

Day-to-day living

In this information, we signpost to where you can find support with some of the day-to-day practicalities if you're affected by lymphoma.

We have separate information about **living with and beyond lymphoma** and about **relationships, family and friends**. 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.

Work

Most people take some time out of work during **treatment for lymphoma**. This could be for a short while. However, you might need to make some changes in the months

Page **1** of **15**

afterwards. It can take a while to build your strength and energy back up, and to recover from any **side effects**. Your approach to work might differ depending on whether you are **employed** or **self-employed**.

Returning to your work can help you feel that life is getting back to normal. However, it can also feel quite emotional and daunting. Take care not to overcommit or do more than is comfortable for you.

> Remember that you don't know how you are going to feel after treatment so try not to commit yourself to too much, too soon. Also think about how much you want the people you work with to know about your situation – this might include colleagues and clients. Barbara Wilson, Founder & Director, Working With Cancer

If and when you go back to work depends on factors such as your age, general health, and your day-to-day responsibilities – for example, whether your work is physically demanding. You might also consider any changes you could make in your work. If you are employed, this can involve **reasonable adjustments** your employer can help you make.

You might also be interested in the Government's Access to Work scheme, designed to help you get or stay in work if you have a physical or mental condition. If you live in Scotland, there is information on the Disability Scotland website about Access to Work and how to apply.

If you are employed

The UK law says that your employer must make any **reasonable adjustments that allow you to continue working during and after your treatment**. This is the case for the rest of your life – not only during treatment or for a limited time afterwards.

> If you are employed, you are protected from discrimination in employment by the Equality Act, 2010 from the point of diagnosis for the rest of your life. This includes in relation to matters such as recruitment, training, appraisals and references. Barbara Wilson, Founder & Director, Working With Cancer

Speak to your HR department or line-manager about the possibility of making any changes to your work. You could ask for an assessment of your work set-up and any suggestions to help make adaptations that could help you. For example:

- any adaptations to your workplace that could help you, for example technology so that you can use a computer with your voice instead of a keyboard
- a change to your working pattern to avoid peak times of travel
- taking more breaks
- working some of your hours from home
- a short or long-term change in responsibilities you might then build back up gradually to all of your previous tasks
- a phased return, starting with fewer hours or tasks and building these up over time.

It can be a good idea to talk to your employer early, so that they can help to support you and put any adjustments in place. Barbara Wilson, Founder & Director, Working With Cancer

Macmillan Cancer Support has more information about reasonable adjustments, including about talking to your employer.

You could also find out about any employee assistance programmes that could support you with your emotional wellbeing in your return to work.

If you are self-employed

It can be difficult to **manage your finances** and business if you need to take time out of work.

Consider any changes you could realistically make. For example, agreeing to adjusted deadlines with clients, putting some of your projects on hold or subcontracting. It can be helpful to get **specialist advice** to help you understand your options and any sources of financial support you could be entitled to.

You might also be interested in the following resources:

• Macmillan Cancer Support's information to help if you are self-employed and a self-employment and cancer book that you can download or order for free.

- Macmillan Cancer Support's welfare rights service to help you find out about any financial support you're entitled to and how to get it.
- The free **Business Debtline** advice service from **Money Advice Trust**, which aims to help you manage your business budget and find debt solutions.

Further information about work and cancer

- Our Lymphoma, work and you webinar took place in 2022. You can watch a recording of it where our expert panel talk about employer's obligations under the Equality Act. You can also find a list of places that offer information, help and support.
- Acas has information about employment law, HR processes and good practice at work for employers and employees in England, Scotland and Wales. You can also contact their helpline.
- Cancer Research UK has information about **money matters**, including about financial planning, mortgages, pension, credit cards and different types of insurance.
- Working With Cancer offers information to people who are employed, selfemployed, job seeking or a working carer.

Managing your finances

There are various sources of help with costs, including financial support from the government. We outline some of these below. However, you might be interested in getting free and independent specialist advice to help you understand what you are eligible for.

You might also be able to get help with the costs of travelling, as well as free prescriptions.

