THE UK SEPSIS TRUST

SEPSIS AND FATIGUE

Fatigue is one of the most common things people experience following sepsis, and it can be difficult to describe. It's different to the everyday tiredness that we all experience at times.

In this document, you can find more information on what fatigue is and tips for managing it.

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WHAT IS FATIGUE?

Fatigue can be described as complete physical and/or mental exhaustion that is not relieved by sleep or rest periods. It's common following any illness and, whilst your journey is unique, for most people it will improve as you get better. Fatigue can continue for weeks, months or even years, making recovery significantly more challenging. Fatigue ranges from mild to extreme, with the signs and symptoms taking many forms. It will vary from person to person, but some of the most common can include:

- Being very weak and excessively tired nearly all the time.
- Feeling dizzy, faint, and/or sweating.
- Muscle and/or joint pain.
- Finding it hard to sleep, not feeling refreshed when you wake.
- Problems with memory.

Fatigue has a close relationship with energy and activity. Activity doesn't just mean taking time out to exercise – anything we do which requires energy counts as an activity. It could be a physical task like showering, walking or making a cup of tea, a cognitive task such as reading a book, listening to a podcast or talking on the phone, or an emotional task like worrying or speaking about your experiences with a loved one or a health professional.

WHY MIGHT YOU GET FATIGUE AFTER SEPSIS?

The precise science of why some people experience fatigue remains uncertain, but it is due in part to the inflammation that happens during sepsis and its effect on the body's cells, organs and tissues – this, naturally, includes our brain and our muscles. The physical deconditioning which occurs when we have an acute illness and subsequent period of inactivity will also contribute. This is in part because our body enters a 'catabolic' state when we are critically ill – we break down proteins in muscles and other tissues in an attempt to survive, so we lose muscle tissue. This is sometimes why some survivors find they have an abnormally high appetite once they get home!

HOW CAN YOU HELP YOURSELF?

Don't be surprised if your tolerance to activity is reduced and you have new physical limitations – this is generally considered normal and to be somewhat expected in the early stages of recovery.

You can start by doing an honest appraisal of where you're at and acknowledging any limitations you're experiencing, which, although difficult, can give a real insight as to where you are and help you to establish your new baseline. Work out the level of activity you can currently do comfortably without excessive fatigue. As mentioned, this might be significantly reduced compared with your previous level of activity. Try not to judge yourself, compare, or make any assumptions – you are where you are, and acknowledging this is particularly important. A fatigue scale can also help identify where you are now, along with monitoring your symptoms over time. An example of which can be found here.

Keeping an accurate diary and activity planner for a couple of weeks can really help you understand the baseline you are starting from. Document what you are doing and any symptoms you're experiencing, including periods and type of activity, rest, fatigue, and sleep. This information can then help you to plan and prioritise your time and future activities, along with measuring your progress and identifying what to discuss with your health professional.

Our Recovery Diary includes diary templates for this purpose.

THE SPOON THEORY

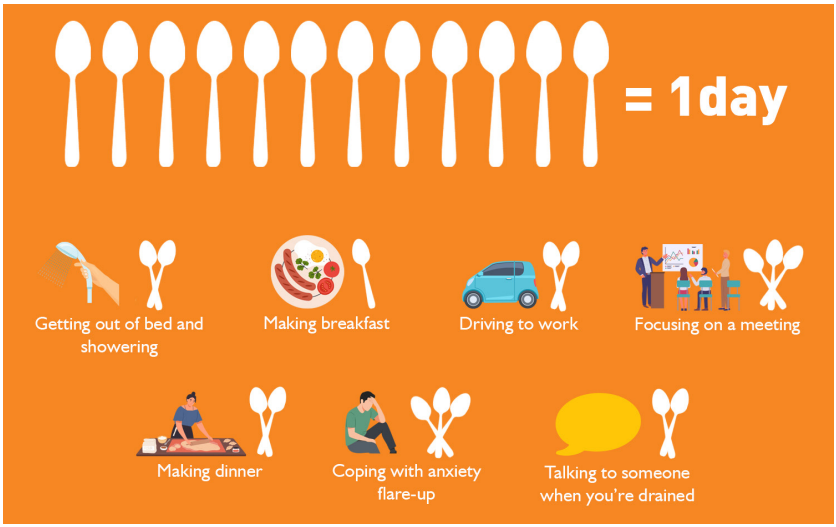
It can be helpful to visualise the energy you have as units. A metaphor commonly used in energy management is the Spoon Theory. The Spoon Theory metaphor was created to help people understand what it's like to experience fatigue and to manage their daily activities. It suggests that each day, you have a finite number of 'spoons' representing your energy level, and each activity or task requires a certain number of spoons to complete. Once the spoons are used up, there is no way to replenish them except through rest and sleep.

When you're well, you might have an unlimited supply of spoons and not have to think about where you're using them. Your body's natural reserves and your sleep cycle will replenish those you use without you noticing. But when you're recovering from sepsis or managing ongoing fatigue and pain, you start the day with a very limited number of spoons and have to be mindful about where you're using them.

