

Day-to-day living

Lymphoma can affect people in different ways and you might need to make some changes in your everyday life to help you to live well. Some people call this finding their 'new normal'.

This information tells you where you can find support with day-to-day practicalities if you're affected by lymphoma. You might also be interested in getting help from an **occupational therapist** (OT), who can make suggestions and organise equipment to help you manage in your day-to-day life.

We have separate information about **living with and beyond lymphoma**. You might also be interested in our **Live your Life programme**.

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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**.

It can take time to adjust to life after a diagnosis of lymphoma, but there is support available.

Working

Most people need to take some time out of work during, and often for a little while after, **finishing treatment**. It can take months to regain strength after lymphoma treatment and some people have **side effects** like **fatigue** (extreme tiredness) that last for a while afterwards.

Returning to your work can help you feel that life is getting back to normal. However, the thought might also be daunting, both physically and emotionally. Take care not to over-commit or do more than is comfortable for you.

If you are employed

By law, your employer must make any 'reasonable adjustments' that allow you to continue working during and after your treatment. Under the **Equality Act 2010**, this applies for the rest of your life, not just while you are having treatment or for a limited time after finishing.

Speak to your HR department or line-manager about the possibility of making any changes to your work. For example, you could discuss:

- a short or long-term change in responsibilities, which might involve gradually building back up to your full range of tasks
- changing your working pattern to avoid peak 'rush-hour' commuting times
- taking extra breaks
- working some of your hours from home
- a phased return, starting with fewer hours or tasks and building these up over time when you are ready
- any adaptations to your work place that could help you, for example technology so that you can work a computer with your voice instead of using a keyboard, or offering you a different desk chair. The occupational health team at your work place could do an assessment of your work set-up and make adaptations that could help you.

On the UK government's website, you can find out about Access to Work – a scheme offering support if you have a disability or health condition.

I found it helpful to be open about my cancer. It meant that the people I worked with had a chance to know how I was and what help I might need. I'd recommend that you don't over-commit, so don't promise to get something done by a certain date in case you then don't feel well enough to.

Barbara Wilson, Founder and Director of Working With Cancer

Statutory Sick Pay (SSP)

If you are employed and have to take time out of work for health reasons, you might be entitled to **statutory sick pay** (SSP). This is a weekly payment that you get paid by your employer for up to 28 weeks. Find out more about SSP and **how to claim** it on the UK government website.

If you are self-employed

Consider how to manage your work and **finances** if you're unable to work. It can be helpful to get **specialist advice** about this. Note that, under the Equality Act 2010, it is unlawful for people to discriminate against you because of your lymphoma. Macmillan Cancer Support has information about rights and **discrimination at work**.

Macmillan Cancer Support also has information about **self-employment and cancer**. Their **welfare rights service** can help you find out about any financial support you're entitled to and how to get it.

The **Money Advice Trust** has a free **Business Debtline** advice service to help manage your business budget and find debt solutions.

Further information about work and cancer

- Cancer Research UK has information about **money matters**, including about personal finances, such as your mortgage, pension, credit cards and insurance.
- The Money Advice Trust has a National Debtline advice service to help people manage their money.
- Working With Cancer offers information to people who are employed, selfemployed, job seeking or a working carer.

Managing your finances

Money and finances can cause worry for many people, particularly if your earnings have lowered since you were diagnosed with lymphoma.

There are various sources of financial support, but it can feel overwhelming to look into such a complex topic. You can, however, get free and independent **specialist advice** to help you understand what you are eligible for.

Financial support available under the Equality Act 2010

Even if you don't consider yourself to be disabled, under the Equality Act 2010, a diagnosis of cancer automatically meets the government's definition of disability. This means that there's a wide **range of financial support** you might qualify for from the government. Some of this depends on your savings and earnings.

Examples of support you might be able to claim are:

- A tax-free benefit to help with the extra costs caused by long-term ill health or a disability. For people aged 16 to 64, this is called **Personal Independence Payment (PIP)**. For those under the age of 16, it's called **Disability Living** Allowance for children (DLA).
- Attendance Allowance, which is a tax-free benefit for people aged 65 or over who have a disability and need someone to help look after them. If the person or people who care for you are not paid to care for you, they might be able to claim Carer's Allowance.
- Employment and Support Allowance (ESA), if you are employed or selfemployed and can't work because of illness or disability.

You might also be eligible to receive a grant from your council if you need to make changes to your home, for example having a stairlift fitted.

You can find out **more about financial support** on the government's website.

Prescription costs

- In England, you won't need to pay for any of your prescriptions if you're being treated for cancer, the effects of cancer, **side effects** or **late effects** of cancer treatment.
- There is no charge for prescriptions in Wales, Scotland or Northern Ireland.