Financial support from the government

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 government support you might be able to claim are:

Page **4** of **15** © Lymphoma Action

- Attendance Allowance, to help with the extra costs if you need someone to help look after you. 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 have a health condition or disability that affects how much you can work.
- **Personal Independence Payment (PIP)** for people aged 16 to 64, to help with the extra costs caused by long-term ill health or a disability. For those under the age of 16, it's called **Disability Living Allowance for children (DLA)**.
- Universal Credit, if you're on a low income, out of work or unable to work.

There is **more about financial support** on the government's website. You can find lots of information about **benefits** and a tool to help you **check benefits** and the **financial support you could get**.

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.

The Money Helper website has free, impartial information and resources to help with managing money.

Help with prescription costs

There aren't any prescription charges in Wales, Scotland or Northern Ireland.

In England, you can apply to get free prescriptions if you are being treated for cancer, the effects of cancer, **side effects** or **late effects** of cancer treatment. To do this, you'll need a **medical exemption (MedEx) certificate**. You can ask your consultant, Clinical Nurse Specialist (CNS) or GP for this.

You'll need to complete and post the application form for a medical exemption (MedEx) certificate to the NHS prescription authority. They will then send you the certificate once they've processed it. Chrissie Kirby, Macmillan Haematology Clinical Nurse Specialist

Specialist financial advice

There are some free welfare benefits advice services that can help you understand about the support you might be entitled to. You could try the following:

• Citizens Advice – their website has information about financial support for people who are sick or disabled. You can find out how the best way to contact them on their website, depending on your information needs.

Page **5** of **15**

- 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** and a benefits advice service.

Insurance

Much of the time, an existing policy isn't affected by a lymphoma diagnosis. Check your policy documents to see what you're covered for.

Some types of insurance might be affected by your diagnosis, particularly if you are starting a new policy. Insurance companies might set certain limitations. For example, they could say that you need to be in **remission** for a number of years before they will offer cover. Your premiums might also be higher for a while.

Being honest with your insurance provider about your health generally gives a better chance of any claims being accepted.

Below are some of the types of insurance you might want to consider:

- Car insurance
- Life insurance (also known as life assurance or life cover)
- Travel insurance.

Macmillan Cancer Support have more information about insurance and cancer.

Studies and education

You're likely to need some time off from studies, especially during treatment. Talk to staff at your school, college or university to find out how they can support you. This includes offering you any reasonable adjustments and making allowances such as:

- more time to do homework or coursework
- extra time to complete tests and exams
- support during lessons, such as someone (a scribe) to take notes for you
- changes to your school, college or university to help you get around, for example, disabled access routes if you use a wheelchair.

On the GOV.UK website, you can find out more about **disability rights and reasonable adjustments in education**.

Page **6** of **15**

If you're at school

If you need a lot of time out, **your school and local council** should offer help to support your education and emotional wellbeing, including helping you to feel included socially.

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 schools have a disability or welfare officer who can advise and provide support.

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, which might include a phased return, when you're well enough to go back.

If you're at college or university

Depending on your circumstances, you might decide to:

- continue with your studies, possibly with reasonable adjustments
- take a break from your studies for example, you could take a year out to give yourself time to recover from treatment and its side effects
- leave your studies.

If you take time out or leave your studies, 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 for medical appointments or any special equipment you need.

Young Lives vs Cancer offers more information and support about **education**. You can also find information about going **back to education after cancer** on the Teenage Cancer Trust website.

Driving and public transport

You might need to give some thought to travelling, particularly for medical appointments. This might involve **driving**, using **public transport**, and looking into any **help with travel and travel costs**.

Driving

For most people with lymphoma, it's considered safe to drive. However, check with your medical team if any of your treatment or medication means that it is illegal or unsafe for you to drive. For example, some can make you feel sleepy or unwell, which can affect your concentration and ability to drive safely.

