

Day-to-day living

Living with lymphoma can have an impact on day-to-day life. This page tells you where you can find out more and get help with some of these everyday practicalities.

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Lymphoma and its treatment affects everybody differently. You may find that it affects you in ways you didn't expect. You might need to make changes to your everyday life to help you cope. Some people call this finding their 'new normal'.

Working

Some people carry on working during treatment for lymphoma. Others need to take time off. What you choose to do is affected by how you feel, the treatment you're having and the type of work you do.

Going to work can help you to feel that life is getting back to normal but it can also be daunting, both physically and emotionally. It can take months to feel strong again after lymphoma treatment and you may experience **side effects** for some time afterwards.

Your employer must, by law, make any 'reasonable adjustments' that allow you to continue working while you are having treatment and afterwards. This law protects you for the rest of your working life, not just while you're ill or having treatment.

Talk to your manager or HR department about any adjustments you may need to help you at work. Examples of 'reasonable adjustments' include:

- reducing or changing your hours
- a phased return to your usual working hours, starting with shorter days or weeks and gradually building them up as you feel able to
- working from home
- adjusting the kind of work you do (for example, moving to a less physical role)
- changes to your workplace (for example, installing a wheelchair ramp)
- special equipment you may need (for example, software to help you cope with peripheral neuropathy)
- time off for medical appointments.

I was actually unable to work for 2 years because of fatigue and after that I was trying to slowly build up to getting back into full-time work. Trying to manage the fatigue has been a really big part of returning to work. One of the things I try to do is pacing.

Rachel, diagnosed with nodular lymphocyte-predominant Hodgkin lymphoma

If you are self-employed, you may need to consider how you will balance your workload if you continue to work, or organise your **finances** if you are unable to work. You are still protected by the Equality Act 2010 and it is unlawful for clients to stop doing business with you because of your lymphoma.

For more information on work and lymphoma:

- Our **Work and lymphoma playlist** has several videos about working with and after lymphoma, including personal experiences and frequently asked questions.
- Macmillan Cancer Support provides information about work and cancer for **employed** and **self-employed** people.
- **Working with Cancer** is an organisation that helps people with cancer get back in to work or to find work.

Studying

If you have lymphoma, you're likely to need time off from your studies, particularly during treatment. Talk to your school, college or university about your situation.

If you're at school and you need a lot of time off, **your school and local council should provide support** to make sure your education doesn't suffer. This might include:

- home tutoring or a hospital teaching service
- keeping you informed about what's going on at school
- helping you to stay in contact with other pupils
- helping you to settle back in when you're well enough to return to school.

Your teachers might talk to you, your parents or your medical team to ensure that your needs are properly understood and effectively supported.

If you're at college or university, you may decide to carry on with your studies, take a break for a while, have a year out to give yourself time to get over treatment and its side effects, or leave your course completely. Whatever you decide, your education provider should be as flexible and supportive as possible. By law, you are entitled to 'reasonable adjustments' to allow you to continue your studies while you are having treatment and afterwards. **CLIC Sargent** has information about taking time out of college for treatment and about 'reasonable adjustments' to help you to continue your education, training and employment. If you take time out, you may be entitled to a refund of your tuition fees. Contact your student finance office to check.

You may be eligible for **Disabled Students' Allowance** to help with any additional costs caused by your lymphoma and its treatment or side effects (for example, additional travel expenses or any special equipment you need).

You might worry that the time you miss at school and college may affect your exam results and career options. However, research suggests that if the central nervous system isn't affected, young people who've had lymphoma achieve just as well academically as people who haven't.

Driving and getting around

In general, it should be safe for you to drive if you have lymphoma. However, some treatments or medicines may make you feel drowsy or sick or may affect your concentration.

Even if it is generally safe for you to drive, you might feel tired on days that you have treatment. If possible, arrange for someone to drive you to and from your appointments.

