it, break it into smaller

parts, change how you're doing it, or build in some rest.

The aim isn't to find the maximum amount you can possibly do.

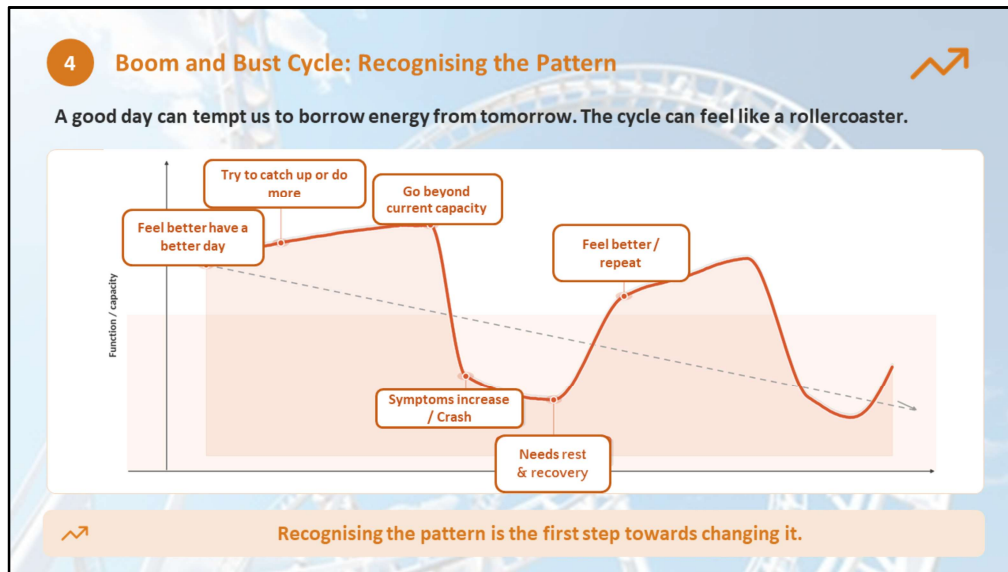
It's about finding a more manageable and consistent pattern, rather than repeatedly doing a lot when you're feeling able and then needing a long period to recover afterwards.

And your baseline isn't fixed. Just like we talked about with our £10 energy example, what you have available can change from day to day. If you're having a more difficult day, it's okay to adjust what you're doing.

So we're really trying to get curious about the pattern rather than getting it perfect: What can I manage? What happens afterwards? And is there anything I could adjust?

Because when we repeatedly do more than our body can manage and then have to significantly cut back while we recover, we can start to get into what we call a boom-and-bust pattern or cycle.

And that's what we're going to look at next.



So, when we regularly go beyond that manageable baseline, we can sometimes get into what we call a boom-and-bust cycle **which can feel like we are on a rollercoaster**. On a better day, it's completely understandable to want to catch up, maybe doing housework that's built up, seeing people, going out, or just making the most of feeling a bit better.

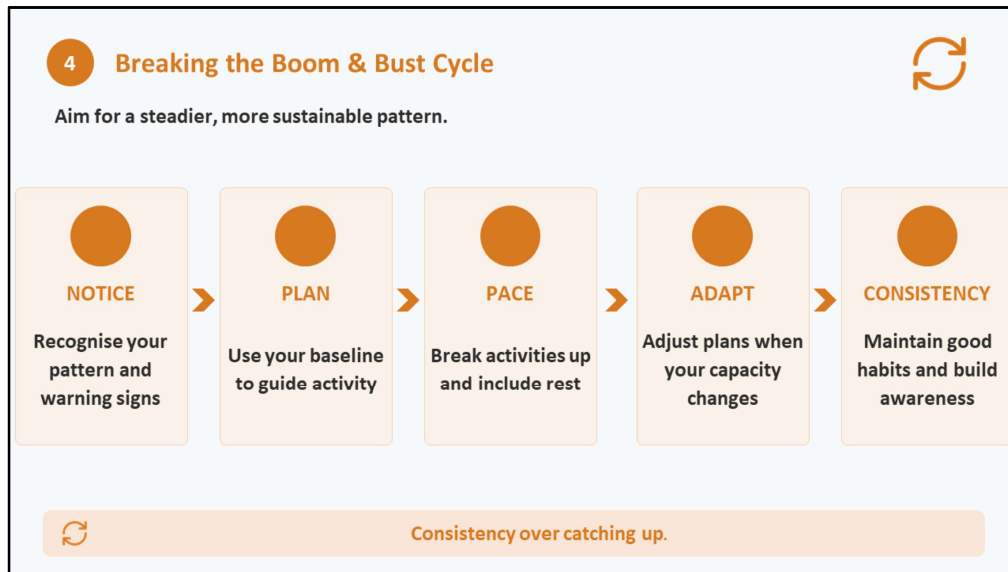
The difficulty is that we can sometimes do more than our energy allows. 4. Symptoms then increase, or we have a crash, and we need to significantly reduce what we're doing while we recover.

