

Lymphoma

action



Living with and beyond lymphoma

Day-to-day living

Relationships, family and friends

Coping with symptoms, treatment and side effects

Feelings and emotions

Emotional wellbeing



This book has been researched and written by Lymphoma Action, the only UK charity dedicated to people affected by lymphoma.

We would like to thank our incredible supporters whose generous donations enable us to offer our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.

To make a donation towards our work, please visit lymphoma-action.org.uk/Donate

Your lymphoma type, stage and date of diagnosis



Your treatment plan

Key contact

Name: _____

Role: _____

Contact details: _____

Job title/role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist (CNS) or key worker	
Emergency contact number	

About this book

Over 20,000 people are diagnosed with lymphoma each year in the UK. If you, or someone you know, is one of them, this book is for you. Whether you're newly diagnosed, going through treatment, on watch and wait (active monitoring) or in remission, we're here for you.

We hope that this book helps you to live well, with and beyond lymphoma. It covers practicalities, medical matters and emotional wellbeing. You'll find tips to help you cope with treatment and its side effects, and signposts to further sources of information and support.








You might also be interested in some of our other books. See page 206 for other resources you might find helpful.

This book is split into sections; you can read just the ones that are relevant to you at any given time.

Important and summary points are written in the chapter colour.

If you would like a copy of this book in large print, please contact us (page 207).

Contents

 Day-to-day living	7
 Relationships, family and friends	33
 Coping with symptoms, treatment and side effects	49
 Medical matters after treatment	131
 Feelings and emotions	151
 Emotional wellbeing	173
 Information and support	207



“ *I am still navigating the waters post-treatment: the financial elements from not being able to work, the challenges of now having a hidden disability and the logistics around motherhood. I am learning how to filter emotions into those I can control and those I can't, while being gentle with myself.*

Jacqueline, diagnosed with non-Hodgkin lymphoma

Day-to-day living

Diet and nutrition	8
Alcohol, smoking and recreational drugs	15
Physical activity (exercise)	17
Driving and getting around	21
Work	23
Finances	27
Study	28
Travelling to another country	29

Diet and nutrition

Eating well is an important part of living well. It can improve your general physical and emotional wellbeing, help you to prepare for treatment and to recover from it.

The Eatwell Guide (page 10) is an NHS resource to help people get a healthy, balanced diet.

The key points of the Eatwell Guide are summarised in the table below:

What to include in your diet	What this means
At least five portions of different fruits and vegetables each day.	As a general guide, a portion is: 80 grams of fresh, tinned or frozen fruit or vegetables or 30 grams of dried fruit or vegetables.
Plenty of carbohydrates each day.	Around a third of what you eat should come from carbohydrates. Wholegrain or wholewheat varieties (such as bread and pasta) are often high in carbohydrates.

<p>Some protein each week.</p>	<p>Fish, eggs, tofu, beans and pulses. Meat – choose lean cuts and limit your intake of processed and red meats (such as bacon and sausages).</p>
<p>Some milk and other dairy or dairy alternative products each week.</p>	<p>Milk, cheese, yoghurt (including dairy-free alternatives).</p>
<p>Plenty of (non-alcoholic) fluids.</p>	<p>Around 6 to 8 cups (roughly 1.2 litres) each day and more in hot weather. Water and milk. Tea and coffee – you could choose decaffeinated options to lower your caffeine intake.</p>

Search 'Eatwell Guide' on the NHS website for more information. You can also download a copy on the GOV.UK website. The Vegetarian Society have a version for people who eat a vegetarian diet, and The Vegan Society have a version for people who eat a vegan diet.

Eatwell Guide

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.

Check the label on packaged foods

Each serving (150g) contains

Energy	Fat	Saturated fat	Salt
300	1.3g	0.3g	0.2g
2000	Low	Low	Low

Energy	Fat	Saturated fat	Salt
13%	4%	7%	15%

Typical values (as sold) per 100g edible portion of an adult's reference intake

Choose foods lower in fat, salt and sugars

Eat at least 5 portions of a variety of fruit and vegetables every day



Eat less often and in small amounts

Per day 2000kcal 2500kcal = ALL FOOD + ALL DRINKS

Frequently asked questions about diet and lymphoma

In this section, we cover some common questions about diet and lymphoma. Speak to your medical team for advice specific to your situation.

Can any foods cure lymphoma?

There is no evidence that any foods can prevent or treat cancer. Be wary of claims saying that it can.

Cancer Research UK advise against following an alternative cancer diet. These include Gerson therapy (coffee enemas) and macrobiotic diets (which aims to avoid foods containing toxins). There is a lack of scientific evidence to say that any are effective, and some could make you very unwell and lead to a lack of nutrients. Search 'alternative cancer diets' at cruk.org.uk for more information.

Can I diet?

Generally, you should not try to lose weight during treatment. This is because your body needs nutrients and energy, so restricting your intake or cutting out food groups can make it harder to recover from treatment. If you are thinking of dieting, speak to your doctor for advice on whether it is safe to do so – including after treatment.

Should I eat organic foods?

Organic foods and drinks are made with restricted use of man-made fertilisers and pesticides. There is no conclusive evidence that organic foods can prevent cancer or stop it from coming back. However, some people choose to follow an organic diet if they're concerned about traces of fertilisers, pesticides and herbicides in products. With all products made for consumption, the levels of these chemicals are closely monitored to ensure that they stay below the level considered to put people's health at risk.

Should I eat 'superfoods'?

Some people think that 'superfoods' have great health benefits, including reducing the risk of cancer. Foods such as broccoli, blueberries and raspberries are sometimes called superfoods. A healthy, balanced diet (page 8) is an essential part of good health, but it's unlikely that any one food can make a significant difference.

Can sugar make my lymphoma worse?

Some people ask whether sugar 'feeds' or 'fuels' cancer and makes it grow. All of the cells in our body get their energy from sugar. Cancer cells usually grow more quickly than healthy cells, so they often use a lot of energy. There is no evidence that eating sugar makes lymphoma or any type of cancer grow. There is also no evidence that eating a low-sugar diet lowers the risk of developing cancer or leads to better outcomes if you're diagnosed.

Eating a lot of sugar can have other health risks, however. These include obesity, which is linked to the development of other types of cancer. It is also important to eat a healthy, balanced diet with foods that are high in nutrients.

Will supplements help me?

There's no evidence that dietary supplements can prevent or cure cancer. If you eat a healthy balanced diet, you don't usually need to take an additional vitamin or mineral supplement. However, if eating is difficult, your medical team might advise you to take a general multivitamin and a mineral supplement to help you get the nutrients you need.

Some people believe that purple cornflower (Echinacea) can boost your immune system, fight cancer and improve side effects of treatment. However, there is no evidence to support these claims.

Are there any foods that are unsafe to eat while I have a lowered immune system?

If you have lymphoma, or your blood counts are low after treatment for lymphoma, your immune system might not work as well as it should. This increases your risk of developing an infection. Speak to your medical team for advice on how to reduce your risk of developing a food-related infection.

Are there any fruits that could affect treatment for lymphoma?

Your body makes chemicals called 'CYP enzymes'. These break down medicines once they're absorbed into your bloodstream. Certain fruits, including grapefruit and Seville oranges, can block CYP enzymes and have an effect on how medicines work. Your doctor might advise you against these fruits and any products that contain a lot of them while you're having treatment – but this depends on which treatment you are having. Other fruits that might affect how CYP enzymes work include blackberries,

pomegranates and some varieties of grapes. If you have any uncertainties about food and drink safety, seek advice from your medical team.

Is it helpful to drink green tea?

Scientists think there is a possibility that green tea might reduce the risk of some cancers and stop cancer cells from growing, but far more research is needed.

Check with your doctors whether green tea could affect your treatment or any medications. For example, researchers have reported that green tea could stop the drug bortezomib working as well as it would do otherwise. Findings so far have come only from animal studies. More research is needed to tell whether this applies to humans.

Can I eat out at restaurants or have a takeaway?

Food safety is particularly important if you're affected by lymphoma, and especially if you have a low number of neutrophils (neutropenia – see page 101).

Most establishments display their food hygiene rating (out of 5) in their window. You can also check the food hygiene rating of pubs, clubs, cafes, takeaways, deliveries and restaurants using [scoresonthedoors.org.uk](https://www.scoresonthedoors.org.uk)

Search 'food myths' at [cancerresearchuk.org](https://www.cancerresearchuk.org) to read what the evidence says about different foods causing or preventing cancer.

Alcohol, smoking and recreational drugs

A healthy lifestyle includes not smoking, taking recreational drugs or drinking a lot of alcohol.

Search 'alcohol units' at [nhs.uk](https://www.nhs.uk) for information about what counts as a unit of alcohol.

Ask your CNS or consultant whether it's safe to drink alcohol while you're having treatment. It's usually OK to have the occasional drink between treatments when you feel well enough, but check with your medical team first because alcohol can:

- interact with some drugs and affect how well they work.
- worsen some side effects of treatment, including sore mouth (oral mucositis), digestive problems, fatigue and difficulties sleeping.

Keep in mind that you might feel the effects of alcohol more quickly than you did before you had treatment.

Smoking and e-cigarettes (vaping)

Smoking increases your risk of developing infections, especially in the lungs. If you are currently having treatment for lymphoma, the risk increases further. If you've had radiotherapy to the lungs, it's particularly important not to smoke. This is to limit the risk of damage to the lungs.

Some drugs used to treat lymphoma can also affect your lungs, including the chemotherapy drug bleomycin and the targeted drug brentuximab vedotin (see page 146).

If you smoke, stopping can help to lower these risks.

