

Fatigue

This page is about cancer-related fatigue – extreme tiredness that’s not proportional to activity and doesn’t necessarily go away after rest. It affects almost everybody who has cancer at some point in their illness.

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What is fatigue?

Cancer-related fatigue is significant physical, emotional or mental exhaustion that’s not proportional to recent activity. It doesn’t feel the same as normal tiredness after working hard or exercising: it’s much more troublesome and it doesn’t necessarily go away after rest or sleep.

People often say that fatigue is the most distressing **symptom of cancer** and cancer treatments. They describe it as a ‘paralysing’ feeling or as ‘being drained of energy’. Someone once described it as ‘like having no bones – sitting up was sometimes too much of an effort.’

Why does cancer cause fatigue?

It's not clear exactly why cancer causes fatigue. It's probably a combination of factors, including:

- physical effects of the cancer and **cancer treatments**
- changes in the levels of hormones involved in normal patterns of sleeping and waking caused by the cancer itself or by some treatments
- muscle weakness caused by lower than normal levels of activity
- **sleeping difficulties**
- the **emotional impact** of having cancer
- eating less because of **sickness** or poor appetite
- **side effects** of cancer treatments, such as **anaemia** or infections
- genetic factors.

Some medicines (such as antihistamines, antidepressants, strong painkillers and **anti-sickness drugs**) may also contribute to fatigue in people with cancer.

Who gets cancer-related fatigue?

Fatigue affects almost everybody who has cancer. It's often listed as the most common symptom in people with blood cancer, including lymphoma. It is usually mild-to-moderate but it can be more severe.

You are more likely to be affected by fatigue if:

- you are already fatigued at the time of cancer diagnosis
- you have another illness, such as lung disease, kidney disease or heart disease, as well as cancer
- you also have anxiety or depression
- your lymphoma is **stage 3** or 4
- you are taking opioids (strong painkillers)
- you have **anaemia** (low levels of haemoglobin in your blood).

How does fatigue feel?

Fatigue is a distressing symptom that can have a big impact on your life. It can be difficult to explain to other people.

Fatigue affects people differently. Some people find they can't do as much as they used to. Others feel so tired they can't do their usual activities. Everyday tasks, like getting dressed or making a cup of tea, can feel overwhelming.

You might feel you don't have enough energy to see friends and family. You might lose interest in things you usually enjoy, or lose your motivation to do things. If you work or go to school, you may need some time off because of fatigue.

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

Some people with fatigue find it difficult to sleep even though they are tired. Others struggle to stay awake and may fall asleep when they don't intend to.

How long does fatigue last?

Fatigue usually gets better gradually after you finish cancer treatment. The time it takes varies from person-to-person, but it's common for fatigue to last for months after treatment has ended. For some people, it can last a year or more. In a few people, it may persist for several years, although it usually gets less troublesome over time. For some, energy levels might never be quite the same as they were before.

If you have fatigue that starts or gets worse months after treatment, tell your medical team.

How is fatigue assessed?

Fatigue is a very personal symptom that's difficult to assess. Your medical team might suggest measuring your fatigue by asking you to give it a score between 0 and 10 (where 0 = no fatigue and 10 = the worse fatigue you can imagine).

- 1–3 is mild fatigue.
- 4–6 is moderate fatigue.
- 7–10 is severe fatigue.

They might also use questionnaires that ask about the impact of fatigue on your day-to-day activities.

How is fatigue managed?

If you are affected by fatigue, tell your medical team. They can offer you advice about what support is available for you.

Medicines to treat fatigue have had mixed results and aren't recommended for routine use. However, there are lots of things you and your medical team can do to reduce the impact of fatigue on your life.

- Your doctor should look for factors that might be making your fatigue worse, such as **anaemia**, depression or anxiety, pain, dietary issues, medicines or other illnesses. Treating these factors might also improve your fatigue.
- You might be referred for **cognitive behavioural therapy** CBT, or talking therapy) to help you develop ways of coping with fatigue. It can also help you deal with **stress, sleep issues**, depression and anxiety – all things that can make fatigue worse. CBT is provided by a specialist therapist.
- If fatigue is interfering significantly with your day-to-day life, you might be referred to a physiotherapist or occupational therapist to help you develop strategies to reduce the impact of fatigue on your activities and routines.

- If your fatigue is particularly disabling, your team might consider changing your **cancer treatment**. This is a difficult decision and the treatment team will look for the right balance between treating the cancer and improving your quality of life.
 - If you are receiving **palliative care**, your doctor might talk to you about using steroids to help with fatigue. These are helpful in the short-term, but they're not recommended for long-term use because of negative side effects.
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What can I do to cope with fatigue?

Fatigue can be very distressing but there are lots of strategies that can help you cope with it.

The three Ps: Plan, Prioritise and Pace yourself

We all have a limited energy supply. Some days, we have more energy than others. Consider how much energy you've got and how much energy it takes to do each activity you want to do. Use this to help plan your day. If you don't have enough energy to do everything you'd like to, think about your priorities; consider what can wait for another day and what can be delegated.