Then when we start to feel a bit better again, there's that temptation to catch up, and the same pattern can repeat.

This isn't about blaming ourselves for doing too much. Often we're doing things that need done, or things that are important to us.

It's simply about starting to recognise your own pattern. Once we can see it, we can begin to think about how we might make activity a little more manageable and consistent.

Boom and bust describes a pattern that can happen when our activity varies considerably depending on how we feel.



So if we recognise that boom-and-bust pattern, what can we actually do about it?

The aim isn't to do less and less. It's about trying to find a steadier, more sustainable pattern.

First, notice your own pattern and any early warning signs that might tell you you're starting to do too much.

Then plan around what you know is generally manageable for you, rather than what you can manage on your very best day.

Pacing can mean breaking activities into smaller chunks, changing between different types of activity, and including rest before you're completely exhausted, rather than only stopping once you've reached that point.

And we also need to adapt. Your energy and symptoms can change from day to day, so

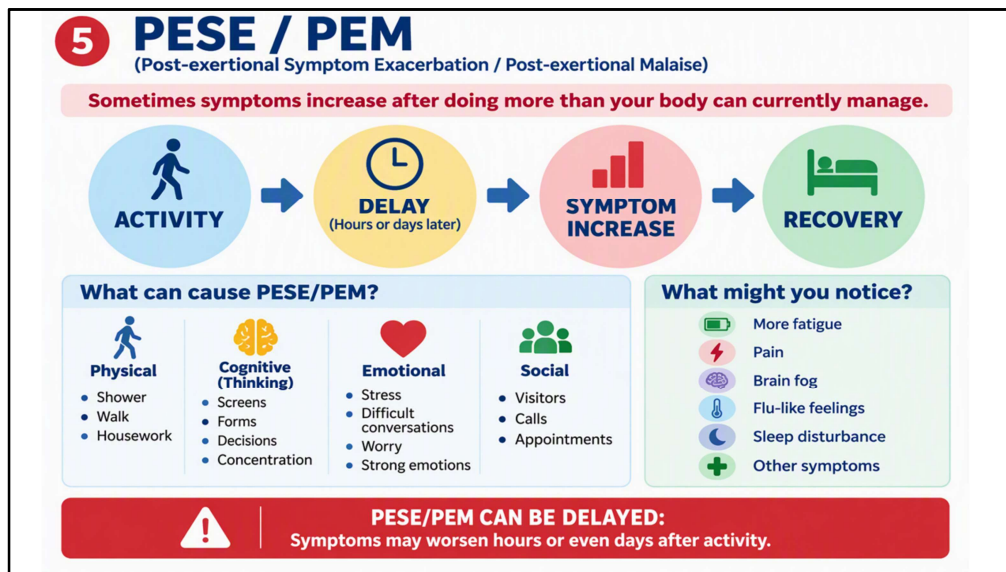
pacing isn't about following a rigid plan regardless of how you feel.

Over time, we're aiming for a little more consistency, trying to reduce those big peaks and crashes where we can.

Sometimes pacing can feel as though you're doing less, particularly if you're stopping before a job is finished or choosing not to do something you would normally do. But the aim isn't to do less overall, it's to spread your energy more evenly and hopefully reduce the amount of time you lose recovering afterwards.