Information and support to help you quit smoking is available from the NHS at nhs.uk/better-health/quit-smoking

Using e-cigarettes (vaping) is also best avoided. Although it does not seem to be as harmful as smoking tobacco, it has not yet been around long enough for us to know the longer-term risks. It can also cause side effects such as irritation of the throat and mouth, headache, cough and feeling sick (nausea) – some of which can be side effects of treatment for lymphoma.

Recreational drugs

Recreational drugs could have an effect on your lymphoma treatment and increase your chances of side effects, so it's important to let your medical team know if you take them. Even after treatment, leading a healthy lifestyle that is free from recreational drugs helps to put you in the best position to maintain good health. See page 80 for information about cannabis for medicinal purposes.

Physical activity (exercise)

Exercise can have a positive impact on physical and mental health. For some people, it's a social activity, while for others, it's 'me time'. In general, it's both safe and beneficial to exercise during and after treatment. It's important to build in rest as well, so take care not to over-do it.

Exercise can:

- lower fatigue
- reduce your risk of infections
- increase your bone and muscle strength
- help you to recover more quickly after treatment.

The UK Government recommendations on exercise for people with cancer are the same as they are for people who do not have cancer. For adults, this is 30 minutes of activity 5 days a week. If you're not able to do as much as this, you can build up the amount gradually.

Ideally, you should do some physical activity every day. Household chores, gardening, carrying a backpack and pushing a shopping trolley all count. You could also take the stairs instead of a lift or escalator.

Getting physical activity outside can be especially helpful. As well as giving you sunlight, there can be additional benefits for being in nature (see page 196).

Search 'exercise' on our website to read more and to watch a video that talks about how to keep active in your day-to-day life.



It's important to find exercise that is enjoyable and safe for you. Make sure you give your body time to recover, so build in time to rest between activities.

Frequently asked questions about exercise and lymphoma

In this section, we cover some common questions about exercise and lymphoma. Speak to your medical team for advice specific to your situation.

What safety precautions should I take with exercise?

Your medical team might recommend avoiding some types of exercise at certain times. For example, you'll probably be advised to avoid contact sports like rugby if you have low platelets (thrombocytopenia, page 107). This is due to the risk of bruising and bleeding.

If you have peripheral neuropathy (page 108) that affects the feeling in your hands and feet, cycling on a stationary exercise bike might be safer for you than cycling on the road.

If you exercise outside, follow sun safety precautions (page 113).

Can I go swimming?

Swimming has many health benefits, but you should avoid it if you:

- Have low neutrophils (are neutropenic, page 101). This is to avoid infection from public pools and changing rooms.
- Have a central line or PICC line (peripherally inserted central catheter) inserted into a vein to give treatments and take blood. This is to avoid risk of the line becoming infected.
- Are having radiotherapy, because chlorine could irritate your skin in the area treated.

Try not to swallow water, to avoid risk of infection.

The UK Government website has information you might find helpful if you want to swim outdoors in rivers, lakes and the sea ('wild swimming'):

- How to reduce the risk of becoming ill after swimming in lakes, rivers and estuaries at [gov.uk/government/publications/swim-healthy-leaflet](https://www.gov.uk/government/publications/swim-healthy-leaflet)
- A tool to check the quality of beach and bathing water in England: [gov.uk/quality-of-local-bathing-water](https://www.gov.uk/quality-of-local-bathing-water)

Ask your medical team for advice about the safety of swimming for you, and any safety precautions to take.

Can exercise prevent a return (relapse) of my lymphoma?

Scientists don't know for certain whether exercise can lower the risk of lymphoma (or any other type of cancer) coming back. However, there is growing support for the possible role of exercise in lowering this risk.

Can physical activity help me to prepare for treatment?

Physical activity can help you to prepare for treatment (prehabilitation, page 58). This can have lots of benefits, including a shorter stay in hospital and fewer side effects.

Where can I find help with exercise and physical activity?

Your medical team can give you advice about activities that are safe and beneficial for you. In some cases, they might be able to refer you to an exercise programme or gym.



See the 'exercise and physical activity' section of our useful organisations list on our website to find resources you might find helpful.

Driving and getting around

In general, it should be safe to drive while you're having treatment for lymphoma. However, some treatments might affect your ability to drive safely. For example, driving is not advised if you are on medication that makes you feel sleepy, sick (nauseous) or affects your concentration. It's also unsafe to drive if you are taking some types of anti-sickness medicines (antiemetics).

- Most car insurance policies ask that you tell them if there are significant changes to your health. If you don't, they might not accept any later claims on your car insurance.
- If you have peripheral neuropathy (symptoms that can affect the feeling in your hands and feet), you must tell the DVLA.

Search 'driving health conditions' at [GOV.UK](https://www.gov.uk) to check how lymphoma might affect your driving and whether you need to report it to the DVLA.

Even if it is generally safe for you to drive, there might be days when you feel tired or sick, particularly after treatment. If possible, ask someone to drive you to and from your appointments. If there is nobody available to do this, speak to your key worker (usually your CNS) for advice.

Help with travel costs and arrangements

Travelling to and from medical appointments can be costly. You might be interested in finding out from your CNS:

- whether there is any free or reduced-cost parking at your hospital
- if there is a transport service at your hospital
- whether there are any local community travel services available to you – your GP might also be able to tell you about these
- about the Healthcare Travel Costs Scheme, under which you might be eligible to claim a refund on travel costs if you're referred for NHS tests or treatments – your CNS should be able to give you the correct form.

Macmillan Cancer Support has more information. Search 'transport and parking' on their website.

Financial support

You might be interested in finding out about possible sources of support on the Government website at GOV.UK

- Search 'support with the cost of transport' for help if lymphoma affects your 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.
- Find information about the access to work support scheme to help you get to and from work if you have a disability or health condition.

- Find out about transport services for disabled people, including how to get help. Search ‘transport services disabled’.
- Read about the blue badge scheme, which allows you to park your vehicle closer to where you’re going if you’re disabled.

Macmillan Cancer Support’s welfare rights advisors can give you information about help with travel and other costs. Search ‘welfare rights advisors’ at [macmillan.org.uk](https://www.macmillan.org.uk) or call them on 0808 808 00 00.

Work

If you’re employed, it’s a good idea to tell your line manager or your human resources (HR) department about your lymphoma, especially as you’re likely to need some time off during your treatment. Most employers are supportive and flexible. Speak to your HR department or line-manager about how to find out what support is available to you.

For example, you could consider:

- reducing or changing your working hours to avoid the rush-hour commute
- changing your duties or delegating some of your tasks, at least for a little while
- working some or all of your hours from home.

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

“ *I finished my treatment in June and was back at work the following month. For my mental wellbeing I really needed to get back to some sort of normality.*

Surinder, diagnosed with nodular lymphocyte-predominant Hodgkin lymphoma



If, for example, in months or years to come, you get cancer-related fatigue, you might discuss flexible working arrangements with your employer. They need to consider your requests and either agree to them or work with you to come to an alternative, workable solution, unless there is a good business reason not to.

If you're self-employed, you might need to think about whether you can postpone any projects or get support from other organisations (for example, by sub-contracting). You might also need to consider how you tell any clients about the situation.



- Search 'lymphoma, work and you' on our website to watch a webinar and find sources of support
- Macmillan Cancer Support has information about cancer and being self-employed. Search 'self employed' at macmillan.org.uk

Going back to work can help you to feel that life is getting back to normal. However, keep in mind that you'll need to pace yourself. It can take months to feel that you have your usual energy levels back, and it's possible to get side effects for quite a while after treatment. The emotional effects of what you have been through can also make it difficult to concentrate.

“ *I went into work one day and my business partner looked at me and said: ‘You need time off, don’t you?’ I did as I was absolutely wiped. I needed to take more time off over the next two years. I learnt*

not to beat myself up for needing to take this time to recover.

Penny, diagnosed with follicular lymphoma



Search ‘working after cancer’ on our website for more information and to watch a video that gives tips on things to consider when returning to work after a diagnosis of lymphoma.

Finances

Lymphoma can put a strain on your finances, particularly if your income is lowered.

Getting to and from hospital can also be costly. If you are travelling by car, check whether your hospital offers free or reduced price parking to people affected by cancer. See page 22 for more about transport.

Under the Equality Act 2010, if you have ever had a diagnosis of cancer, you automatically meet the government's definition of disability.

Financial support

There is a range of financial support that you might be entitled to. Some of these depend on your earnings and any savings you have.

Financial support can be a complicated topic, so it's best to get professional guidance to find out what you're eligible for. You could try searching 'benefits' on the following websites:

- Citizens Advice at citizensadvice.org.uk
- The UK Government website at GOV.UK
- Macmillan Cancer Support at macmillan.org.uk

In addition to support offered through government schemes, there might be charities and other local organisations that provide one-off payments (grants). You could ask your clinical nurse specialist, local Citizens Advice and local library if they have any suggestions you could try.

Search 'welfare rights advice' at [Macmillan.org.uk](https://www.macmillan.org.uk) to find information about the Macmillan Cancer Support welfare rights advice service. You can talk to a specialist advisor for free to find out about sources of financial support you might be entitled to. Call 0800 808 00 00.

Study

If you're in education or training, you're likely to need to take some time off, particularly during treatment. Talk to your school, college or university about this. You might also need to talk to your employer if you are an apprentice. They should be as flexible as possible, within the limitations of the qualification boards. They might ask your hospital team to give them a supporting letter to tell them about your lymphoma.