In England, Scotland and Wales, you must tell the **DVLA** about your lymphoma if:

- you develop any conditions that affect your brain or nervous system (for example, **cancer-related cognitive impairment**, **peripheral neuropathy** or **CNS lymphoma**)
- your doctor has expressed concerns about your fitness to drive
- you can only drive a specially adapted vehicle or a certain type of vehicle
- your medication causes **side effects** that might make it unsafe for you to drive
- you have a bus, coach or lorry driver's licence.

In Northern Ireland, you must tell the **DVA** if you have, or have had, a medical condition or disability that may affect your driving, or if an existing condition worsens.

The government has a full list of **medical conditions that can affect your driving**. If you have any of these, you must inform the DVLA or DVA. You should also tell your car insurance company if your treatment affects your ability to drive.

If your lymphoma has affected your mobility, you may be entitled to **help with transport**. This might include reduced or free train or bus fares, exemption from vehicle tax, or help towards the cost of buying or leasing a specially modified vehicle. You may also be entitled to a **Blue badge** to help you park closer to where you're going.

Travelling to and from hospital can be costly. If you are having chemotherapy or radiotherapy, you may be eligible for free hospital transport. Your medical team should advise you how to access it. If this service isn't available in your area, you may be able to claim a refund of your travel costs through the **Healthcare Travel Costs Scheme**.

Some hospitals offer free parking for cancer patients – check whether yours does before your appointment.

Finances

Having lymphoma can put a strain on your finances, particularly if you are unable to work.

Financial support

If you're too ill to work, you may be entitled to statutory sick pay (SSP). This is paid by your employer for up to 28 weeks.

Under the Equality Act 2010, a diagnosis of cancer automatically meets the government's definition of disability and there's a wide **range of financial support** you may qualify for from the government. Some of these depend on how much you earn and what savings you have.

- **Disability Living Allowance for children (DLA)** is a tax-free benefit for children under 16 to help with the extra costs caused by long-term ill health or a disability.
- **Personal Independence Payment (PIP)** is a tax-free benefit for people aged 16 to 64 to help with the extra costs caused by long-term ill health or a disability.
- **Attendance Allowance** is a tax-free benefit for people aged 65 or over who have a disability and need someone to help look after them.
- **Employment and Support Allowance (ESA)** offers financial support if you are employed or self-employed and you can't work because of illness or disability.
- **Carer's Allowance** is extra money to help you look after someone with substantial caring needs.

In England, you shouldn't have to pay for any of your prescriptions if you are being treated for cancer, the effects of cancer, or side effects or late effects of cancer treatment. (There is no charge for prescriptions in Wales, Scotland or Northern Ireland.) You may be eligible for a voucher from your health authority towards buying a wig. You may also qualify for tax credits, housing benefit and help towards any adaptations you may need.

Financial support can be complex so it's best to seek professional guidance about what you're eligible for.

- **Citizens Advice** have benefits advisers you can contact by phone, online, by web chat or in person at your local centre. Some Citizens Advice Bureaux have caseworkers specially trained to help people with cancer access all the benefits they're entitled to through a benefits advice project funded by Macmillan Cancer Support.
- **Macmillan Cancer Support** has information about financial support if you are living with lymphoma or caring for someone with lymphoma. They also run a **benefits advice service** by phone and at some branches.

- The [UK government website](#) has information about the various benefits that may be available to you.
- [Maggie's Centres](#) have benefits advisers offering free advice specifically for people affected by cancer.
- Your specialist nurse may also be able to help you access the support you're entitled to.

Life insurance

If you already have life insurance, being diagnosed with lymphoma shouldn't affect your cover as long as you were honest about any medical conditions you already had when you took out the policy. Depending on the [type](#) and [stage](#) of your lymphoma and the level of cover you have, you may be able to make a claim. Check your policy documents to see what is covered and what isn't and notify your insurance provider about your lymphoma.

If you want to start a new life insurance policy, having lymphoma can make it difficult.