How it works:

Let's say you have 12 spoons for the entire day.

Every activity 'costs' a certain number of spoons. You can find an example on the next page.



You can see how fast those spoons get used up – and if you run out like above, you're already 3 spoons 'over'. That's when crashes can happen.

How you can use the Spoon Theory:

1. Each morning, check in with how many "spoons" you have. It may not always be 12 – some days it's 8, or 4.

2. Plan your day based on energy, not just tasks. Prioritise and drop things if needed.

3. Rest before you're out of spoons – not after. Recovery takes more spoons than rest.

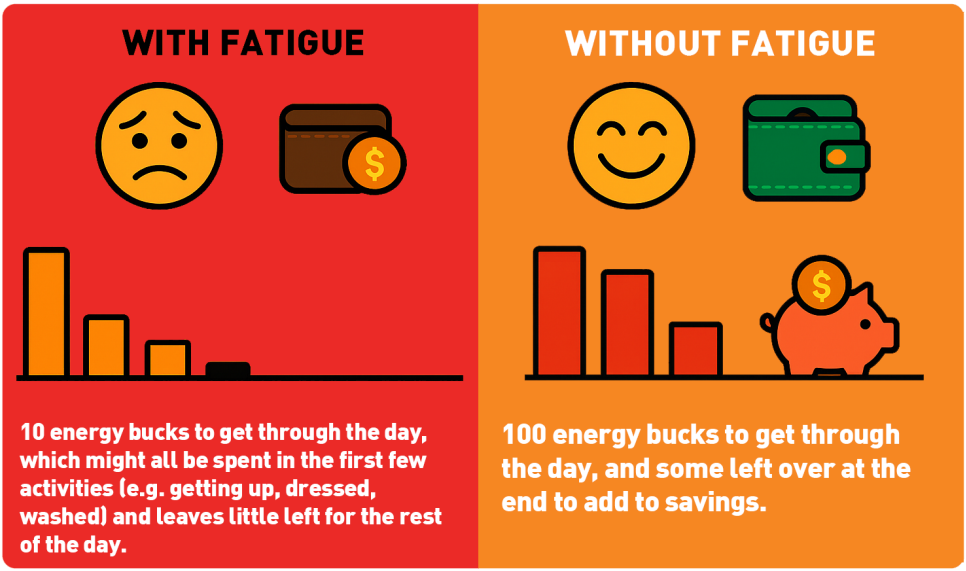
4. Tell others: "I'm low on spoons today" – it's a gentle way to ask for understanding without needing to explain everything.

ENERGY BUCKS

Another way you could visualise your energy levels is as 'energy bucks'. The more bucks you have in the bank, the more activity you can sustain. Remember, following sepsis your threshold or tolerance to activity is lower so you have fewer energy bucks to spend.

You may only have so many energy bucks to spend each day, and you therefore must be mindful about how you're spending them. You wouldn't want to use them all up in one go; it's better to spend small bits at a time and keep topping them up. When you're well, you don't have to think so carefully about your energy budget as you can draw upon your reserve or 'overdraft' when you need to.

ENERGY BUCKS: WITH VS. WITHOUT FATIGUE



THE 3 Ps OF FATIGUE MANAGEMENT

PRIORITISNG

Think about what you deem as essential – what really needs to be done (this is different from what you think should be done). Assigning different colours or labels to tasks can be useful here: those marked as essential are top priority, others are to be done if possible, and a final group are nice to do tasks for when you have anything left in the energy bank. Consider delegating tasks and remember to prioritise rest periods. Include work or study in this prioritisation exercise – you might be in this for the long haul, so these activities you'd previously have classed as essential might have to be a consideration for a lower grading at some point.

Don't forget to give yourself permission to do the things you enjoy - this can help find a balance during your recovery.

PACING

You may be tempted to do more – or 'catch up' with tasks – when feeling energised, but with fatigue this will often lead to extended periods of feeling drained or crashing. This is commonly known as 'boom and bust'.

Pacing is about balance, managing activities and factoring in rest, even if you feel you can do more. Spend just enough time doing an activity so you get the most out of it, without pushing yourself so you use up all of your energy budget, or spoons.

For example, if after a 10-minute walk you're completely exhausted, try doing 5 minutes the next time. Even if you feel you can do more, don't, gradually build up from there. This can help you find your baseline or what you can do comfortably without using all of your spoons!

Or, if you identify gardening as a priority activity, consider breaking it into more manageable chunks along with some important rest periods. It's okay if it takes you longer to achieve a task. If you have historically been the sort of person who likes to get the entire garden finished in a day, try to gently accept that at the moment, you might need to break down the tasks over a period of several days.

With practice, you should start to understand when to stop and take a break. Pacing can be a challenging concept, and nobody gets it right all of the time. It's also unique, so what works for one person might not necessarily work for you and – like implementing anything new – it can take time to adjust. Remember, you're doing your best so try not to be too hard on yourself when things don't go according to plan. Along with the other Ps you can start to consider how to best approach each activity.