Ultimately, energy management isn't just about avoiding crashes. It's about trying to use the energy you have in a way that gives you more choice and, where possible, keeps some energy for the things that are important to you.

So the key message isn't 'do less'. It's notice, plan, pace and adapt, aiming for something that's more manageable for you.



PESE or PEM (post-exertional symptoms exacerbation or post-exertional malaise) is when symptoms become worse after physical, mental, emotional or social activity. The increase in symptoms is often greater than we would normally expect from the activity.

One of the important things to understand is that symptoms don't always get worse straight away. They can be delayed, often by 12 to 48 hours, and sometimes recovery can take days or longer.

For example, you might manage a family gathering and feel reasonably okay at the time, but notice the following day that your fatigue, pain, flu-like symptoms or brain fog has become much worse.

So what can we do to help manage this?

The first thing is to notice your patterns. Think about what you've been doing in the day or two before your symptoms increased. Remember, it's not just physical activity that uses energy.

Secondly, try to stay within what's manageable for you. This might mean breaking activities into smaller parts, reducing how much you do or spreading activities across different days.

Thirdly, plan rest before you're exhausted, rather than waiting until your symptoms force you to stop.

And finally, adjust your plans when you need to. If you're experiencing a flare, reduce demands and allow time for recovery rather than trying to push through or catch up.

The aim isn't to avoid everything that's important or enjoyable. It's to understand your limits, make activities more manageable and, where possible, reduce the frequency and severity of symptom flare-ups.

5

Notice the Signs & Respond Early

Your warning signs are personal, learning yours can help you respond sooner.

Thinking: Brain fog, word finding, poor concentration
Body: Heaviness, increased fatigue, pain and dizziness
Emotional / Sensory: Irritability, feeling overwhelmed, noise/light sensitivity

1. Notice Spot your signs	2. Reduce Lower or postpone demands	3. Rest & Recover Use the rest you need; keep to the basics (medication, diet, hydration)	4. Resume Gently Return to baseline when able to	5. Learn What might I learn for next time?
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New, severe or unexplained symptoms need appropriate medical advice.

We've talked about PESE/pem and how symptoms can increase after activity. Another useful part of managing fatigue is starting to recognise your own early warning signs. These will be different for everyone. You might notice brain fog or difficulty finding words, your body feeling heavier, an increase in pain or fatigue, or perhaps feeling more irritable, overwhelmed or sensitive to things like noise or light.

The idea is to start noticing those signs that your energy may be running low, rather than waiting until you've completely run out.

If you do notice them, think about what you could change at that point. Could you reduce or postpone something? Could you take a break, move somewhere quieter, reduce screen time or give yourself a bit less to think about?

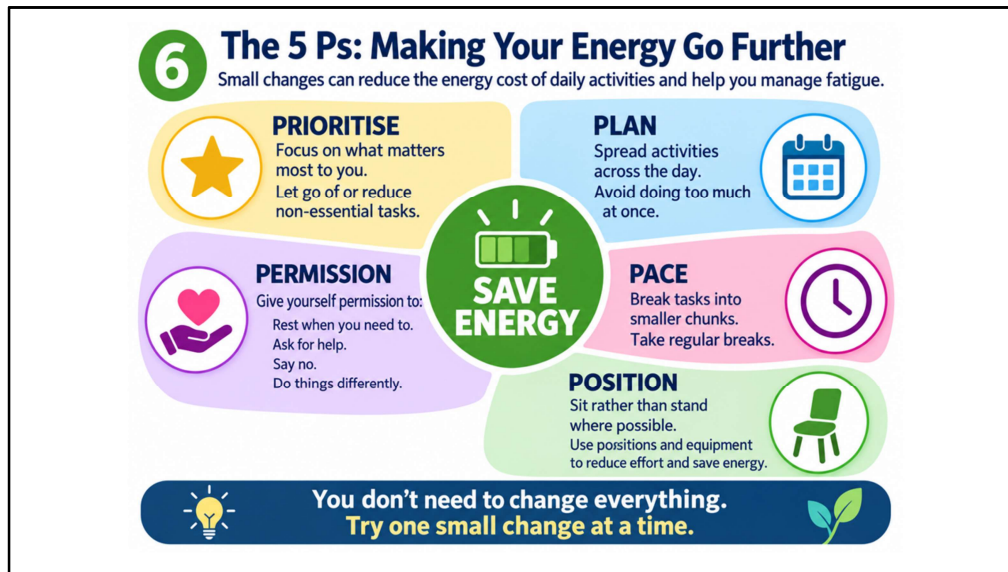
If you do experience a flare, give yourself time to recover and return to your usual activities gently, depending on how you're feeling, rather than feeling you have to catch up straight away.