It might not be safe to drive if you are having intensive chemotherapy. Usually, we ask people not to drive for the first cycle of chemotherapy at least. Some drugs can make you feel drowsy and affect your reaction time. Chrissie Kirby, Macmillan Haematology Clinical Nurse Specialist

If you're affected by **peripheral neuropathy** (a type of damage to your nerves that can cause symptoms such as numbness in your hands and feet or 'pins and needles'), you might need to stop driving for a while. In England, Scotland and Wales, you must **tell the DLVA**.

Even if it is usually safe for you to drive, you might feel tired after having treatment. It can be helpful to arrange for someone to drive you to and from appointments. You can speak to your GP or CNS if you don't have a friend or family member you could ask. They might know about any hospital or local community travel support services available to you.

Who do I need to tell about my lymphoma diagnosis if I'm a driver?

On the GOV.UK website, you can **check if a health condition affects your driving** and find information about **lymphoma and driving**. If you have completed treatment and you're unsure if it is safe for you to drive, ask a member of your medical team for advice.

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

Page **8** of **15** © Lymphoma Action

- your brain or nervous system is affected, for example, you are experiencing 'chemo brain' (cancer-related cognitive impairment), peripheral neuropathy or have central nervous system (CNS) lymphoma – ask your doctor or clinical nurse specialist if you are unsure
- 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.

Find out more about **telling the DVLA about a disability or medical condition** on the GOV.UK website. You can **contact the DVLA** if you have any questions.

In Northern Ireland, you must tell the DVA if you have:

- currently, or have had, a medical condition or disability that could affect your driving
- if an existing condition gets worse.

You can find out more about telling the DVA on the DVA website.

Car insurance

Tell your car insurance company if your lymphoma or treatment affects your driving – ask your medical team if you are unsure.

It is important to give your insurers this information 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 travelling costs

There can be additional travel costs if you're affected by lymphoma – for example, the added expenses of travelling to medical appointments. It can also be most costly if you need to make changes to how you'd usually travel.

You might be interested in finding out whether your hospital offers and free or reduced-parking that you are eligible for – you can ask your CNS or another member of staff at your hospital or treatment centre.

You might also be interested in the following scheme and sources of support:

• Access to Work, a support scheme for people who have a disability or health condition. This can include help with the costs of getting to and from work if you can't use public transport.

Page **9** of **15**

- Blue badge scheme, which lets you have a parking space that's closer to where you're going than you might otherwise be able to. There are, however, certain eligibility criteria that you need to fulfil in order to get one.
- Healthcare Travel Costs Scheme, under which you might qualify for 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.
- Help with transport costs if your lymphoma affects your movement and ability to get around. 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.
- Travel cost concessions and exemptions, such as **applying for a free bus pass** or **Railcard**.

Macmillan Cancer Support has more about transport and parking costs. You can also find out about their welfare rights advice service, which can give you more information about help with travel costs.

Pets

If you have a pet, try to lower your risk of infection from them:

- Wash your hands well after touching pets, especially before you eat.
- Take care to avoid bites and scratches.
- If possible, keep pets out of areas where you prepare or handle food.
- Disinfect any surfaces you prepare or handle food on, especially if pets have been on them.
- Wear gloves when cleaning up animal waste or litter trays ideally, get help from someone else with this aspect of pet care.
- Ask someone to check your pet regularly for ticks if you find one on your pet or yourself, remove it, wash your hands and have your pet treated. The NHS has guidance on how to remove a tick safely.

Macmillan Cancer Support has more information about **pet care**, including ideas about getting help from other people and organisations.

Healthy living

Your medical team can give you advice specific to you and your situation. The general guidance for staying well is to follow a healthy lifestyle and to take steps to lower your risk of infection.

A healthy lifestyle includes:

- good diet and nutrition.
- exercise that's suitable for you
- restful sleep
- keeping a healthy weight
- not smoking or vaping
- keeping your alcohol intake to within recommended limits
- managing stress
- following sun safety advice
- not using recreational drugs.

Sleep

Having lymphoma can make you more likely to have trouble sleeping. You might, for example, have difficulty falling or staying asleep (insomnia), wake earlier than you'd like to, want to sleep a lot of the time, or having unsettling dreams or nightmares.