PLANNING

Decide how and when you are going to do the activities you have set yourself and how difficult you anticipate them to be. This will be easier when you start to identify any patterns and can be a trial-and-error exercise. You will hopefully start to recognise times of the day/week when you feel more energised and this might be a time to plan more 'demanding' activities that require more spoons.

Another important consideration is what equipment or support might you need for your activities – this might include something to sit on, walking aids, or other people.

Remember to plan your rest periods too. It can be helpful to think of rest being prescribed like an important medication!

GOAL SETTING

Goal setting can help with gently increasing your activities as tolerated. Goals can be a strategy to help with setting the priorities of what you wish to focus on and build a plan on how you will get there; this will commonly involve lots of smaller steps. Goals might include physical goals, like increasing activity, but can also include social and emotional goals.

Overall, goals don't necessarily have to be at a similar level to your previous level of activity – this could set you up to fail – so try to make those goals as achievable as possible to begin with.

Try to ensure your goals are specific, realistic, achievable and sustainable. Start small, don't be hard on yourself if don't achieve them and celebrate your achievements when you do.

Take some time to think about what's important to you and where you might like to get to in the coming days, weeks or months. Consider areas that you are finding most challenging now, what's most important to you, or what you are really missing in your life.

Remember to check in with your goals at diffierent times. This can be an opportunity to ask yourself if it remains important and if it is realistic right now. It might be an opportinity to review and amend your goals.

Questions to consider when setting and working towards your goals:

- Is this something I really want to do?
- Is this something that is important to me?
- Is this something that will help me manage my overall recovery?
- Can I realistically see myself achieving this goal?
- Have I been specific enough?

Think SMART

SMART Goal Template: Building Up to a 1-Hour Walk in 3 Months

S - Specific

I will gradually increase my walking so that I can complete a continuous 60 minute walk with my partner.

- Starting point: I can currently walk for _____ minutes/or _____ distance without stopping.
- Current walking days per week: _____ days.

M - Measurable

I will track my progress by:

- Recording walk duration after each walk.
- Increasing walking time by _____ minutes every _____ week(s). As tolerated by my symptoms.
- Completing a continuous 60-minute walk by (date): _____ (3 months from start date).

Progress milestones:

- End of Month 1: Walk continuously for _____ minutes.
- End of Month 2: Walk continuously for _____ minutes.
- End of Month 3: Walk continuously for 60 minutes.

A - Achievable

To make this achievable, I will:

- Start at my current ability level (_____ minutes).
- Walk _____ times per week.
- Allow rest days between longer walks.
- Adjust pace to a comfortable, conversational speed.

Support available:

- My partner will: _____.
- I will manage challenges by: _____.

R - Realistic

This goal matters to me because:

- I want to _____.
- Walking with my partner will help me feel _____.
- Improving my fitness will support my _____.

T - Time-Bound

- Start date: _____.
- Target date (3 months later): _____.
- Weekly check-in day: _____.

TOP TIPS FOR FATIGUE

- Try to find that delicate balance between activity and rest. Too much rest might lead to further deconditioning and too much activity might lead to worsening fatigue and can be detrimental.

- Remember, activity is anything we do that needs energy. It might be going for a gentle walk, reading a book… even sleep requires energy!

- You might consider some activities worth a blow out! This might use all your spoons for the day or even a few days. Give yourself permission to do this and acknowledge that there might be a consequence but that's okay. Some activities are worth it and might have more positive mental health benefits.

- Remember that fatigue does not just apply to physical elements. A cognitive and/or emotional activity will affect your energy levels. Think about how draining worrying can be!

- Consider how you talk to yourself. This is really important, as we are often our own worst critic. Try replacing "I can't do that anymore" or "I should be able to do that" with "At the moment, I'm choosing not to do that". It's a subtle difference but over time it can start to shift the narrative.

- Using a diary or planner can really help to make sense of things and identify patterns. You could use paper or digital versions. Find something that works for you.

- Celebrate the achievements, no matter how small! Sometimes life is unpredictable and the unexpected can often happen. Try not to be too hard on yourself if things fall below your expectations despite all the best planning and preparation.

- Ask for and accept help. This might not come naturally but can make a real difference.

- Remember, it's okay to have 'me' time. Use this to relax, distract and switch off as much as possible or do something you really enjoy and don't feel guilty!

WHAT TO DO IF YOU'RE WORRIED OR THINGS ARE GETTING WORSE?

If symptoms persist or worsen over time, then we would encourage you to speak to your GP or health professional to ensure nothing else is contributing, and to explore fatigue specialist services.

HELPFUL LINKS AND FURTHER INFORMATION

UK Sepsis Trust - sepsistrust.org/get-support/

THE UK SEPSIS TRUST

The UK Sepsis Trust registered charity number (England & Wales) 1158843 (Scotland) SC050277.
Company registration number 8644039. Sepsis Enterprises Ltd. Company number 9583335.

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