



Leeds Community Healthcare Trust
**MULTISYSTEM
REHABILITATION
SERVICE**



Fatigue information for patients

Fatigue as a symptom:
a shared experience



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What is fatigue?

Fatigue is a personal experience which can impact your physical, emotional, cognitive, social and functional health.

It is different from the typical tiredness that we all experience as fatigue may not improve with rest.

You may feel:

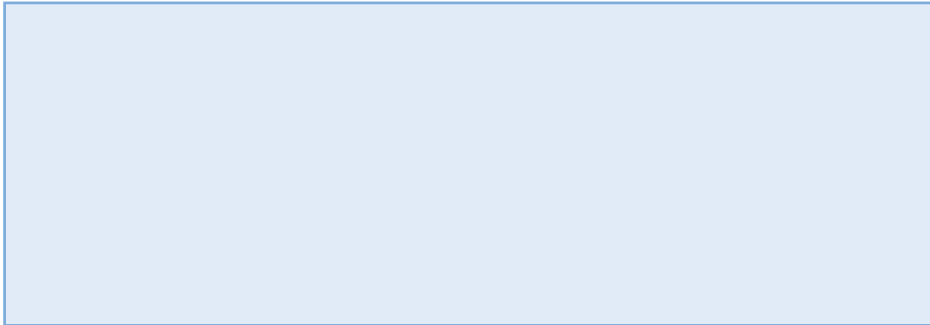
- Exhausted or 'sleepy'
- Physically and/or mentally weak
- A lack of drive or motivation
- Feelings of irritability, frustration, or being overwhelmed.

Fatigue can be linked to chronic pain conditions such as Arthritis, Fibromyalgia, ME, sleep disorders, autonomic issues that lead to low blood pressure, or it may occur without any of these factors.

The words we use to describe our fatigue are often an indication of where it bothers us most. Such as:

- My bones feel heavy (**physical fatigue**).
- My brain is like mush (**cognitive fatigue**).
- I can't be bothered to do anything (**emotional fatigue**).
- Spending time with people drains my energy (**social fatigue**).
- I can't keep up with daily tasks (**functional fatigue**).

Record below how you would describe your fatigue:



Look at the words you used to describe your fatigue, and you may see how fatigue is affecting you most.

This is a way to encourage understanding and make it easier to identify areas of life most affected by fatigue and find ways to address them.

It impacts on everything including everyday activities and can make even small chores or routine tasks seem impossible.

When living with a long term condition, fatigue is the most common symptom and can be hard to manage.

But it's important to remember that you're not alone.

Fatigue is the result of living within a reduced energy budget. Going over the energy budget can feel fulfilling but is often followed by **Post Exertional Symptom Exacerbation (PESE)**.

PESE is when symptoms like fatigue get worse after doing physical or mental activities.

Fatigue impacts on every aspect of life from who you are, how you feel, what you do, how others may respond to you and your self-worth.

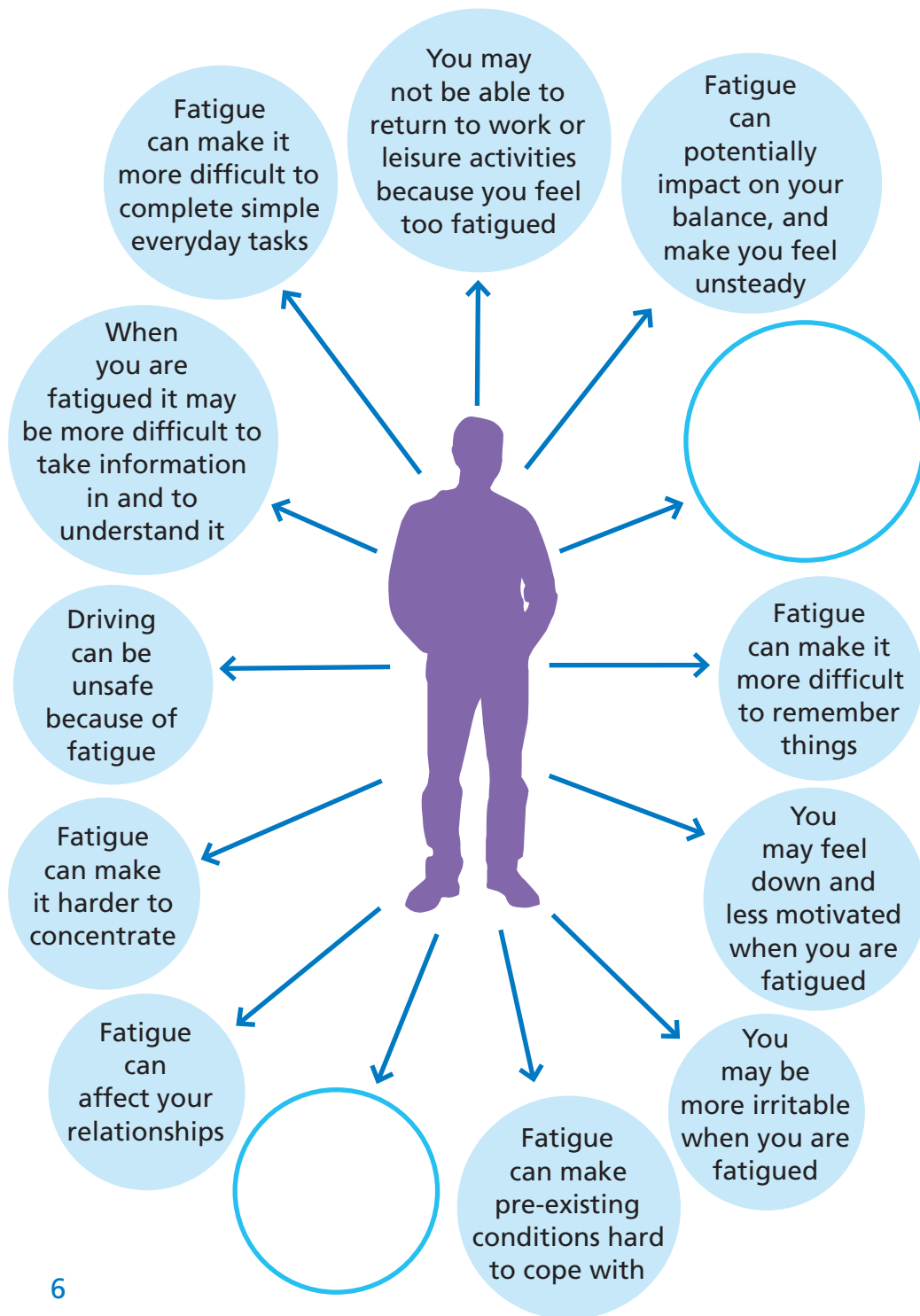
Fatigue can be:

- Distressing isolating and frustrating.
- Complex, multi-dimensional and multi-factorial.
- Experienced even with good quality sleep.
- Something that can be managed.

How you use your limited energy budget does have an impact on your recovery.

If you overexert yourself, you could experience a worsening of symptoms, like fatigue or brain fog. By managing energy carefully (through pacing and resting), you can avoid pushing beyond your limits, allowing your body to recover gradually and prevent setbacks.

On the diagram on the next page, circle the statements you agree with. Add any extra things you can think of.



What causes fatigue?

Internal causes/primary factors:

- **Pre-existing medical conditions** (such as pain, ME/CFS, or other chronic illnesses).
- **Poor sleep quality** (even if you sleep for long periods, the quality of sleep can be affected by your condition).
- **Low mood or depression** (often linked with chronic illness and can worsen fatigue).
- **Personal values and self-expectations** (e.g. the belief that you should push through fatigue or avoid being seen as 'lazy').
- **Stress** (both physical and emotional stress can increase fatigue levels).
- **Past trauma** (which can contribute to heightened sensitivity to pain and fatigue).
- **Immune system dysfunction** (which can be a factor in conditions like ME/CFS).
- **Increased inflammation** (common in conditions like fibromyalgia, arthritis, and ME/CFS).

External causes/secondary factors:

- **Lack of understanding or awareness** (how chronic illness affects fatigue).
- **Diet and nutrition** (poor diet or imbalances can affect energy levels and overall health).
- **Deconditioning** (muscle weakness or physical decline due to inactivity, often a result of pain or fatigue, discussed later in the booklet).
- **Stopping activities, you enjoy or reducing social interaction** (this can lead to emotional fatigue and a sense of isolation, which can make fatigue worse).

- **Medication side effects** (some medications for pain or other symptoms can increase fatigue).
- **Pressures and expectations** (from work, family, friends, or yourself, which can cause stress and worsen fatigue).
- **Societal values or stigma** (misunderstanding about invisible illnesses like ME/CFS or fibromyalgia, and how it impacts daily life).
- **Financial pressures** (concerns about money, debts, housing, etc. can cause ongoing stress that worsens fatigue).
- **Environmental factors** (such as living in an environment that isn't supportive of rest or recovery, like noise, overcrowding, or lack of a comfortable space).

Use this space to write if some of these areas could be impacting the management of your fatigue.

<i>Pre-existing medical conditions</i>	
<i>Side effects of medication</i>	
<i>Sleep disturbance</i>	

<i>Poor diet or nutrition, erratic eating patterns</i>	
<i>Going over your energy budget (PESE)</i>	
<i>De-conditioning (not doing enough)</i>	
<i>Stress, worry, anxiety, feelings of failure, low mood, unable to meet my goals/expectations</i>	
<i>Infections or other illnesses</i>	
<i>Unmanaged pain</i>	

If you recognise some of these issues, please seek support from your GP or healthcare professional.

Phone battery analogy

Our energy levels can be seen as a battery pack of power.



How much energy do you have in your battery pack right now?

How much energy are you generally able to get in your battery pack?