Many things can affect your sleep: **side effects of treatments such as steroids**, **cancer-related fatigue**, and heightened stress and anxiety.

You might be interested in listening to tips for restorative sleep from Dr Mike Scanlan, a retired therapist and lecturer in mental health. He shares techniques that many people find helpful in our Lymphoma voices podcast: *Putting the day to bed really matters.*

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 this might help.

For more information about sleeping and tips to help you sleep well:

 read the top tips for difficulty sleeping shared by members of our closed Facebook community

Page **11** of **15**

- consider the guide on how to sleep better from Mental Health Foundation
- find information and resources on the NHS website about sleep.

Smoking and using e-cigarettes (vapes)

We know that smoking is harmful to health. However, the long-term effects of vaping are not yet known.

Not smoking can mean:

- greater effectiveness of your lymphoma treatment
- fewer side effects of treatment
- quicker recovery after treatment
- being less likely to develop lung infections
- lower risk of developing late effects of lymphoma treatment.

For more information on smoking and e-cigarettes, you might be interested in:

- Cancer Research UK's information about whether vaping is harmful
- National Cancer Institute's information about the harms of cigarette smoking and the benefits of quitting
- Information and resources to help you stop smoking on the NHS website and on Cancer Research UK's website.

Recreational drugs

Leading a **healthy lifestyle** that's free from recreational drugs helps to give you the best chances of staying in good health. This is the case whether or not you are having treatment at the moment or you're in **remission**.

The benefits of not taking recreational drugs include:

- helping your body recover after treatment
- helping you to get ready for any treatment you might need in the future (prehabilitation).

The disadvantages of taking recreational drugs can include:

- making your lymphoma treatment less effective
- increasing your chances of side effects.

Let your medical team know if you take any recreational drugs, in case they affect your lymphoma treatment.

Page **12** of **15**

The NHS website has information about **getting help if you would like support to stop taking recreational drugs**.

We are sometimes asked about cannabis and cannabis products for medicinal purposes, such as to ease the treatment side effect of nausea and vomiting. You can read more about this on our webpage about nausea and vomiting. You can also find out about cannabis, CBD oil and cancer from Cancer Research UK and Macmillan Cancer Support.

Vaccinations

Take advice from your medical team or GP about vaccinations. You can ask which ones are safe and recommended for you, and when to have them.

As a general guide, people affected by lymphoma might be advised:

- to wait 6 to 12 months after finishing treatment before having a vaccination
- not to have live vaccines (made using live viruses or bacteria).

Usually, the advice is to have the **annual winter flu vaccination**, **pneumococcal pneumonia vaccination** and the non-live shingles vaccination (Shingrix®)

Which vaccinations you're advised to have and when might differ if you have had a transplant. Follow the vaccination schedule from your medical team. Chrissie Kirby, Macmillan Haematology Clinical Nurse Specialist

Children and young people might be advised differently (for example, needing **repeats of vaccinations** they have already had) – please take the advice of your medical team.

We have separate information about the COVID-19 vaccination and boosters.

Repeats of vaccinations

Your medical team might advise that you have repeats of vaccinations you've already had. Whether or not you do depends on the **type of lymphoma** you've had, your **treatment**, and how old you were when you had it. Sometimes, doctors advise you to have **blood tests** to check your immunity before deciding whether or not you

Page **13** of **15**

need any repeat vaccines.

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.

Acknowledgements

- Chrissie Kirby, Haematology Clinical Nurse Specialist, Hampshire Hospitals NHS Foundation Trust.
- Members of Macmillan Cancer Support's Cancer information development team and service Knowledge specialist team.
- Peggy Newton, Social Care Practitioner, Young Lives vs Cancer.
- We would like to thank the members of our Reader Panel who gave their time to review this information.

Content last reviewed: June 2024 Next planned review: June 2027 LYMweb0124Day-to-day2024v4

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Company Registration No 03518755

Charity Registration (England and Wales) No 1068395 (Scotland) No SC045850

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Page **14** of **15**

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