

## Cancer-related fatigue

This information is about cancer-related fatigue, a type of extreme tiredness that can be physical, mental and emotional. Fatigue affects most people who have cancer.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk).

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## What is cancer-related fatigue?

Cancer-related fatigue is exhaustion that's at a much higher level than would usually be expected – you might feel tired very quickly after doing quite little. It can be physical, emotional or mental exhaustion.

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**I experienced fatigue before I was diagnosed and during my treatment. I had to just lie down and take the weight off my feet. The difference between fatigue and tiredness is, in my opinion, remarkable; fatigue hits you like a steam train whereas tiredness can creep up on you.**

Martin, diagnosed with diffuse B-cell lymphoma

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Fatigue can have an effect on various areas of your life, including your **relationships**. You might not be able to do all the activities you usually would. You might need to take time out of **work** or **education**, or adjust your hours of work or study, if you can.

Fatigue can also make you feel low and irritable and can affect **thinking processes** such as memory and concentration.

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**I found it made a big difference to talk about my fatigue – to be open and honest about it with friends and employers. I found that people understood when I said I needed to rest. I couldn't do everything but I could still do some of the things I wanted to if I paced myself. You need to be patient with yourself.**

Martin, diagnosed with diffuse B-cell lymphoma

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## Who gets cancer-related fatigue?

Most people who have cancer experience fatigue at some point. It's a common symptom in people with **blood cancer**, including **lymphoma**. Many people who are treated with **chemotherapy** and **radiotherapy** report feeling fatigued at some point during their treatment.

If you have lymphoma and another condition that affects your energy levels, you might be more at risk of developing fatigue. Sometimes, also addressing these issues can improve fatigue.

Examples of conditions, and sometimes medications for them, that can affect your energy levels can include:

- lung, kidney or heart disease
- another type of cancer
- low testosterone in men
- menopause in women
- an underactive thyroid (**hypothyroidism**)
- diabetes, if you have uncontrolled blood-sugar levels and, particularly if have been taking **steroids**.
- low red blood cells (**anaemia**)
- **depression**

- **anxiety.**

Other factors that can increase the risk of fatigue include:

- having a higher **stage** (3 or 4) of lymphoma compared to lower stage (stage 1 or 2) lymphoma
- taking strong painkillers, such as opioids
- having, or recovering from, an **infection**.

**Steroid** treatment can also affect energy levels. Some people experience an increase in energy while they are taking them. However, you might feel more tired when you stop taking them. Your medical team will give you advice to help you lower your dose gradually.

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## Diagnosing cancer-related fatigue

It can be difficult to test or measure fatigue. Your doctor will talk to you about your symptoms and how they're affecting you. They might also use a questionnaire to find out about how it affects you. Some hospitals use a system called electronic patient reporting outcome measures (ePROMs). This uses a set of questions to help assess your symptoms and any concerns you have, including fatigue.

Fatigue is most commonly assessed around the time of diagnosis or during treatment. However, it can happen months or years after treatment, as a **late effect** of treatment. If you think you might be experiencing cancer-related fatigue, speak to your medical team or your GP for advice.

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## Managing cancer-related fatigue

Cancer-related fatigue can have a significant impact on your general sense of wellbeing. Although there are no specific treatments for fatigue, there are things that can help. Speak to your medical team for advice and to find out how they can support you. Your medical team or GP can discuss **factors that might be making your fatigue worse** and offer ways of addressing these. Sometimes, this includes making changes to your **lymphoma treatment**.

## Healthy lifestyle

It's important to eat a **healthy diet**, with food that gives you enough energy and nutrients. Your clinical nurse specialist can give you advice to help with this. They might also refer you to a dietitian for tailored advice on what to eat and drink. This can be helpful particularly if you have difficulties with eating, for example, as a **side effect of treatment**.

**Exercise** is one of the best ways of improving fatigue. It can help directly, by increasing muscle strength. It could also help indirectly, by improving factors that can add to your fatigue – for example pain, **low mood and anxiety**, sleep problems. It might also help immunity.

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**I have a dog called Floyd, and was glad that I had a reason to get out of the house each day. Some days I felt so fatigued and wiped out, that all I could do was find a seat and throw the ball to Floyd. But on other days when I could take a walk, I found that exercise – and just being out of the house – was really helpful.**

Pam, diagnosed with extra-nodal marginal zone lymphoma

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## **Planning your activities**

Think about how to manage your **day-to-day activities** to help save your energy for things you need and want to do. It might help to visualise your energy as a bank. Times of rest represent adding to funds, while tasks and activities that use energy represent withdrawals.