- Search 'study' on the Teenage Cancer Trust website at [teenagecancertrust.org](https://www.teenagecancertrust.org) for information about studying after a diagnosis of cancer.
- If you're in your 20s to 40s, visit the Shine Cancer Support website at [shinecancersupport.org](https://www.shinecancersupport.org) and search 'education' or 'work' for information on these topics.

Travelling to another country

If you're thinking of going to another country, speak to a member of your medical team or your GP about whether your plans are safe.

Most doctors advise against travelling to another country if you're having treatment for lymphoma. This is because of the increased risk of being exposed to new infections, as well as difference in medical care. If you are going to a place where you don't speak the local language, this can make communication more difficult if you do need medical attention.

You might be advised to wait a while before visiting a country where the sun is strong. If you've had radiotherapy, your skin might be more sensitive in the area treated and therefore more sensitive to sun damage.

For some parts of the world, you'll need to take precautions to avoid malaria (a tropical disease that's spread by mosquitoes). Your GP or travel clinic can advise you whether you need anti-malaria tablets and which ones are best for you. Avoid mosquito bites by using air conditioning in your accommodation, if you can. Sleep under a mosquito net, and cover up with trousers and long sleeves in the evenings. Use an insect repellent; those that contain the active ingredient DEET (N,N-Diethyl-m-tolumide) are generally considered to be most effective.

It's also important to get the right insurance in place before you travel. Ideally, this should include medical cover, which could save you from paying for any unexpected tests or treatment you need while you're away. It could also cover the cost of travel tickets if you need to return home early. For this reason, it can be helpful if others travelling with you have their cover provided by the same insurer – some companies insist on this approach.

Search 'travel insurance' on our website for more information and answers to frequently asked questions.

Travel vaccinations

If you travel to another country, you might need particular vaccinations.

Your GP or local travel clinic can advise you on which vaccinations you need. Check that these are safe for someone who has, or has had, lymphoma. Most are, but some 'live' vaccines are not (see page 140). If a live vaccine is strongly recommended for people travelling to the area you plan to visit, ask a member of your medical team for advice.

Get advice about travel vaccinations at least 8 weeks before your trip. Some have to be given well in advance if they are to work.

Search 'travel vaccinations' on the NHS website at [nhs.uk](https://www.nhs.uk) to find out more.

Tips for travelling to another country

- If you're taking medication, carry some in your suitcase and some in your hand luggage. Take extra supplies in case your baggage gets lost. You can ask your GP to write a letter explaining the situation, though note that there is usually a cost for this. Your hospital doctor or CNS might be able to offer this for free.
- Make sure that drinking water is sterilised, to kill bacteria. The easiest way is to boil it.
- Don't have ice in your drinks, unless you know it's made from sterilised water.
- Avoid salads and unpeeled fruit, unless you're sure they have been washed thoroughly in sterilised water.



“ My partner Paula, who is now my wife, was fantastic throughout everything I was going through. Having that support was so valuable during such a challenging time.

Geoff, diagnosed with a type of T-cell lymphoma

Relationships, family and friends

Changes to relationships	34
Your partner	37
Effective communication	39
Talking to children about lymphoma	42

Changes to relationships

Lymphoma can change relationships. Some interactions might feel strained, with people feeling nervous about saying something insensitive and upsetting you. Others might grow stronger, as you support one another through challenges.

Practical changes can also be difficult to adjust to and affect relationships. For example, you might find it hard to accept help with transport to medical appointments, or if a friend offers to walk your dog or help with childcare. Most people want to help, so consider letting them know how they can support you.



If someone close to you has lymphoma, we're here to support you too. Search 'support' on our website to find out how. You'll also find information on our website about caring for someone who has lymphoma, and you can order or download a copy of our book for family and friends: *When someone close to you has lymphoma*, which has practical tips and emotional support.

There might be times when you feel angry or resentful because people around you seem to carry on with their lives as normal. These feelings are natural but can be very painful, particularly if you have no outlet for them. Finding ways to express yourself can be hugely beneficial and can help you to adapt to your situation – see page 174 for ideas.

“ *My family live nearby and once treatment had finished, family and friends expected me to return to how things had been beforehand. But nothing felt the same.*



My clinical nurse specialist said that I shouldn't cut myself off entirely, so gradually – and ever so carefully – we have started to see people.

Hayley, diagnosed with Hodgkin lymphoma

Sometimes, people say or do things that you might find patronising or annoying. You might get irritated by their well-meant suggestions. Some people might not seem to realise that you are unwell if you look the same way you did before your diagnosis. At the same time, many people with lymphoma say that people are over-cautious with them.

Friends and other people you know might, for example, pretend not to see you and cross the road to avoid conversation. This might be out of concern not to say the wrong thing, but it can bring about a great sense of isolation. Keep in mind that people are not acting out of malice.

It might help to take the lead in approaching others – say hello. Try to reassure them that you’re still the same person and encourage them not to feel worried about talking to you.

Research suggests that support from others can help people to cope better with change. In general, effective communication (page 39) has a positive impact on relationships.

Mental Health Foundation produce information about healthy relationships. They outline how relationships can benefit emotional wellbeing and sets out key steps to improving relationships:

- **Time:** set aside time to connect with friends and family.
- **Presence:** be fully ‘with’ the person or people you’re with, rather than trying to multitask or thinking about what you’ve just done or are going to do later.
- **Listen:** focus on the person you’re talking to and really pay attention to what they’re saying.
- **Be listened to:** talk with honesty and let yourself be listened to.
- **Recognise healthy and unhealthy relationships:** choose to spend time with the people who have a positive impact on your mental wellbeing. Limit the time you spend with the people who have a negative impact on how you feel.

For free, downloadable ‘thinking tools’ that aim to help you live and communicate well, visit thinkaboutyourlife.org

Your partner

It doesn't matter how long you've been together or what else you've dealt with, a cancer diagnosis affects relationships.

There might be times when you and your partner are in different places, mentally and emotionally. For example, one of you might want to quietly process what's happening while the other wants to talk things through.

You might also have different ideas about the best approach. Maybe your partner asks you to 'take it easy' but you want to carry on with your daily routine as far as possible. These differences, in addition to each of you finding your way through such an unfamiliar situation, can cause anxiety, frustration and tension and lead to a breakdown in communication. Find tips to help with communication on page 39.

Sex during treatment

Sex during treatment is generally safe, but ask your medical team if there are any precautions you should take. This is especially important if you're on treatment or your platelet count is low (thrombocytopenia – see page 107). You are also generally advised not to start a pregnancy during treatment or too soon after.

If you're currently having chemotherapy, use a condom to avoid passing chemotherapy to your partner, to protect against infection and to prevent pregnancy (which is not recommended during treatment for lymphoma).

See page 120 for more about lymphoma and pregnancy.

Some types of chemotherapy can cause difficulty getting or keeping an erection ('impotence' or 'erectile dysfunction') in men. In women, they can cause vaginal dryness. Both of these effects are temporary, but can be worsened by psychological factors, such as how you feel about yourself. Ask your medical team for help if these problems affect you. Doctors are used to talking about sensitive issues and should offer suggestions to help.

Lowered sex drive

You might not feel like having sex when you're going through treatment. This isn't uncommon and sex drive usually returns in time. It can happen for various reasons including heightened stress and anxiety, fatigue, changes to body image and self-confidence, and feeling generally unwell. If you feel less connected to your partner emotionally, this can also affect your sexual desire.

Being open with your partner about your feelings can help to build emotional closeness, which, in turn, can help with physical intimacy. Although it might feel awkward to start a conversation on the topic with your partner, you might find it becomes easier once you start.

If your sex drive is lowered, talk to your partner about it and let them know that it doesn't mean that you no longer find them attractive. Being open can help to develop emotional closeness, which, in turn, can help with physical intimacy. Remember that there are other ways to express affection, whether through physical touch or in other ways.

Relate is a charity that offers relationship information and support, including self-help resources, counselling and workshops. Visit [relate.org.uk](https://www.relate.org.uk)

Effective communication

When life is challenging, communication can become strained. Often we take our feelings out on those who are closest to us. In general, honesty and openness is helpful in allowing an opportunity to talk through difficulties. It can also prevent assumptions, hurt feelings and misunderstandings.

‘I statements’

‘I’ statements focus on you and your feelings instead of another person’s behaviours and actions. They can help you express yourself while lowering the risk of angry, hurt or defensive responses and the perception of blame. The table on page 40 gives examples.

When you’re using ‘I’ statements, think about:

- how you feel or felt and the possible reason or reasons for this
- how you’d like things to be different, possibly with an idea for how this could happen.

Statement	Rephrased to an 'I' statement
<p>You're always telling me to rest. I wish you'd stop trying to do everything for me.</p>	<p>I felt frustrated earlier when you told me to rest. I know this was out of care, but I want to do things when I have the energy to. It helps me to feel more like myself. Can we agree that you'll trust me to tell you when I need to rest?</p>
<p>It was embarrassing when you told our friends about my treatment. I didn't want them to know all the details you gave.</p>	<p>I wasn't expecting you to tell our friends so much about my recent treatment. Let's agree on some things it feels OK to say about and some details to keep private.</p>



Search 'communicating' on our website for more about communicating effectively with the people around you about lymphoma.

Avoid using extreme words or generalisations like ‘always’, ‘never’ and ‘everything’ when describing someone’s actions. These are often exaggerations and can increase the risk of the person you’re talking to feeling blamed. Instead of ‘you never prioritise me’, you could say something like, ‘I feel like less of a priority to you sometimes’.