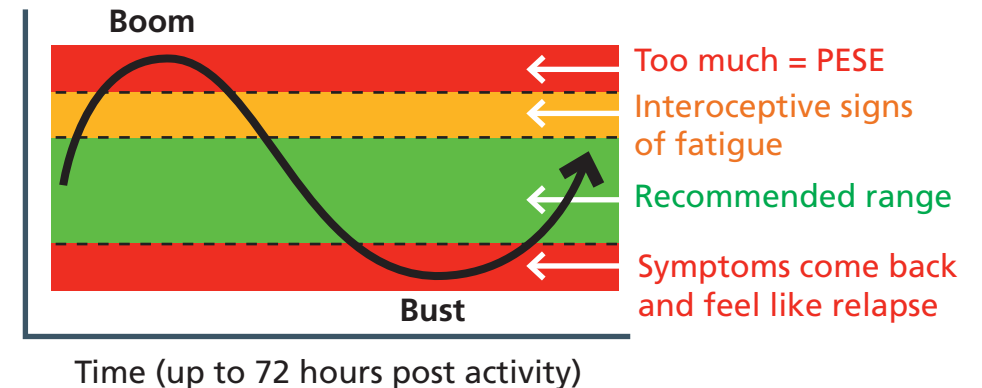
Everything we do takes up energy. Each task we do takes some charge from that battery. Ideally, we should have enough battery power to allow us to complete all our activities before running out at the end of the day.

Every activity, no matter how small, requires energy. Think of your energy as a battery - each task you do drains a little from it. Ideally, you want enough energy throughout the day to complete all your activities without running out before you've finished. However, with chronic fatigue, the 'battery' may drain more quickly, making it harder to accomplish everything you'd like to do.

Awareness

Knowing how your body responds to fatigue is called awareness - the feeling of knowing what is happening in your body.

Awareness of the sensation of fatigue is crucial for understanding your battery charge.



A fatigue diary may help you understand your energy patterns.

Therefore, adjusting your expectation from what you think you should be doing to what your energy budget may allow you to do, is the most important starting point to managing fatigue.

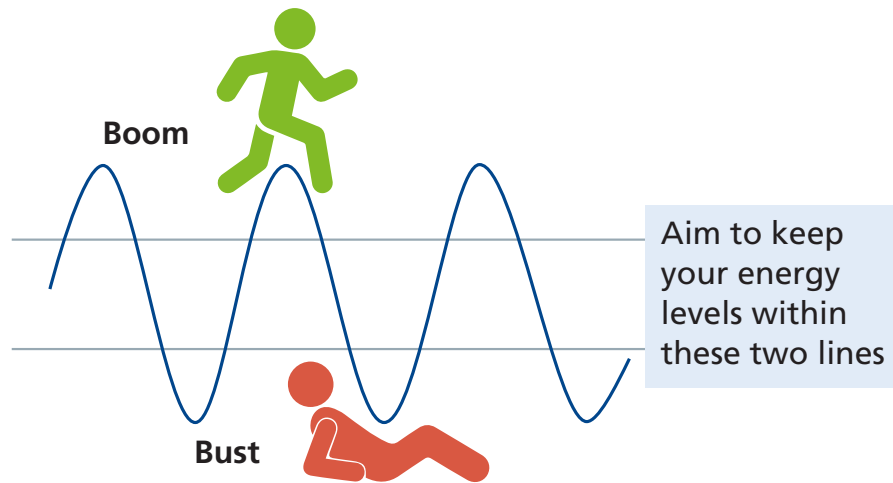
For some people, they may have heightened or over awareness of sensations in the body. For others, awareness of sensations maybe dulled. Both these states of under and over awareness of body sensations makes managing fatigue a challenge.

When we have fatigue, we are unable to fully recharge the battery, leaving us at risk of running out of energy before we have done all we expect of ourselves.

Our minds may expect the same level of activity as before the onset of chronic illness, but our 'batteries' may struggle to fully recharge, leaving us unable to meet those expectations.

Working on empty can cause an exacerbation of symptoms such as muscle and joint pain.

Post Exertional Symptom Exacerbation (PESE)



This is an illustration of what happens when you go beyond your energy budget. You might have heard of this also being called Post Exertional Malaise or The Boom Bust Cycle.

Lots of people who experience fatigue find themselves in what we call the Boom Bust Cycle. This is when we do too much on a good day(s) and then have a 'crash' period afterwards. People often describe trying to fit everything in while they feel like they have some charge in



their battery. It is tempting to do as much as possible while the energy is there and push past our limits - this 'flattens the battery' even more. When the battery has been flattened, there is no choice but to stop and actively rest to 'recharge'.

Recovering from Post Exertional Symptom Exacerbation (PESE)

Going over your energy budget causes your symptoms to increase.

To avoid PESE, we must work to the optimum of our energy pack and not stretch too far ahead or beneath it. We must remember that our use of energy impacts on our recovery.

PESE can manifest up to 72 hours after doing too much. Once you have stabilised your energy budget, you can work to a slow incremental increase of between 5%-10%.

If this is successful without signs of unmanageable fatigue, increase the amount again three times in a slow, stepwise way.

Research has shown that by slowly and incrementally increasing activity, our battery is able to charge more fully. It is therefore more effective on our physical and psychological wellbeing to pace, prioritise and plan activities.

Call 0113 843 3496 if you require this information in large print, braille, audio or another language.

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(Urdu)

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تو 0113 843 3496 پر کال کریں۔

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