And afterwards, it can be useful to reflect: Were there any early warning signs? Was

there a particular trigger? Is there anything I could do differently next time?

It's not about getting it right every time. It's about gradually getting to know your own pattern, so that where possible, you can respond a little earlier.

And just to be clear, new, severe or unexplained symptoms shouldn't automatically be put down to fatigue and should be medically assessed by your Gp or a Doctor.



So we've talked about recognising our energy patterns. Now we're going to look at some practical strategies that might help make everyday activities a little more manageable.

These are called the 5 Ps, and you don't need to use all five or change everything at once.

Prioritise is about thinking what really matters. What needs done today, what could wait, and is there anything someone else could help with?

Plan means thinking ahead. If you have something coming up that might take quite a bit of energy, could you spread other activities out or plan some rest before and afterwards?

Pace is about how you do things. This might mean slowing down, breaking activities into smaller parts or taking breaks before you're completely exhausted.

Position is about reducing the effort involved. Could you sit rather than stand, keep things within easy reach or use equipment to make something easier?

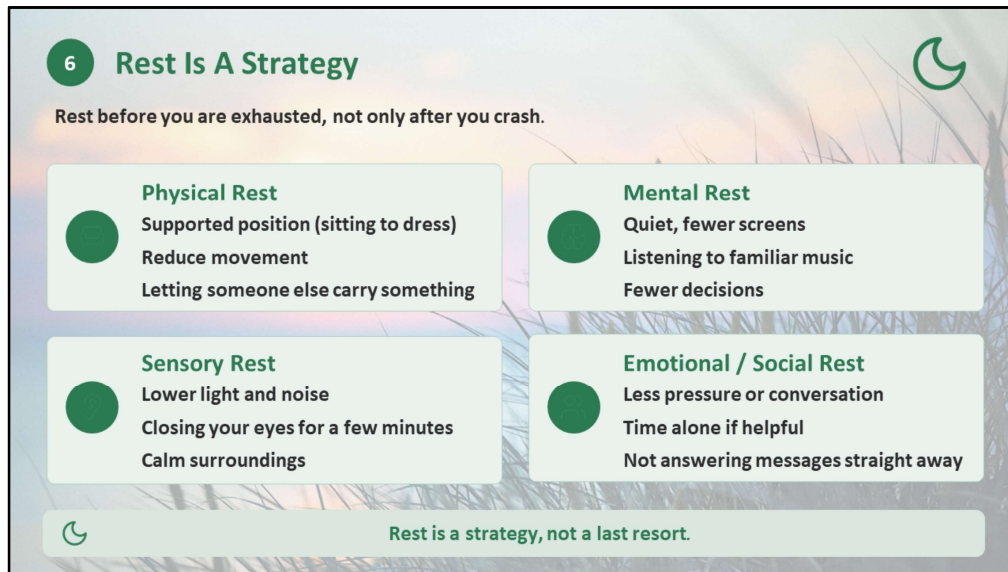
And finally, Permission is about giving yourself permission to do things differently, ask for help, say no or leave something for another day. This can sometimes be the hardest one.

For example, if you have a hospital appointment, you might prepare things the day before, avoid planning too much else that day and allow some time to rest afterwards.

The idea isn't to completely reorganise your life. It's about finding small adjustments that might help you manage your energy.

So think about one activity that takes quite a lot out of you. Could one or two of these Ps help make it a little easier?