Tips for sharing information about your lymphoma

To save you from having to repeat information and lots of similar conversations, you could:

- Have a key contact, who passes information between you and groups of friends or colleagues
- Send group messages with updates (for example, by email or WhatsApp) – this can also be helpful in asking for help
- Set up a private blog that you give people you choose access to
- Use social media – although be aware that your posts will remain online for years to come
- Let people know that they can find out about lymphoma on our website. They can also get in touch and speak to a member of our helpline team (page 207).

“ *During treatment I was overwhelmed by the number of calls and texts asking how I was doing. I was happy that people cared, but was struggling to keep up with the conversations and started to worry that I wasn't replying to everybody. I therefore decided to set up an Instagram page so that I could post updates on there.*

Nicola, diagnosed with follicular lymphoma



Talking to children about lymphoma

Talking to children about lymphoma is tough, whether you are their parent, grandparent, or any other relative. You might be concerned about frightening or upsetting them. Perhaps you don't have the emotional energy to cope with their questions and how they respond to the answers you give them. Give yourself some time to think about how and when you might speak to your child. There's no one 'right' way of telling them.

Cancer Research UK has information about talking to children. Search 'talking to children' at [cancerresearchuk.org](https://www.cancerresearchuk.org)

Research shows that children cope better if they have some understanding of what's happening. From a young age, children notice anxieties and frustrations within their home. It can be very troubling for them if they don't know why these tensions are there. It's also important for children to know that nothing they did, or didn't do, has caused your lymphoma, and that they can't catch it from you.

Talk about your lymphoma to help a child feel more secure and trusting of you. Let them know it's OK to talk about the situation.

You know your child best. Trust your intuition and be guided by how much or little he or she wants to know.

It's also a good idea to let your child's school know about the situation, so that they can offer support. If you have more than one child, talk to them at the same time, so that they don't think that a sibling is being given more or different information.

Tips on talking to children about lymphoma

- **Be honest.** This helps them to understand the situation and encourages them to express their feelings in return. Use language that is appropriate to their age and development.
- **Consider if you'd like someone with you,** for example, a partner or friend. Some hospitals offer a nurse or social worker to be there.
- **Choose a time when you're feeling calm and when you feel able to deal with questions.** Try not to put yourself under pressure to have all the answers, though. It's OK to say something like, 'I don't know the answer to that, but shall we talk about it and then I can try to find out more?'
- **Help prepare children for likely changes.** For example, think about how their daily routine might change – for example, who will pick them up from school on the days you have treatment. Let them know that you could lose your hair.
- **Tell them how you feel,** for example, tired or in pain. Reassure them that this isn't linked to how you feel about them.

Remember that it's a lot for a child to make sense of so you might need to revisit the information a number of times.

Some children find it helpful to do something creative while they try to understand the situation and to express their feelings. For example, you could offer drawing, painting, plasticine or modelling clay.

“ *Children often express themselves through play and arts and crafts, especially when they do not have the verbal ability to articulate their feelings. Many young people struggle to initiate communication and feel self-conscious or uncomfortable talking about feelings. ‘Diluting’ the situation, perhaps when in the car or doing a small task together, can potentially be a more comfortable, familiar way of checking-in with them.*

Sandra Richardson, Counsellor working with children and young people

Some hospitals let children visit the treatment unit. This can help to lessen their fears. Often, the hospital environment is not as bad as they might expect. Prepare them for any physical changes they might see, so that it is not so alarming when it happens.

“ *We explained that although their dad doesn't look poorly now, he is poorly and he needs to start some treatment. The treatment is going to make him look sick and feel sick.*

Natasha, whose children were 8 and 13 when their dad was diagnosed with lymphoma





- Search ‘Talking to your child if you have lymphoma’ on our website for more tips. You might also find our short video animation explaining what lymphoma is and how it develops helpful – search ‘what is lymphoma animation’
- Cancer Research UK has a list of resources – search ‘resources to help you and your children when you have cancer’ on their website
- Fruitfly collective have a set of resources, including some that are free, to help children and families cope when a parent has cancer. Find their website at fruitflycollective.com
- Macmillan Cancer Support have a set of free books for children and young people. Search ‘children and young people’ at be.macmillan.org.uk

You might be interested in seeking support from a professional therapist, such as a counsellor – either to talk to them on your own, as a couple, or with your family. One place you could try looking is the British Association for Counselling and Psychotherapy website at bacp.co.uk where you can filter your search to look for someone who provides support with ‘relationships, family and children.’



“ Don’t be scared to ask your medical team for help. For example, I found it helpful to take preventative measures to manage side effects. I was given medication to help control my nausea. I could have been quicker to accept this help, to make the earlier cycles of chemotherapy easier.

Christy, diagnosed with Hodgkin lymphoma

Coping with symptoms, treatment and side effects

Coping with symptoms of lymphoma	51
Holistic needs	57
Getting ready for treatment (prehabilitation)	59
Coping with hospital visits	61
Fatigue	65
‘Chemo brain’ (cancer-related cognitive impairment)	73
Sickness (nausea and vomiting)	78
Hair loss and other changes to your hair	81
Changes in weight and hunger	90

Bowel problems	92
Urinary and bladder problems	98
Anaemia	101
Neutropenia	101
Thrombocytopenia	107
Peripheral neuropathy	108
Skin problems	113
Sore mouth	115
Fertility	118
Early menopause	124
Our Live your Life programme	128

Coping with symptoms of lymphoma

Very often, symptoms of lymphoma ease once you start treatment. However, they can continue during, and for a while afterwards.

In this section, you'll find suggestions to help you cope with some of the common symptoms of lymphoma. Your medical team can offer advice specific to you.



Getting help with symptoms and side effects might be part of addressing your 'holistic needs'. This means any physical, practical, emotional, social and spiritual needs you might have – see page 57 for more about holistic needs.

Search 'side effects' on our website for more information.

Swollen lymph nodes

Although the lymph nodes themselves aren't usually painful, they can cause pain in surrounding areas if they are swollen and press against nerves and tissues. Where you feel pain depends on which nerves the swollen lymph nodes affect.

Usually, swollen lymph nodes start to get smaller once you start treatment. However, if they cause discomfort or you feel self-conscious about them you might choose to try to distract attention away from them – for example, by using accessories or wearing a bright colour.

“ *I was very aware of a big lymph node in my neck so I'd often wear a little scarf. I had another one under my arm and I would always wear something with sleeves because I was so aware of these big lumps and bumps.*

Doreen, diagnosed with small lymphocytic lymphoma (SLL)



If you have swollen lymph nodes that other people such as friends and colleagues might easily see, you could mention them. Being open in this way could help to ease awkwardness, for example, if you are worrying that they might be pretending not to notice.

Swollen lymph nodes usually get smaller upon starting treatment for lymphoma. Whether or not you are having treatment, you can ask your medical team for advice about managing pain.

On page 139 you'll find guidance on checking your lymph nodes.

Sweats

Sweats often stop once you begin treatment for lymphoma, particularly those that leave your bed clothes and sheets soaking wet. However, they can continue for a while during and after treatment. There are things you can try to help ease sweats. There might also be medication that your medical team can prescribe to help.

Tips for coping with sweats

During the day:

- Wear loose-fitting clothes that are made of natural fabrics, such as cotton and linen, as these tend to keep you cooler
- Wear breathable footwear to help prevent your feet from becoming sweaty
- Wear light layers of clothes so that you can easily remove a layer if you need to
- Drink plenty of cold, non-caffeinated fluids (around 2 to 3 litres a day) to replace those lost through sweating
- Avoid spicy foods, sugary drinks and caffeine
- Exercise earlier rather than later in the day, to help ease night sweats.

At night:

- Keep your bedroom cool: use a fan, adjust your thermostat or open your window
- Save your bed sheets from getting too wet by placing a soft towel underneath you in bed. You could also consider a mattress protector or waterproof sheet made from a soft fabric.

Hyperhidrosis UK at hyperhidrosisuk.org has information about excessive sweating, including some self-help tips that you might like to discuss with your medical team.

Itching

Itching caused by lymphoma usually settles once you start treatment. Try not to scratch as it can worsen the itch and leave lasting marks. Some people find that pressing or tapping the skin around the itch helps to reduce it.

Keep your nails very short and wear cotton gloves in bed in case you scratch while you're asleep.

Some products are more likely to worsen the itch than others. In general, soaps, perfumes and cosmetics that are fragrance-free and labelled as 'hypoallergenic' have a lower risk of causing skin irritation. It's a good idea to avoid common skin irritants such as chlorine, and products that are lanolin or alcohol-based.

You could also try soothing itchy areas with a cool pack. Avoid applying this directly to your skin as this can cause ice burn. Instead, you could wrap a cool pack or bag of frozen peas in a dry towel and hold this to your skin.

Applying cream could also help soothe an itch – ask your medical team if they can recommend one.

If your itching is intense or disruptive to your sleep or day-to-day life, seek advice from your medical team. They might be able to prescribe a corticosteroid medication to

help ease it, for example hydrocortisone or prednisolone. Sometimes, doctors prescribe other medications that are usually used to treat symptoms of other conditions, such as allergies (antihistamine), depression, nerve pain and epilepsy. In some cases, if the itching is ongoing, you might be offered a referral to have light therapy (phototherapy).

The National Eczema Society website at eczema.org has information that you might find helpful. Search:

- 'itching and scratching' for tips to help you cope
- 'phototherapy' for information about this type of treatment.

Coughing and breathing difficulties

If you have swollen lymph nodes in your chest, you might experience difficulties including:

- a dry cough
- shortness of breath
- noisy breathing
- pain in the middle part of your chest (behind your breastbone)
- a feeling of pressure or 'fullness' in your chest.