Ask your Clinical nurse specialist for a **medical exemption (MedEx) form** (also known as an FP29A form) so that you do not have to pay NHS prescription charges.

You can find out more about **help with health costs** on the NHS website.

Getting specialist financial advice

The following free services have welfare benefits advisors to help you understand about the support you might be entitled to:

- **Citizens Advice**, which offers an advice service. Their website also has information about **financial support for people who are sick or disabled**.
- Macmillan Cancer Support has information about money, finance and insurance. They also have a welfare benefits advice service and some grants to help with the extra costs that living with cancer can bring.
- Maggie's has information about **money and benefits** as well as offering a benefits advice service.

Some hospitals offer benefits advice. Ask your clinical nurse specialist about this or if they can signpost you to any other local services that might be helpful to you. Anya Aspinall, Clinical Nurse Specialist

Free and impartial information about financial support is also available on the UK government website and from Money Advice Service, set up by the government.

Macmillan Cancer Support produce a book called: **Planning and managing your finances**, which is free of charge to download.

Life insurance

Life insurance is also known as 'life assurance' or 'life cover'. Honesty about your diagnosis and any other health conditions means that any claims are more likely to be successful.

A lymphoma diagnosis shouldn't affect an existing policy. However, starting a new one might be more difficult, depending on the type and grade of lymphoma you have. Insurance companies might say that you need to be in **remission** for a number of years before they will offer cover, and your premiums might be higher for a while. Check your policy documents to see what you're covered for.

Macmillan Cancer Support has more information about different types of insurance, including about **life insurance**. They also have a financial guidance team that can talk to you about pensions, mortgages, insurance, retirement, borrowing and savings.

There are other **types of insurance** you might want to find out more about in relation to your health on the Macmillan Cancer Support website. You can also find out about **travel insurance and lymphoma** on our website.

Studying

Most students with lymphoma need time off from studies, especially during treatment. Talk to your school, college or university to find out how they can support you. This includes making any reasonable adjustments and allowances. Examples might include:

- having longer to complete homework or coursework
- having more time during tests and exams
- offering extra support with lessons, such as someone to take notes
- making changes at school to help you get around, for example, providing disabled access routes if you use a wheelchair.

If you're at school

If you need a lot of time out, **your school and local council** should offer help. As well as lowering the impact on your education, the support they offer should consider your emotional wellbeing, including helping you to feel included socially. Examples of support could include:

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

Your teachers can talk to you, your parents or carers and your medical team to help them understand your needs and offer the right support for you. Most educational schools have a disability or welfare officer who can advise and provide support.

If you're at college or university

You might decide to carry on with your studies, or you might choose to take a break. One possibility might be to have a year out to give yourself time to recover from treatment and its side effects. However, some people leave their 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 during and after your treatment. If you take time out, you might be able to get a refund of your tuition fees. Your student finance office should be able to give you information about this.

You might also be eligible for **Disabled Students' Allowance** to help with any additional costs you have because of your lymphoma and its treatment or side effects. This can be used towards expenses such as travel costs to and from medical appointments or any special equipment you need.

Young Lives vs Cancer (formerly known as Clic Sargent) has information about studying on treatment.

Driving and getting around

For most people with lymphoma, it's considered safe to drive. However, some treatments or medicines can make you feel drowsy or unwell, which can affect your concentration. Check with your medical team if any of your medication means that it is illegal or unsafe for you to drive. Even if it is usually safe for you to drive, you might feel tired on days that you have treatment. It can be helpful to arrange for someone to drive you to and from appointments. If you don't have a friend or family member who can help with this, speak to your GP or nurse specialist. They might know about any hospital or local community travel support services available to you.

Who should I tell about my lymphoma?

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

- you are affected by anything that affects your brain or nervous system, for example 'chemo brain' (cancer-related cognitive impairment), peripheral neuropathy or CNS lymphoma.
- your doctor has raised concerns about your fitness to drive
- you need a specially adapted 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 could affect your driving
- if an existing condition worsens
- if you have had treatment in the past five years for **non-Hodgkin lymphoma**.

See the GOV.UK website to **check if a health condition affects your driving** and for information about **lymphoma and driving**.

Tell your car insurance company if your lymphoma or treatment affects your driving. This is important because you could be fined if you don't. Also, if you need to make a claim and you haven't disclosed your medical condition, your claim could be rejected.

Help with travel and travel costs

It can be costly to get around, particularly if you have to travel to and from lots of medical appointments. You might be interested in finding out about:

• Access to Work, a support scheme for people who have a disability or health condition. This can include help getting to and from work.