Remember, you don't need to change everything at once. Start with one small change that feels manageable.



So following on from that , it can be helpful to think about what type of rest you actually need, because different things can use our energy in different ways.

Physical rest is about reducing the demands on your body. That might mean getting into a more supported position, reducing unnecessary movement, or letting someone else carry something.

Mental rest is about giving your brain a break from concentrating, processing information and making decisions. That could be something as simple as listening to familiar music or putting your phone down.

Sensory rest is about reducing some of the input around you, things like noise, light or busy environments. For example, closing your eyes for a few minutes might reduce some of that sensory input.

And emotional or social rest might mean having some time when you're not having to

talk, listen, respond or manage other people's needs, perhaps not answering messages straight away.

You might need more than one type of rest at the same time, and what feels restorative will be different for everyone.

So rather than just thinking 'I need to rest', it can be useful to ask yourself: 'What has taken my energy, and what type of rest might I need just now?'

Rest doesn't have to be something we only do once we've completely run out of energy. It can be something we use as part of managing our energy throughout the day.

6

Choosing The Right Rest

Ask yourself: What kind of fatigue am I noticing?

- Physically exhausted → comfortable supported rest
- Mentally foggy → Quiet, eyes closed
- Overstimulated → Reduce noise/light
- Emotionally drained → Calm support or time alone
- Socially tired → Time away from others

Rest is not just stopping - it's choosing the right way to recharge your body and brain.

So we've looked at different types of rest. The next step is thinking about which type of rest might actually be helpful for you at that moment.

A useful question to ask yourself is: 'What kind of fatigue am I noticing?'

If your body feels physically exhausted, you might need to reduce physical demands and find a comfortable, supported way to rest.

If you're mentally fatigued, perhaps your concentration is going or you're struggling to process information, you might benefit more from reducing screens, decisions and information for a while.

If you're feeling overstimulated, reducing noise, light or other sensory input might be more helpful.

If you're emotionally drained, you might need some quiet time, reassurance or support from somebody you trust.

And if you're socially tired, you might simply need some time where you don't have to talk, listen or respond to anyone.

So the main message is that rest isn't always about completely stopping. It's about asking, 'What has taken my energy, and what might help reduce that demand just now?'

The more you start to recognise your own pattern, the easier it can become to choose something that actually feels restorative.

7 Activity Diaries - How They Help

Why keep a diary?

To spot patterns in your activities, rest, fatigue and symptoms.

What can it tell you?

Notice busy days, warning signs, habits and how you feel afterwards.

What could you change?

Could you spread activities out, plan rest or adjust commitments?

A diary is a tool, not a test

If it feels stressful or takes too much energy, other ways of noticing patterns are OK.



An activity diary can be a useful way of understanding how what we do throughout the day affects our energy and symptoms.

It's not just about physical activity. We can include things like thinking, socialising, emotional demands and rest.

The aim is to start noticing patterns. For example, you might find that after a particularly busy day, your symptoms increase later that evening or even the **following 12-48 hours**

It can also help you recognise habits, commitments or times when you might be pushing beyond what you can comfortably manage.

Once you've spotted these patterns, you can start thinking about small changes. Could you spread activities out, plan rest earlier or do something differently?

It's important to remember that a diary doesn't need to be perfect. And it won't suit everyone. If keeping one feels overwhelming or uses too much energy, there are other ways we can explore these patterns.

The diary is simply a tool to help you understand what works for you.

8 Read, Watch, Do

Choose one small change, test it, then review what you learned.

Read

RCOT: How to manage your energy levels

<https://www.rcot.co.uk/learn-about-occupational-therapy/ot-advice/lift-up/energy>



Watch

How to complete a diary

<https://vimeo.com/791871065>



Do

Keep a simple activity, rest and symptom diary for one week

<https://world.physio/toolkit/world-pt-day-2021-activity-diary>



 One small change at a time.

We've covered quite a lot today, and we wouldn't expect you to go away and try to change everything at once.

This slide gives you a few resources and something practical you can try.