Symptoms should go away once you start treatment. If you have lowered immunity (immunosuppression), you are at an increased risk of developing infections, including chest infections. This can also cause coughing and breathing difficulties.

Contact a member of your medical team if you:

- become short of breath
- cough up thick, yellow or green phlegm (mucus)
- have a cough that gets worse or is painful
- have a fever (temperature above 38°C/100.4°F).

These could be signs that you have developed an infection and need antibiotics.

Tips to help soothe a cough

- Drink plenty of fluid to help loosen the mucus in your chest.
- Prop yourself up when you lie down as coughs are often worse when you lie down – you could sleep with an extra pillow under your head or back.
- Try a hot honey and lemon drink. This is generally as effective as cough medicines that you can buy in a pharmacy. Boil a cup of water and add the juice from half of a lemon. Stir in 1 to 2 teaspoons of honey.

Holistic needs

'Holistic' means considering you as a whole person, not just in terms of your medical needs. Your medical team should work with you to look at your holistic needs. We have covered this topic in the section on coping with symptoms, treatment and side effects. However, the purpose of it is to identify any physical, practical, emotional, social and spiritual needs you might have. In reality, one area often impacts on another.

Considering ways that could help you to live well is sometimes called a holistic needs assessment (HNA). An HNA is usually completed as a questionnaire during a conversation between you and a member of your medical team, such as your clinical nurse specialist or other key worker. An HNA can help with a range of areas including:

- Physical needs, for example about changes in appetite, fatigue and dry, sore and itchy skin.
- Practical needs, for example in relation to household chores, looking after your family, working or studying.
- Emotional needs, for example feeling anxious, low or isolated.
- Social needs, for example considering relationships with friends and family.
- Spiritual needs, for example concerning a faith or religious beliefs, or questioning the meaning of life.

Some hospitals use a digital version of the HNA, known as an electronic Holistic Needs Assessment (eHNA). You need to have access to a device such as a smartphone, tablet or laptop for an eHNA.

Holistic needs assessments are not **only** for at the point of diagnosis. You should have one regularly, including after diagnosis, before and after treatment.

You and your medical team can work together to look at any information and support needs you have and put together a personalised care and support plan. It can include needs that are physical, emotional, social or financial. For example, about day-to-day life, work, vaccinations and travel – there's more about these areas in the first chapter of this book.

Getting ready for treatment (prehabilitation)

Prehabilitation is the process of getting ready, physically and mentally, for treatment.

Some people need to start treatment sooner than others. Your medical team might suggest a prehabilitation programme for you before starting treatment. This depends on the time available and on your needs.

Prehabilitation involves different aspects of health and wellbeing, including good diet and nutrition (page 8), taking physical activity (page 17) and looking after your emotional wellbeing (page 173)

“ *Before I went in for treatment, I tried to increase the exercise I was doing by going for a walk every day. This helped reduce anxiety and meant I was fitter and more prepared for a spell in hospital. I made sure I ate well too, as I knew I was likely to be off my food.*

Corrin, diagnosed with lymphoma

Depending on whether it is relevant to you, it might include helping you to stop smoking or to reduce your alcohol intake. For some people, it also includes managing any other medical conditions, such as anaemia (page 101) and diabetes.

The NHS website has advice, information and tools to help you make healthy lifestyle choices at [nhs.uk/live-well](https://www.nhs.uk/live-well)

The benefits of prehabilitation can include:

- a shorter stay in hospital
- fewer side effects of treatment
- a quicker recovery
- fewer post-treatment complications
- improved overall physical and mental wellbeing, leading to a greater potential to live as fully as possible, during and after treatment.

In some cases, prehabilitation can help to make different treatments available that you might not otherwise be able to have. This is because some treatments are only suitable for people who are well enough to have them.

Your medical team can work with you to identify your individual prehabilitation needs and advise you on how best to meet these. Sometimes, this is called a ‘personalised prehabilitation care plan’ (PPCP).



For more information and resources:

- Search ‘preparing for treatment’ on our website
- Search ‘prehabilitation’ on Calderdale and Huddersfield NHS Foundation Trust’s website at cht.nhs.uk
- The Scottish Government also have a document: *Key Principles for Implementing Cancer Prehabilitation across Scotland*. Search ‘key principles’ at prehab.nhs.scot

Coping with hospital visits

Going through tests and treatment for lymphoma can mean having a number of trips to hospital. For some of these, you might need to stay in hospital overnight.

It can help to prepare yourself mentally for staying in hospital overnight. Your hospital should give you information about where to go and what to expect on the day of your appointment.

You might like to think through whether there is any particular information you would like in advance of your visit, for example:

- Will I be on a same or mixed sex ward?
- When can friends and family visit?
- Is there any help towards the costs of parking?
- If I'm taking medication, should I bring this with me?
- Is it OK to bring my own snacks?

There's more about staying in hospital on the NHS website – search 'staying inpatient' at [nhs.uk](https://www.nhs.uk)

Tips to make hospital visits easier

As an outpatient:

- Take something to stop you from getting bored while you're in the waiting room – for example, a book, phone, tablet or some mindfulness colouring
- If you arrive early, you could go for a walk or a coffee while you wait. Let the ward or department staff know where you're going and tell them when you get back
- Speak to your medical team in advance if you're worried, for example, if you're claustrophobic and feel anxious about having a scan.

As an inpatient:

- Take things from home, like pictures and your pillow.
- If you need to block out noise, try ear plugs. You might also want to take an eye mask for nights
- Take comfortable clothing for during the day and nightwear, including slippers and a dressing gown if you want to
- Think about what you could take with you to keep you from getting bored. For example, you could take a phone or tablet with films, music or podcasts on, or some books
- Our closed Facebook community shared thoughts about preparing for the day of chemotherapy treatment. You can read these at lymphoma-action.org.uk/ChemoTips
- In case you need to stay in hospital unexpectedly, keep a list of what to pack, or have an overnight bag ready. Search 'staying in hospital' at nhs.uk for more tips.

Coping with medical procedures and needles

You'll need to have a number of medical procedures throughout your lymphoma experience, for example:

- **Blood tests:** most people affected by lymphoma have blood tests as part of their diagnosis, frequently throughout treatment and as part of follow-up checks.
- **Biopsy:** a biopsy is needed to confirm a lymphoma diagnosis. It can also help doctors find out more about the lymphoma to plan your treatment.
- **Chemotherapy lines:** You might have chemotherapy through a central line (or line), or a central venous catheter. These are thin tubes put into one of your veins to give you chemotherapy.

Some people feel very nervous about medical procedures. For example, you might feel uneasy or 'squeamish' about needles. Talk to your medical team if you feel anxious in any way, so that they can offer support.

Guy's and St Thomas' NHS Foundation Trust has tips to help if you feel fearful of needles. Search 'fear of needles' on their website at: [guysandstthomas.nhs.uk](https://www.guysandstthomas.nhs.uk)

“ *I was worried that having a biopsy would be painful, but the doctor numbed the area and I didn't feel a thing. The nurse*



asked if I wanted to see the biopsy. It wasn't something I would have asked to see, but now it was offered, how could I say 'no'? It amazed me that they could cut something so small out.

Jean, diagnosed with
Burkitt lymphoma

Fatigue (extreme tiredness)

Cancer-related fatigue is exhaustion that can be physical, emotional, mental or a combination of these. It's at a much higher level than 'usual' tiredness. You might feel tired very quickly after doing quite little.

Fatigue is very common in people with cancer – this can be due to the cancer itself, side effects of treatment, low mood, heightened stress and anxiety.

There are also some factors related to lymphoma and its treatment that can increase the likelihood of experiencing fatigue. These include:

- having a higher stage (3 or 4) of lymphoma compared with lower stage (stage 1 or 2) lymphoma
- taking strong painkillers, such as opioids
- having a low number of red blood cells (anaemia, page 101)
- having, or recovering from, an infection
- older age.

If you have lymphoma **as well as** one or more of the following, you might be at an increased risk of fatigue:

- menopause in women (page 124)
- low testosterone in men
- underactive thyroid (hypothyroidism, page 147)
- diabetes if your blood-sugar levels are not controlled
- lung, kidney or heart disease
- having another type of cancer as well as lymphoma.



For more information about who gets cancer-related fatigue, search 'fatigue' on our website.

Fatigue can make everyday tasks difficult. For example, you might feel that you don't have enough energy to shower or get dressed. Thinking processes (cognition, page 73) such as memory and attention can also feel difficult.

Fatigue can be difficult to describe. People often talk about 'all-encompassing' feelings of 'weakness' and 'exhaustion'. Some people use words like 'debilitating', 'paralysing', and being 'drained of energy'.

“ *My fatigue was worse after treatment. I think maybe adrenaline powered me through the treatment. I need to rest more than I used to and think it's important to give yourself enough compassion and space.*

Christy, diagnosed with
Hodgkin lymphoma

On page 65, you'll find suggestions to help you explain how fatigue impacts on you.

Managing fatigue

A healthy lifestyle is important to managing fatigue. This includes getting some physical activity (page 17), eating well (page 8) and getting enough rest (page 67).

“ *I think fatigue is massively underestimated by lots of people, maybe partly because it's hard to measure. I think it's good to keep doing little bits of what you can do, but to be kind to yourself and to give yourself a break. I gave myself little 'wins' each day, mentally – even if it was just getting out of bed. I would think, 'it's a good day because I've managed to do something'. I felt these wins helped me to feel like I was in control.*

Penny, diagnosed with
follicular lymphoma



We list some suggestions for ways to help manage fatigue.

- Track your energy levels (page 68).
- Pace yourself (page 71).
- Make some changes to your routine.
- Take care of yourself emotionally and physically (page 17).