If you have, or have had, [Hodgkin lymphoma](#), you will probably not be able to take out a new life insurance policy until you have been in [remission](#) for 2–3 years. At first, your insurance premiums will be higher than usual but they should come down the longer you stay in remission.

If you have, or have had, [non-Hodgkin lymphoma](#), whether or not you can get a new life insurance policy depends mainly on the grade of lymphoma you have.

- Life insurance is not normally available for people with [low-grade non-Hodgkin lymphoma](#).
- If you have [high-grade non-Hodgkin lymphoma](#), you should be able to take out life insurance if you have been in remission for 3–5 years. At first, your insurance premiums will be higher than usual but they should come down the longer you stay in remission.

You may need to use a company or an insurance broker that specialises in insurance for people with medical conditions. Your insurance company will need to write to your doctor to get all the information they need. They should not do this without your permission.

We have separate information about [travel insurance](#).

Sleeping

Many people have difficulties sleeping from time to time. Sleep problems include insomnia (difficulty falling or staying asleep), waking too early, sleeping a lot of the time and having nightmares. All of this can contribute to **fatigue** (extreme tiredness that doesn't necessarily go away with rest).

Having lymphoma can make you more likely to experience sleep problems. **Side effects of treatment**, pain, **stress** and anxiety can all have a negative impact on the quality of your sleep.

There are things you can try to help improve the quality of your sleep. To help set your body (internal) clock:

- Go to bed and get up at the same time each day.
- Do something relaxing before bed, such as reading, listening to music or having a bath.
- Avoid stimulants (foods and drinks that temporarily increase your alertness, such as coffee) close to bedtime.
- Get some natural light during the day.
- Keep your room dark at night. This includes minimising exposure to 'blue light', given off by mobile phones, laptops and tablets – check to see if yours has a blue light filter you can set to reduce the amount it gives off.

The Mental Health Foundation produce a **guide on how to sleep better**.

The NHS website gives **tips to help you get a more restful night**. It also outlines **possible treatment options for insomnia**.

If you have ongoing difficulties sleeping, speak to a member of your **medical team**. They can give advice specific to your situation and may, for example, suggest changes to your **lymphoma treatment** if this is affecting your sleep.

Hobbies and interests

Doing things you enjoy can help you cope with the **emotional impact** of lymphoma. Being **active** can also help with some of the physical effects of lymphoma and its treatments, such as **fatigue**, as well as improving your overall health. However, make sure you pace yourself and don't get frustrated if you can't do as much as you used to. You might find it helpful to set yourself a goal to aim for – but make sure it's realistic and try not to be overambitious.

At first, getting back to the things you used to do might be daunting but your confidence is likely to build up gradually. You might find it helpful to build up your stamina or concentration slowly, setting realistic goals each week.

Smoking and drugs

The relationship between smoking and lymphoma isn't clear but there is some evidence that smoking increases your risk of getting some types of lymphoma. If you're a smoker and you've already been diagnosed with lymphoma, you might feel there's no point in giving up smoking. However, stopping smoking has a number of benefits for people with lymphoma:

- Your lymphoma treatment is likely to work better.
- You may have fewer **side effects** and a faster recovery from treatment.
- You're less likely to pick up lung infections.
- Your risk of developing **late effects** of lymphoma treatment, such as heart disease, lung disease, stroke and second cancers, is lower.
- You might live longer.

It can be very hard to quit smoking, especially if you're already going through a stressful time, such as lymphoma treatment. You're much more likely to quit successfully if you get help and support, either from your GP, a local Stop Smoking service or online.

- **Smokefree** is an NHS service that provides free online, mobile, telephone and face-to-face support to help you quit.
- **NHS Choices** has information and advice to help you quit smoking.
- **Cancer Research UK** has more information on the methods you can use to give up smoking.

Recreational drugs

During treatment for lymphoma, your body is working hard to break down and process lots of different medicines. Taking recreational drugs can affect the way your body deals with your treatment and may make your treatment less effective.