- Help with transport costs if your lymphoma has affected your mobility. This could include reduced ticket prices for public transport, exemption from vehicle tax or help with the costs of buying or renting a specially modified vehicle.
- Transport support services for disabled people including how to get help.
- The **blue badge scheme**, which allows you to park your vehicle closer to where you're going if you're disabled than you might otherwise be able to.
- Whether your hospital offers free or reduced-price parking. Note that policies vary across the four UK nations. Macmillan Cancer Support has more information about transport and parking costs.
- The Healthcare Travel Costs Scheme, which might qualify you to claim a refund on travel costs if you are referred for NHS tests or treatment. Your CNS should be able to give you the relevant form.

Macmillan Cancer Support's welfare benefits advisors can give you more information about help with travel costs.

Leading a healthy lifestyle

It's important to take guidance from your medical team. However, the general advice is to follow a healthy lifestyle and to take steps to **lower your risk of infection**.

A healthy lifestyle includes **eating well**, doing **exercise** that's suitable for you, keeping a **healthy weight**, limiting your **alcohol intake** and not **smoking**. The **NHS website** has information about these lifestyle factors.

Giving yourself time to relax, have fun and do enjoyable things is also important in coping with the **emotional impact of living with lymphoma**. However, pace yourself and be realistic about how much you can do. At first, you might feel nervous about getting back to the things you did before your diagnosis, but many people find that their confidence builds up in time.

Smoking

Stopping smoking (or not smoking at all) has a number of health benefits. As well as increasing your life expectancy, the advantages can include:

- greater effectiveness of your lymphoma treatment
- fewer side effects of treatment
- quicker recovery after treatment

- being less likely to pick up lung infections
- lower risk of developing **late effects** of lymphoma treatment.

National Cancer Institute has more information about **cigarette smoking and the benefits of quitting**.

If you smoke, you can find information and resources to help you quit on the **NHS** website and the Cancer Research UK website. You can also find information about ecigarettes and vaping on the Cancer Research website.

Sleeping

Lots of people have difficulties sleeping sometimes. Sleep problems include difficulty falling or staying asleep (**insomnia**), waking too early, sleeping a lot of the time and having nightmares. Having lymphoma can make you more likely to experience such difficulties. For example **side effects of treatment** including **cancer-related fatigue**, **stress** and anxiety can all lower the quality of your sleep.

If you have ongoing difficulties sleeping, speak to a member of your medical team. They can give advice specific to your situation, which might include suggesting changes to your lymphoma treatment if it could be affecting your sleep.

The NHS website gives **tips to help you get to sleep** as well as **tips to beat insomnia**. In general, the guidance on getting a restful night includes to:

- 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 devices like TVs, mobile phones, laptops, tablets, e-readers and video games consoles. Check to see if yours has a blue light filter you can set to reduce the amount it gives off.

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

Recreational drugs

Recreational drugs could make your lymphoma treatment less effective. They can also increase your chances of side effects. For these reasons, it's important to let your medical team know if you take any.

Even if you are not currently having treatment, leading a healthy lifestyle that's free from recreational drugs helps to put you in the best position to maintain good health. It helps your body recover after treatment and can help to **prepare you for any treatment** you might need in the future. The NHS website has information about **getting help if you would like support to stop taking recreational drugs**.

Some people ask whether cannabis or cannabidiol (CBD) oil can help with **nausea and vomiting**. In the UK, cannabis and products made from cannabis are not licensed to treat nausea or vomiting caused by **chemotherapy**. Very rarely, specialist doctors can prescribe medical cannabis on a case-by-case basis, but only if other treatments haven't been effective and if it is suitable for you. Home-grown cannabis and cannabis bought illegally contain lots of active chemicals in unpredictable amounts. It is not safe to use instead of medical cannabis. This is because you can't control the dose you're getting and it could be contaminated with other chemicals.

Vaccinations

Most vaccinations are safe for people who have had lymphoma, but it's important that you take advice from your doctor about your specific situation.

As a general guide, people affected by lymphoma:

- might need to wait 6 to 12 months after finishing treatment before having a vaccination
- are recommended to have the annual winter flu vaccination and the pneumococcal pneumonia vaccination.

We have separate information about the COVID-19 vaccine.

Live vaccines

Live vaccines are made using living viruses or bacteria. They could lead to a serious infection in people who have lymphoma or have recently been treated for lymphoma. Check with your doctor or specialist nurse before having any live vaccines.

Repeats of vaccinations

Lymphoma and its treatment can affect your immunity so you might need to repeat vaccines you've already had. Sometimes, doctors advise you to have blood tests to check your immunity before deciding whether or not you need any repeat vaccines.

Whether or not you need to have vaccinations you've already had depends on your **type of lymphoma**, the **treatment** you had, and how old you were when you had it. Most people need to have repeats of childhood vaccinations after having a **stem cell transplant** or if their **spleen has been removed (splenectomy)**. Your medical team can give advice specific to you.

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

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