You might also be interested in the tips for coping with fatigue that people affected by lymphoma shared on our closed Facebook. Search 'top tips fatigue' on our website.

Track your energy levels

A fatigue diary allows you to keep track of your activity levels each day. You can use it to look for any patterns. For example, you might notice that you feel more fatigued a certain number of days after chemotherapy, or after a social occasion.

By taking note of any triggers to your fatigue, you can plan your activities and periods of rest.

You'll find a template of a fatigue diary on the next page. It might be helpful to think about which activities fit into each category for you – this might differ from person to person. You can also download a copy from our website at lymphoma-action.org.uk/fatigue

Activity isn't only physical – it can include using your brain (taking mental or emotional energy) for things like working in a desk job or having a conversation with a friend.

- If you're having treatment, put a cross in the boxes on the days you have treatment.
- Use a colour-coded system to indicate your level of activity, relaxation and sleep.

After a couple of weeks, you might start to notice any patterns. This can help you to plan, prioritise and pace your activities.



- Search 'physical wellbeing' on our website to find a webinar about coping with fatigue.
- For digital resources to help track fatigue and energy levels, you might be interested in Macmillan Cancer Support's RESTORE or search for the Untire app.

Week 1

	Morning - am											Afternoon/Evening - pm												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Week 2

	Morning - am											Afternoon/Evening - pm												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Colour each square to keep track of what you have been doing (you can do half or quarter squares, too)



High energy activity



Moderate activity



Low energy activity



Relaxation



Sleep

Pace yourself

We all have a limited energy supply, and some days it's higher than others.

Imagine your energy capacity for each day as a bottle or tank. Some days, it has more energy in it than others. To help plan your day, think about how much energy you're starting with and how much energy each activity takes up. You could use the diagram below to help.

If you don't have enough energy to do everything you'd like to, think about which tasks or activities are your priorities. You could ask for help with some things, or do them on another day.



Figure: Use the empty bottle on the right to plan your day as in the example on the left

Make changes to help you in your day-to-day life

Consider when your energy is usually at its highest. Then, if possible, you can then use this time for your most important activities.

- Ask people in your social support network or family, friends and neighbours for help – this way, you can save your energy for the tasks you most enjoy, or those that only you can realistically do.
- If you work, consider how you might be able to organise your day so that you work when your energy levels are higher. See page 23 for more about managing work.

Set yourself realistic goals. Breaking your to-do list into smaller tasks can make it more manageable. Make sure you rest, too. Plan breaks into your day so that you can sit or lie down for a short while between activities.

People often ask whether it's helpful to nap during the day. During treatment, a nap might help give your body the extra rest it needs. However, with long-term cancer-related fatigue, napping in the day could disrupt your night-time sleep pattern. In this case, having a rest (without sleeping) might be better.

Get enough rest

Build relaxation into your day-to-day life. This includes having a regular sleep pattern (page 194) and getting enough rest between activities. You could consider trying a complementary therapy like massage, yoga or acupuncture but check with your medical team first to make sure this is safe for you. You'll find more about complementary therapies on page 203.

Macmillan Cancer Support has resources about fatigue. Search 'coping with fatigue' at [macmillan.org.uk](https://www.macmillan.org.uk)

'Chemo brain' (cancer-related cognitive impairment)

'Cognitive' relates to thinking. It includes things like memory, attention and concentration.

Cancer-related cognitive impairment (CRCI) means a change to your thinking processes. People with CRCI often describe it as feeling 'hazy' or 'in a mental fog'. You might have difficulties with planning, learning new things and making decisions. It can be hard to remember names, keep up with a conversation or what's happening in a film.

Cancer-related cognitive impairment is often called 'chemo brain' or 'chemo fog'. However, it can also affect people having other types of cancer treatment, or people who haven't had treatment at all.

Lots of things could contribute to chemo brain, including:

- the lymphoma itself using your body's energy and resources
- side effects of treatment, with stronger treatments sometimes increasing the risk
- other conditions related to the lymphoma or its treatment, such as having a shortage of red blood cells (anaemia, page 101)
- fatigue (page 65)
- the emotional impact of living with lymphoma, including stress, anxiety and low mood.

CRCI can be very difficult to live with. If it affects you, talk to your medical team so that they can help you to manage it. They might also look at whether there is anything underlying or contributing to CRCI and offer support accordingly – for example, treatment for an infection or supporting you with low mood.

Most people find ways of limiting the effect on their daily life – see page 77 for tips.

Chemo brain can come and go. If you're having treatment, the symptoms might change at different times in your treatment cycle. Usually, chemo brain improves once you finish treatment, though for some people, it lasts much longer. Symptoms might change from day-to-day, or at different times of the day. How tired or busy you are can make a difference.

If you experience CRCI and you have any uncertainty about whether it's safe for you to drive, speak to a member of your medical team for advice.

Getting specialist help

If CRCI affects your daily life, your medical team might be able to offer additional support, such as:

Mind (cognitive) training

This focusses on helping to order your thought processes and find ways of coping that work for you. For example:

- Cognitive behavioural therapy (CBT) using 'brain training' techniques that challenge your brain and give you exercises to use skills like using your memory. You might work with a Cognitive Behavioural Therapist, or your medical team might suggest an online resource to do at home.
- Memory and attention adaption training (MAAT), which is a type of CBT. It focuses on finding different ways ('compensatory strategies') to manage your difficulties.

Search 'CBT' at [nhs.uk](https://www.nhs.uk) for information about cognitive behavioural therapy.

Medication

There is no clear evidence to say that medication could help people with the symptoms of chemo brain. Doctors therefore prefer to try other approaches to managing chemo brain before considering medication.

Researchers have looked at whether drugs for other conditions could be helpful. These include those usually used to manage depression (antidepressants) and dementia. Studies have also looked into whether taking certain supplements could be helpful. For example, the hormone erythropoietin, or products containing the herb Ginkgo biloba. At the moment, however, there is no clear answer to these questions.

If you are thinking of taking any herbal supplements, speak to a member of your medical team first to check that they are safe for you.

Tips...

...to help with focus.

- Try to do just one thing at a time.
- Be patient with yourself, particularly with things that need a lot of attention.
- Find somewhere quiet to focus on a task or conversation.

...to help with remembering.

- Note things down. Leave yourself written reminders or set up alerts on your phone.
- To help remember things like names, spell them out in your head or make visual links.
- Use a calendar on your wall or on your phone to keep track of appointments.
- Add to the shopping list when you start to run low.
- Use navigations systems if you find it hard to remember how to get to places.

...to help with cancer-related cognitive impairment in general.

- Consider letting people know about your difficulties. For example, it might help to ease pressure if it's hard for you to find the words you want during conversations.
- Find ways of managing stress (page 192) and fatigue (page 65), as these can also affect your thinking processes.
- Try keeping your mind active with puzzles like crosswords, word searches and Sudoku.

If you're interested in finding out more about research looking into the diagnosis and treatment of chemo brain, search 'chemo brain research' at cancerresearch.org.uk

Sickness (nausea and vomiting)

Nausea (feeling sick) or vomiting (being sick) are common side effects of many treatments for lymphoma. They can be worse if you are feeling highly stressed or anxious (page 192).

If you experience sickness, talk to your medical team. There are lots of anti-sickness medications (antiemetics) they can prescribe. These are usually more effective if you start them early. It's also important to let them know if you have difficulties eating and drinking, or taking other medication, because of sickness.

Even if you don't feel like eating, try not to skip meals, because hunger can make nausea worse. Some people find it helps to eat little and often. You might find it easier to eat quite plain foods that aren't too strong or greasy. Toast, crackers, breadsticks, rice and pasta can be good choices.

See page 90 for more tips to help if you don't feel as hungry as usual.

Tips to help with treatment-related sickness

- Limit strong food smells if these trigger feelings of sickness – for example, eat it at room temperature (as hot foods tend to produce more smells).
- Choose cool, citrus flavoured, fizzy drinks. These tend to be more soothing than still or hot drinks and can help to settle your stomach.
- Eat food you like, although some people avoid their most favourite foods in case they start to associate them with being sick.
- Try adding ginger to your diet for example, ginger beer, ginger tea, ginger biscuits, ginger cake or root ginger. Some people find that this helps to alleviate sickness.
- Eat a cracker or a dry biscuit before you get up if you feel sick in the mornings.
- Don't skip meals or snacks. Hunger can make sickness worse.
- Try eating five or six small meals a day instead of three large meals. A full plate can feel overwhelming.
- Try wearing acupressure (travel sickness) bands on your wrists.
- To help manage sickness, you could also try behavioural techniques, such as distraction and relaxation. Visit nopanic.org.uk/relaxation-technique for an example.

“

I found that my appetite was very up and down and often completely disappeared in the days following treatment. It was a case of eating small things when I felt like it rather than worrying about set mealtimes. I also used to sit and nibble ginger biscuits and have ginger tea, which I think made a bit of a difference.



Callum, diagnosed with Hodgkin lymphoma

Some smells might also trigger feelings of sickness – for example, perfumes, aftershaves, shower gels or hand creams. If this affects you, try using fragrance-free products. You could also ask friends, family and colleagues to avoid wearing strong fragrances around you.

Cannabis for medicinal purposes

Researchers have studied whether the chemicals made by the cannabis plant (cannabinoids) can help people affected by cancer, including with treatment-related sickness.

In the UK, cannabis and products made from cannabis (including CBD oil, cannabis oil and hemp oil) are not licensed to treat nausea and vomiting. In rare cases,

specialist doctors can prescribe medical cannabis-based products for medicinal use (CBPMs). However, this can only be considered if other treatments aren't effective for you.