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**I could cope with what needed to be done during the day, but early in the evening it was as though a light switch had been flicked off inside me and I had to go to bed. Over time this eased. I do think it's important to devote some of your energy to your own happiness and enjoyment and to spend time with family and friends – you deserve to have fun and your spirits lifted. Give yourself something to look forward to with pleasure.**

Sheila, diagnosed with non-Hodgkin lymphoma

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## **Using a fatigue diary**

A fatigue diary is a way of keeping track of your energy levels to help see if there are any patterns. This can help you to see if there are things that make your fatigue better or worse. It might then be possible to plan some of your activities for times when your energy is higher. Be sure to give time for rest between activities too. There's no set amount of time you should keep a fatigue diary for, but often a couple of weeks is enough.

Tips for keeping a fatigue diary:

- Mark the days that you have treatment, for example, using a cross.
- Use a colour-coded system to mark your level of activity (including rest and sleep) throughout the day.

You can [download a copy of our fatigue diary](#) on our website. There are also some apps available to help reduce fatigue and exercises to help improve your energy levels.

### **Work and education**

At least for a little while, many people affected by fatigue stop or lower the number of hours they [work](#) or study during or after treatment.

If you work, you might delegate some of your duties to colleagues for a while. Some people come to an agreement with their employer to work from home for part or all of their hours. If you are self-employed, find out what [financial support](#) is available to you if you need to take some time out of work.

If you are in education, talk to your school, college or university about your situation. Find out how they can support you with your [studies or training](#). If you are at school, you might also be entitled to support from your local council to help reduce the impact of your lymphoma on your education.

You could also speak to your GP or clinical nurse specialist about the possibility of a referral to an occupational therapist (OT). They could help by suggesting and making any adjustments to your work or educational environment and pattern, to help maximise your energy. They could also support you in helping your employers or teachers understand the impact of cancer on your work and studies.

## Tips to help manage fatigue

- Plan and prioritise your activities and workload – set realistic goals that you can break down into manageable chunks.
  - Plan regular rest breaks – short rests planned throughout the day are better than long ones.
  - Ask family and friends for help where you can – save your energy for the tasks that only you can do or for the ones you most enjoy.
  - Talk to your GP or clinical nurse specialist about whether an occupational therapist could help you – they can give practical advice to help you manage at work, school or home, including organising equipment and adaptations.
  - Make time to keep up with fun and enjoyable parts of your life, including spending time with **family and friends**.
  - Use devices or equipment you could use to make tasks easier or quicker.
  - Try to get into a **sleep routine**, to help you get a restful night.
  - Consider relaxation techniques and **complementary therapies**, for example **mindfulness meditation**, **acupuncture**, **yoga** or **massage** – speak to a member of your medical team before trying one, to check it's safe for you.
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## Frequently asked questions about fatigue and lymphoma

Below, we answer some questions that people often have about fatigue. Speak to your medical team for advice specific to your situation.

You might also be interested in our **coping with fatigue webinar**, jointly hosted with Leukaemia Care. It addresses common questions about fatigue and suggests ways to help you cope with it. You can watch it on our website and the slides are also available to download.

### Is it helpful to take naps?

During treatment, a nap might help give your body the additional rest it needs. However, with long-term cancer-related fatigue, sleeping during the day could disrupt your night-time sleep pattern. In this case, a rest without sleeping might be better.

## Are there any supplements I can take to help with my fatigue?

If you are able to, the general guidance is to eat a **healthy balanced diet**. If you have **difficulties eating**, you might be advised by a member of your medical team to take an additional **multivitamin and mineral** supplement. It's important to check with consultant or CNS before taking supplements. Some are harmful if taken in high doses and can react with other medications and treatment for lymphoma.

## How can I explain my fatigue to friends and family?

Fatigue can be difficult to understand if you've never experienced it. Some people feel upset or frustrated if those around them don't seem to appreciate how exhausted they are.

You could use comparisons to help. For example, you could describe your energy levels as a bank with a limited amount of money to spend, or a car with a limited amount of fuel to use. Christine Miserandino describes her experience of illness-related fatigue, using **spoons to represent units of energy** – you could show them this.

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**I remember saying to my husband, 'When I say I'm tired, I mean I can't function – I can't even make sense of what I'm saying, so I may as well sleep'.**

Nicola, diagnosed with diffuse large B-cell lymphoma

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## How can I cope with the emotional and psychological impact of fatigue?

Fatigue can have a big impact on how you feel and think. Many people struggle with the emotional effects of living with fatigue. Speak to your clinical nurse specialist or GP about how you're feeling.

You could consider getting support from a **talking therapist**, such as a **counsellor** or psychologist. Talking therapists work in different ways to help people with difficult thoughts and feelings. **Cognitive behavioural therapy (CBT)** is one type of talking therapy. Often, it involves adapting the way you think about things in order to cope more easily with your situation. Sometimes, it includes addressing other difficulties that might be connected to the fatigue, such as sleep difficulties and **explaining your fatigue to those around you**.



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**It can take a little while to notice improvements. Instead of reflecting on what you were able to manage to do last week, it can be helpful to compare what you can do now to what you were able to do last month.**

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## References

The full list of references for this page is available on our website. Alternatively, email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or call 01296 619409 if you would like a copy.

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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