Under Read, we've included information from the Royal College of Occupational Therapists about managing your energy.

Under Watch, there's a short video showing you how to complete an activity diary.

And under Do, we'd encourage you to try keeping a simple diary of your activities, rest and symptoms for one week, if that feels manageable.

This can help you begin to notice patterns. For example, what uses your energy, when your symptoms change and whether certain activities might need to be spread out or adapted.

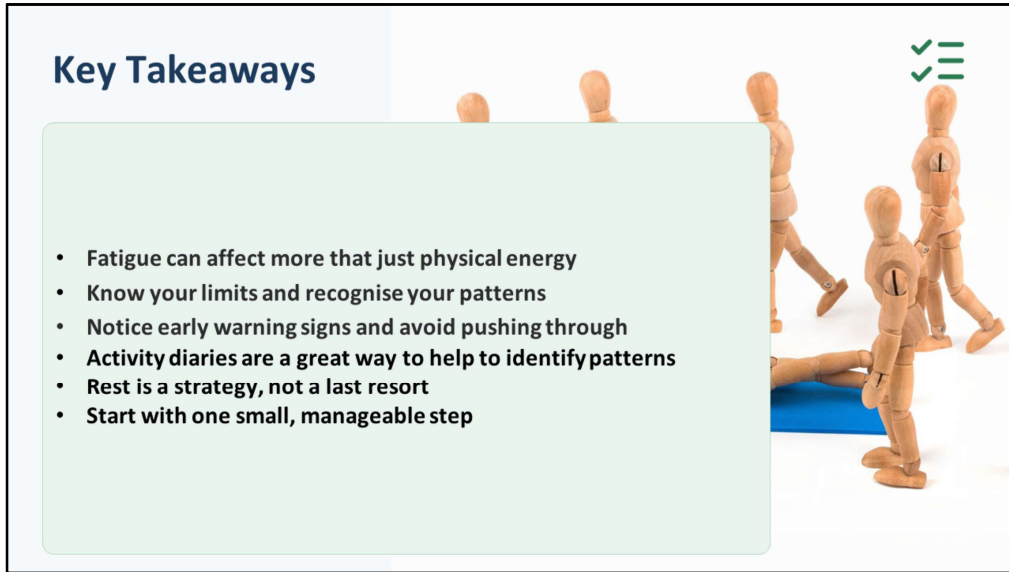
Remember, the diary doesn't need to be perfect, and it won't suit everyone.

The important thing is to start noticing what works for you and think about one small change that might help. .

[Lift up your everyday - managing energy | RCOT](#)
[Pacing and energy management - Action for ME](#)

[Simple Relaxing Body Scan | Nikki Callan](#)
[Breathing and relaxation exercises | NHS inform](#)

[Pacing, Planning and Prioritising - Patient Information Video](#)

The slide features a light blue header with the title 'Key Takeaways'. Below the title is a light green box containing a bulleted list of six points. The background of the slide shows several wooden mannequins in various poses, some standing and some lying down, suggesting fatigue. In the top right corner, there is a green icon consisting of three horizontal lines with a checkmark to the left.

Key Takeaways

- Fatigue can affect more than just physical energy
- Know your limits and recognise your patterns
- Notice early warning signs and avoid pushing through
- Activity diaries are a great way to help to identify patterns
- Rest is a strategy, not a last resort
- Start with one small, manageable step

We've covered quite a lot today, but these are the main things I'd like you to take away.

Fatigue affects more than just our physical energy. Thinking, emotions, socialising and our environment can all play a part.

Understanding your own patterns, recognising your limits and noticing early warning signs can help you make more informed choices about how you use your energy.

Activity diaries can be a useful way of spotting patterns, although they're not right for everyone.

Remember that rest is an important part of managing fatigue, not something we should only do once we're completely exhausted.

Most importantly, you don't need to change everything at once.

Managing fatigue isn't about getting everything right or doing as little as possible. It's about finding a more manageable balance and, where possible, keeping some energy for the things that matter to you.

So if you take one thing away from today, I'd encourage you to think about just one small, realistic change you could try.

Thank you for listening.