Remember that cannabis is illegal in the UK. Buying or getting it from anyone other than a specialist medical doctor could put you at risk of health problems. As well as interacting with your lymphoma treatment, it can contain lots of chemicals, bacteria and fungi, which can lead to serious infections.

Hair loss and other changes to your hair

Some treatments for lymphoma can cause changes to your hair. In most cases, this is short-term. For some people, it lasts longer.

Changes to your hair can include:

- slight thinning
- partial or full hair loss
- a change in the colour of your hair – sometimes with a white streak or band of hair appearing
- a change in texture – such as being more thin, thick, curly or straight than before treatment.

Mostly, hair eventually goes back to how it was before treatment for lymphoma. However, it can still be very distressing and can affect your sense of identity, self-esteem and self-confidence. It can also be a visual reminder of going through treatment.

“ *My hair thinned, which was very difficult as my hair had always been very long. There were some very challenging moments where I did not recognise myself in the mirror. I coped by cutting it shorter several times. I then had it shaved off when I felt ready to fully embrace it. The moment I did this, I felt completely free of any fears I'd had. My hair started to grow back quite soon after I finished chemotherapy, albeit a bit curlier and quite a bit darker than previously, but much thicker and stronger.*

Carly, diagnosed with
Hodgkin lymphoma



Your eyebrows, eyelashes, facial hair, underarm and pubic hair might also be affected by treatment. You might also lose nose hair, although this is not common. If it happens, it can make your nose run more than usual. The skin around your nose might also become sore if you are wiping or rubbing it a lot.

Your fingernails and toenails contain the same protein as your hair and could also be affected by treatment. They might be dry, marked or discoloured and break more easily than usual. You could use nail varnish, but avoid

quick-drying types as these can dry your nails even more. Use acetone-free nail varnish remover because those with acetone are likely to dry your nails out more. Check with your medical team if you'd like to use nail technologies, such as gel manicures.

Preparing for hair loss

Your medical team can tell you if your treatment is likely to affect your hair. However, they won't be able to say for certain. Some people tell friends and family before having treatment that they might lose some of their hair.

“

Before starting treatment, my dad, my brother and I went to a Turkish barbers and had our hair shaved off, and my brother and I removed our beards too. I wanted to take control and saw this as a way of getting the first win over lymphoma.



Neil, diagnosed with Hodgkin lymphoma

Whether or not to cover your hair loss is a very personal decision. If you choose to, there are lots of options. We outline some of these below.

Give yourself as much time as possible to talk to your medical team and to think through options so that you can choose something that's right for you.

We're sometimes asked about scalp cooling as a way to prevent hair loss. Unfortunately, this technique is not suitable for people with lymphoma or other blood cancers because it could make your treatment less effective.

Hair extensions (clipped, woven, taped or glued into your hair) aren't recommended for people affected by treatment-related hair changes. This is because your hair is likely to be more fragile during and for a while after treatment, and they could be damaging to your hair. Speak to a trained hair professional for advice, along with your clinical nurse specialist.

A change of hair style

If you are likely to lose your hair, you might want to prepare yourself by cutting it short before your treatment starts. If you have a beard or moustache, you might choose to shave these.

Wigs

Wigs can be artificial (synthetic or 'manmade') or made from real human hair, or a combination of both. It might be possible to have a wig made from your own hair.

If you're interested in a wig, you could ask your clinical nurse specialist if you can get a synthetic one free of charge on the NHS or another local service. If you'd like a wig but don't meet the criteria for a free wig, ask your clinical nurse specialist if there is a subsidised wig scheme at your hospital that you are eligible for. They might also be able to recommend a wig supplier.

Services differ from one hospital to another. You could check whether there is a wig service available to you at yours. This might be in the form a wig specialist coming into the hospital, or you going to visit the specialist elsewhere.

Some charities offer wigs or funding towards them. Your clinical nurse might be able to recommend some for you. If you are from a black, Asian, or other ethnic minority group, a specialist supplier might be appropriate for you.

If you buy a wig privately, you shouldn't have to pay value added tax (VAT) if you've lost your hair because of cancer. Ask the company for a VAT exemption form when you buy the wig. You won't be able to claim it back later.

For more on wigs, search 'wigs' at:

- cancerresearch.org for tips on choosing, fitting and wearing a wig
- macmillan.org.uk for information about different types of wig and a video about choosing one.

Look Good, Feel Better offer free workshops to people affected by cancer-related changes to appearance. Search on their website to check availability.

Other headwear options

Hats, headscarves, turbans, bandanas and zandanas (pre-made bandanas) are all possibilities.

- search ‘tie bandana’ at macmillan.org.uk for a guide on tying a headscarf or bandana
- search ‘where to find headwear’ at cancerresearch.org for details of organisations that supply headwear options, including wigs, hats and other head coverings.

Cosmetics and camouflage options

Cosmetic or ‘camouflage’ options help to hide hair loss using make-up, sprays, lotions or powders. If you’re considering using any of these, check first with a member of your medical team if they are safe for you.

- **‘Spray on’ or ‘shake-in hair’ products** use tiny fibres that you spray onto or sprinkle over your scalp. This can give the appearance of thicker hair, although they don’t always stay in place if your hair gets wet. You wash them out and then re-apply them.
- **Concealing or masking lotions** are waterproof creams that you apply with cosmetic sponge to add colour onto your scalp. Use a colour that’s a shade darker than your natural hair colour to help cover partial hair loss.
- **Micro-tattoos** use tiny needles to add a coloured material (pigment) to the top layer of your skin. This gives the appearance of closely shaven hair. As the needles pierce the skin, micro-tattooing could increase your risk of infection. Doctors therefore usually advise waiting at least 6 months (depending on which treatment you have) after finishing treatment before micro-tattooing, and it’s possible that your hair might

have already grown back by this time. Micro-tattoos are semi-permanent and fade over time.

- **Micro-blading** is a semi-permanent tattooing technique for eyebrows. It uses needles to add pigment to your skin and this fades over time. As with micro-tattoos, micro-blading can increase your risk of infection. The general advice is to wait at least 6 months after finishing treatment before having it.
- **False eyelashes and eyebrows** are made from synthetic (manmade) materials that you or a beauty therapist sticks on with a special glue. There are also magnetic options that you attach using a magnetic eyeliner.

If you're thinking of using a hair loss concealer such as 'spray-on' or 'shake-on' hair, check with your medical team first to make sure it is safe for you. Always do a patch test before using a product to check for any allergic reactions, even if you've used it before.

- For support on all aspects of hair loss and hair care, before, during and after cancer treatments visit cancerhaircare.co.uk
- Visit mynewhair.org for a list of UK salons that can help you buy, fit or style a wig

Tips for managing hair and scalp care.

- Be gentle with your hair and scalp when you start to lose hair.
- Limit how often you wash your hair. From time to time, instead of washing it, you could sprinkle talcum powder into your hair. Leave it a while then brush it out. This absorbs grease and helps to ease tenderness.
- Use a pillowcase made from 100% cotton to help to reduce scalp irritation.
- Use a wide-toothed comb or a baby brush. They are often gentler than other types such as paddle brushes, round brushes and rat tail combs.
- Use lukewarm water and a mild shampoo and conditioner to wash your hair.
- Avoid hairdryers and other heat-styling tools. Pat your hair with a towel and let it dry naturally.
- Comb or brush your hair gently but avoid plaiting it or tying it tightly. Soft hair ties or ribbons are gentler than elastic bands.
- Soothe a sore scalp by massaging in a mild, unperfumed moisturiser.
- Protect your scalp from sun, wind and cold by wearing a hat or other head covering.
- Wear a towel or hairnet to help catch hairs if you lose hair overnight. If you find hairs on your bed sheets, you could use sticky tape to help pick them up.

When your hair starts to grow back

Hair often starts to grow back from a few weeks after finishing treatment, but it might differ to your pre-treatment hair. For example, it might grow back curlier, softer, or a slightly different colour.

If your scalp is dry, frequent moisturising can help. Try a non-scented gentle shampoo. Ask your hospital how long you should wait after finishing treatment before you colour, chemically straighten or perm your hair.

“ *I usually suggest using scalp oils or moisturising creams on the scalp that are free of fragrances, dyes and synthetics ingredients.*

Bev Wilson, Macmillan Lymphoma
Clinical Nurse Specialist

Colouring and styling your hair

Check with a member of your medical team before colouring or styling your hair, particularly with chemicals.

Small amounts of chemotherapy in your hair strands could react with chemicals used in the styling processes. Natural, temporary dyes might be better than permanent chemical products. If you'd like to dye your hair, you could ask your clinical nurse specialist if a wash-in, wash-out vegetable-based hair dye is suitable for you. These are milder and less damaging to your hair and scalp than chemical ones.

Your new hair might be fragile so you should wait several months after your hair has started to grow back before you have woven-in or glued-in hair extensions.

Changes in weight and hunger

You might worry or feel self-conscious if you lose or gain weight. It can be a difficult visual reminder of your lymphoma and can have a significant impact on your self-esteem (page 189).

Feeling less hungry than usual

Some medicines and treatments for lymphoma can lower your appetite or make you feel full soon after you start to eat. This could be a side effect of chemotherapy. It might also happen if you have lymphoma in your gut (gastrointestinal tract) or if you have radiotherapy to your gut.

For some people, stress and anxiety can have an impact on appetite. See page 192 for tips on managing stress and anxiety.

If you don't feel like eating as much as usual, try eating little and often, with snacks between meals.