After treatment, leading a healthy lifestyle that is free from recreational drugs helps your body recover and prepares you for any treatment you might need in the future.

You may have heard that cannabis (or marijuana) may help with some of the side effects of lymphoma treatment (including nausea, vomiting, sleep difficulties and loss of appetite). There is some evidence to support this, but in the UK, cannabis and cannabis-related medicines are not licensed for this purpose. It is illegal to take, carry, grow or sell cannabis in the UK.

Buying cannabis illegally is risky because it could be contaminated with other chemicals and it's difficult to control the dose you're getting. There have also been reports of people paying for cannabis online without receiving the product.

[Cancer Research UK](#) has more about cannabis and cancer.

If you take recreational drugs, let your medical team know. They could make your treatment less effective and might affect your test results.

Vaccinations



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The routine vaccinations you need vary depending on your age, the treatment you've had for your lymphoma and how long ago you had it.

Speak to your doctor for advice specific to your situation. It is important to have any vaccines your medical team recommends to protect you from infection.

As a general guide:

- You may be told to wait 6–12 months after finishing treatment before having a vaccination.
- It's advisable to have the annual winter flu jab and the pneumococcal pneumonia vaccination.
- If you've had your **spleen removed** or have had a **stem cell transplant**, you need additional vaccines.
- If you're **going abroad**, you might need specific vaccinations.
- You may need to repeat vaccines you've already had because cancer treatment can affect your immunity. This varies depending on your type of lymphoma, what treatment you had, and how old you were when you had it. Your doctor might advise you to have blood tests to check your immunity before deciding whether or not you need any repeat vaccines.
- Most people need to have their childhood vaccinations again after having an **allogeneic (donor) stem cell transplant**.

Live vaccines

Some vaccinations are not recommended for people with lymphoma. Generally, these are 'live' vaccines. Live vaccines are made using bacteria or viruses that are weakened but still alive. These vaccines may be unsafe if you have lymphoma because they could cause a serious infection.

Live vaccines include those given to protect against:

- chickenpox
- measles, mumps and rubella (MMR)
- polio
- shingles
- tuberculosis (BCG vaccine)
- typhoid
- yellow fever.

The nasal spray flu vaccine is also a live vaccine, but the injection is not.

You should discuss any vaccines with your doctor or specialist nurse before having them.

Organising your paperwork

Most types of lymphoma respond well to treatment. However, many people find that having lymphoma makes them re-evaluate their lives and think about the future differently. Some people worry about what will happen to their loved ones if the lymphoma comes back and can't be treated (although it's important to remember that it usually can).

For some people – with or without lymphoma – making arrangements in case the worst happens can help put their mind at rest. Other people find it distressing and prefer not to dwell on an outcome that might not happen. Think carefully about how you feel and do what is best for you.

If you think planning ahead is something that would help you, you may want to consider:

- **Making a will:** The government provides guidance on [how to make a will](#) so you can decide what happens to your money, property and belongings, and who will look after your dependents, after your death. Depending on your particular circumstances, you may be able write your own will but most people use a solicitor. Some employers and trade unions offer a free or discounted will-writing service. If you have legal cover as part of your home insurance policy, check if it covers writing a will. Some charities also offer a free will-writing service.
- **Arranging for somebody else to look after your finances:** You might want to decide who will look after your financial affairs if it becomes difficult for you to do it yourself. [MacMillan Cancer Support](#) has information on the different ways you can do this.
- **Deciding if there are any treatments you do not want in the future:** If you know there are treatments you do **not** want to receive in the future, you might want to make an 'advance decision to refuse treatment' (ADRT), also known as an advance directive or a 'living will'. This is a written record that lets your medical team, and your family, know your wishes if you aren't able to communicate with them. [NHS Choices](#) has guidance on things to consider if you're planning to make an ADRT and how to make one.

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.

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