- Work out when in the day you have the most energy and prioritise the most important activities or work to do during this time.
- Set yourself realistic and achievable goals; don't be too ambitious.
- Break down tasks into manageable chunks.
- Plan regular rest breaks – short rests planned throughout the day are better than long ones. Try not to sleep during these rests as this can disrupt your night-time sleeping pattern.
- Delegate tasks to other people where you can; use your energy for the tasks that only you can do or for the ones you enjoy most.
- Find activities that give you energy.

It might help to visualise your energy as an energy 'bank', with rests as 'deposits' and jobs and activities as 'withdrawals'. It is tempting to overdo things as soon as you have some energy in the bank, but you risk draining your energy reserves completely and exhausting yourself. This kind of 'boom–bust' cycle can make your fatigue worse.

Think about ways you can make tasks easier and use your available energy more efficiently. For example, you might find simple gadgets helpful, such as electric tin openers or long-handled shoe horns.

Keep a fatigue diary

A **fatigue diary** allows you to track your energy levels each day to see if there is a pattern to your fatigue. This can help you identify things that make your fatigue better or worse. It can also make it easier to plan activities and rest periods.

- Put a cross in the boxes on the days you have treatment.
- Use a colour-coded system to represent your level of activity, relaxation and sleep.

Exercise and physical activity

Exercise and other forms of physical activity are some of the best things you can do to help fatigue. There is a lot of evidence that regular exercise improves fatigue, physical health and quality of life in people with lymphoma. Even a short walk a few times a week can be beneficial – although people often find they can build this up over time.

No particular type of exercise seems to be better than any other for fatigue, so do what you prefer or ask your medical team for advice on the type of exercise that would be best for you. Some leisure centres offer community exercise programmes especially for people living with or beyond cancer.

These can be a useful source of support. Alternatively, a physiotherapist can help to set up an exercising schedule.

Try to exercise up to three times a week if you can and increase what you do gradually, depending on how your body is coping. Exercise can make you more tired than you are used to at first, so make sure you rest afterwards. However, in the long run, it will help you feel better.

Macmillan Cancer Support produce a number of useful resources on exercise for people with cancer.

Diet and nutrition

Eating the right foods to provide enough calories, protein and vitamins is very important. You can ask for a referral to a dietitian if you are struggling to eat. Grazing on healthy snacks during the day may help you top up your energy levels.

Relaxation and complementary therapies

Some people find distractions such as games, music or reading help them cope with fatigue. Others find benefits in relaxation and **complementary therapies**, such as:

- acupuncture
- yoga
- massage
- **mindfulness**
- meditation
- **support groups**
- journal writing.

Some people find the herbal remedies ginseng or guarana extract beneficial. However, the scientific evidence is not clear. The dose, purity and safety of some herbal remedies can vary. They may also interact with other medications. If you are taking, or planning to take, herbal remedies, discuss it with your medical team.

Sleep

Try to keep to a regular **sleep pattern**. This might be difficult when you feel as if all you want to do is sleep, but it can help to:

- wake up at the same time every day
- take short daily walks
- avoid alcohol and drinks that contain caffeine for a few hours before bedtime
- have a small, warm, caffeine-free drink before going to bed
- avoid looking at bright screens for an hour or so before bed
- keep your bedroom quiet and at a comfortable temperature
- limit your daytime naps.

Work-life balance

It is important to keep up your social and family life, so include some time for fun and social events when you plan what you can and can't do.

Many people find it difficult or impossible to keep working if they feel fatigued during or after their treatment. You might need to reduce your hours or stop work for a while. A few people are able to negotiate working from home for part or all of their hours. As with other daily activities, plan and prioritise your work, set realistic and achievable goals and break them down into manageable chunks. If available, speak with an occupational therapist for advice about working with and beyond cancer. They may be able to support you with adjustments to your work environment, patterns of work and with educating employers about how cancer can impact upon work roles.

Relationships

Fatigue can also affect your **sex life**. You may feel you do not have the energy for sex. Talking to your partner, explaining how the fatigue is affecting you and exploring other ways to be intimate can be helpful.

Exercise may also help you return to pre-cancer levels of activity.

Get support

If you have fatigue, it is important to tell your partner, family and friends how you are feeling. Ask other people to help – admitting to yourself that you need help and asking for it isn't easy, but it doesn't mean that you have 'failed' in any way.

Asking for help is a positive thing you can do to manage your energy levels. People close to you often welcome the chance to do something practical to help.

Macmillan Cancer Support's RESTORE resource offers online support and tips to help you manage fatigue. It lets you monitor your fatigue levels and allows you to set goals.

You might find the **Untire app** useful. It includes tips to help reduce fatigue and exercises to help improve your energy levels. You can also connect with others through **Untire's Facebook community**.

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**.

References

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

Acknowledgements

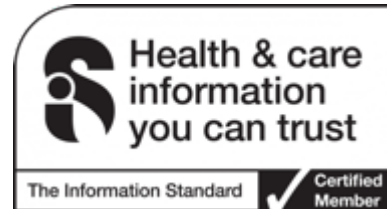
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