You might find that people keep encouraging you to eat, which can be difficult when your appetite is low. You could explain to them that you don't feel as hungry as usual. Reassure them that you are trying hard to keep your energy levels up and get all the nutrients you need. You could also suggest ways they could help you, such as preparing small snacks for you to have throughout the day.

- Choose high protein and high energy foods, like bananas, oats, cheese, yoghurts and nuts. Full-fat products, nut butters and avocado gives more energy than low or reduced fat ones.
- Increase your energy intake by cooking with olive oil, and adding milk powder to meals such as soups, desserts and sauces.
- Try not to drink much for around 30 minutes before you eat as this can fill you up.

If you're eating out, you could order a starter or a child's portion if a full main meal feels too much. See page 14 for more about eating out.

Speak to your medical team if you are losing weight. You could ask if they can refer you to a dietitian. Search 'building up' at macmillan.org.uk to download a free book by Macmillan Cancer Support called *The building-up diet*.

Feeling more hungry than usual

Treatment for lymphoma can make you feel more hungry than usual. Your appetite should return to normal once you finish treatment.

Steroids are often part of lymphoma treatment. They can increase your appetite. They can also affect how quickly your body uses energy (your metabolism), so you might gain weight even if your appetite doesn't increase.

Your weight should return to normal once you stop taking steroids. In general, it's best to avoid dieting during treatment as it can make it harder for your immune system to recover. Your height and weight are also important in calculating treatment doses.

Instead of dieting, focus on eating a healthy diet, being active and giving your body the energy it needs to recover. There's more information about diet and nutrition on page 8. If you're concerned about weight gain, speak to a member of your medical team.

Bowel problems

People with lymphoma can be affected by changes to the digestive system. This can trigger bowel problems, including:

- diarrhoea: passing loose, watery poo (stools) more often and/or in larger amounts than is usual for you
- constipation: finding it hard to poo or pooing less often than is usual for you

- wind (flatulence): passing wind more frequently than is normal for you
- feeling full or bloated.

These problems usually improve after treatment. They can happen because of the lymphoma itself, treatments (such as chemotherapy) and medicines (like painkillers). The emotional impact of lymphoma, and of experiencing bowel problems, can worsen them.

If you're on watch and wait (active monitoring) and experience bowel problems, tell your medical team as it might be a sign that treatment should start.

Some people ask if probiotics can help with diarrhoea. Probiotics are bacteria found in some foods and supplements – they can be helpful in restoring the balance of bacteria in your gut and improve diarrhoea and constipation.

Probiotics might be unsafe for people with lowered immunity, including people who have been diagnosed with lymphoma. If you want to take probiotics, check with a member of your medical team if they are safe for you.

If you're experiencing bowel problems, avoid smoking and alcohol as they can worsen them. You'll find tips to help with both of these on the NHS website.

Diarrhoea

It's important to replace the water you lose through diarrhoea, so stay hydrated. Aim to drink at least 2 litres (3.5 pints) of liquid each day, sipping throughout the day.

- Choose plain water, weak squash or herbal tea.
- Avoid drinks that might make the problem worse, such as fruit juice, caffeinated drinks (such as coffee, Cola and some energy drinks), very hot or very cold drinks, alcohol and milk.

You could consider using an oral rehydration solution to replace lost water and mineral salts. These come as sachets of powder or dissolvable tablets and are available in supermarkets, chemists and pharmacies. However, seek medical advice before taking oral rehydration solutions or any other medicines to treat diarrhoea (antidiarrhoeal medicines) in case they are not suitable for you.

Having diarrhoea uses a lot of energy, so rest when you can. Although you might not feel like eating when you have diarrhoea, try to eat as soon as you feel able to.

Certain foods can help control diarrhoea, but speak to your medical team before making changes to your diet.

They might recommend:

- eating foods that are high in potassium, such as avocados, bananas, bread, white and sweet potatoes, fish, chicken, beef and turkey.
- eating low-fibre foods, such as potatoes, cornflakes, white rice, dry white toast, soup, peeled and boiled vegetables and tofu (bean curd).
- avoiding foods that could worsen your symptoms. This can include fatty, greasy and spicy foods, dairy products and high-fibre foods, such as raw fruit and vegetables, beans, nuts and wholegrain cereals.

Tips for dealing with needing to go to the toilet urgently

- Wear clothes that are quick and easy to take off when you need the toilet, rather than clothes with fiddly zips, buttons or other fastenings.
- Consider wearing a disposable waterproof pad (incontinence pad) to protect your underwear.
- If you are not at home, take spare clothes and a plastic bag to store any soiled or damp clothes.
- If you are going out, find out in advance where the toilets are. Take a body spray and wipes with you to freshen up.

Search 'just can't wait' at bladderandbowel.org to download a free 'Just can't wait' card. This states that you have a medical condition and might need to use the toilet urgently. It's also available as an app.

Constipation

Constipation can be a side effect of some chemotherapy drugs, anti-sickness medications (antiemetics) and painkillers. It can also happen after an illness because of all the medications you've had and because of the pressure your body has been put under.

Speak to a member of your medical team if you haven't been for a poo for a day or two longer than is usual for you. It's often simpler to treat constipation if you seek help sooner rather than later.

Tips to ease constipation

- **Drink lots of fluids**, including water and fruit juices that are high in sorbitol (a type of sugar), including orange, apple, prune and raspberry.
- **Try to get into a regular pattern of going for a poo** as it can help to go at around the same time each day.
- **Take light exercise**, such as a gentle walk to soften your poo and make it easier to go.
- **When you need to go to the toilet, go as soon as you can.** Waiting can make the constipation worse.
- **Avoid alcohol** as it is dehydrating and can make constipation worse.
- **Increase the amount of fibre you eat**, for example, choose oats, wholemeal or granary bread, pulses, dried fruit and vegetables.

A quick way to add fibre to your diet is to sprinkle salads, breakfast cereals or yoghurts with nuts, sunflower seeds, pumpkin seeds, flaxseed, chia or linseed.

If your constipation goes on, your medical team might suggest a medicine that softens your poo and makes it easier to go to the toilet (laxative). Although they are available without a prescription, it's important to speak to a member of your medical team to find out which ones are safe and suitable for you.

Search 'constipation' on the British Dietetics Association website at bda.uk.com for more information about constipation and tips to help manage it.

Wind (flatulence)

Some treatments and some anti-sickness medications (antiemetics) can lead to extra gas in your digestive system and increase wind. It's not a serious medical problem, but it can be embarrassing and uncomfortable.

Some medications can help with wind but seek medical advice before taking them. This is particularly important if you're having lymphoma treatment because some medicines can interact with lymphoma treatments.

Tips to help ease wind

- Chew your food well. This helps to limit the amount of air you swallow and makes it easier for food to pass through your body.
- Avoid foods and drinks that can increase wind. These include cabbage, apples, sprouts, onions, garlic, baked beans, leeks and cauliflower.
- Avoid fizzy/pop (carbonated) drinks and beer.
- Lower your intake of high-fibre foods such as wholemeal bread, bran, cereals, nuts and seeds.
- Avoid artificial sweeteners such as xylitol, sorbitol and mannitol. These are often in sugar-free sweets and sugar-free squash.
- Take regular, gentle exercise, such as walking.

Urinary and bladder problems

Some treatments for lymphoma can cause bladder problems. You might experience these difficulties after radiotherapy to the pelvis, some types of chemotherapy, and some types of immunotherapy. They can also happen if lymphoma affects your kidneys or urinary system.

Examples of urinary and bladder problems you might experience include:

- weeing more than usual in the daytime or during the night
- urgently needing to wee, particularly when you've had chemo
- a burning sensation when you wee
- having blood in your wee
- stress incontinence, where a cough, sneeze or other sudden movement can cause a small leak – this can also make you more susceptible to urine infections, especially if you were already prone to them before treatment.

The treatments that can cause urinary and bladder problems include radiotherapy to the area below your belly button (pelvis), some types of chemotherapy and some types of immunotherapy.

It can help to drink plenty of fluids. Avoid caffeinated drinks, alcohol, spicy foods and tobacco as these can worsen such problems.

If you experience urinary or bladder problems, tell your medical team. They might need to arrange tests to check if you have an infection. In some cases, medicines can be prescribed to help prevent urinary and bladder problems.

“

After completing my chemotherapy, I developed a problem whereby the lining of my bladder started to bleed. Fortunately, I was quick to get my bloods checked as something just didn't feel right. I got the medical attention I needed and received lifesaving blood. Please ask your medical team for help if you need to – that's what they are there for.



Christy, diagnosed with
Hodgkin lymphoma

For reassurance, you might choose to wear a disposable waterproof pad (incontinence pad) or thin liner to protect your underwear. A mattress protector can prevent damage to your bed and make cleaning easier if you might have an accident overnight.

Anaemia

Anaemia means that there is too little haemoglobin (a chemical that carries oxygen) and too few red cells (that carry haemoglobin) in your blood. Many people with lymphoma are affected by anaemia, either because of the lymphoma itself or as a side effect of treatment.

Symptoms of anaemia include:

- extreme tiredness (fatigue)
- shortness of breath when doing physical activity
- feeling your heart fluttering or pounding (palpitations)
- feeling dizzy or faint
- a paler skin colour than is usual for you
- headache
- aching bones.

Tell your medical team if you have any symptoms of anaemia. They might suggest a blood test to check your haemoglobin level. If you have anaemia, they can advise you on how best to manage it. There are different treatments for anaemia, depending on its cause.

Neutropenia

Neutropenia means having a low number of a type of white blood cell (neutrophil). Neutrophils help your body fight infections. Lymphoma and its treatment can cause neutropenia. If you have neutropenia, you have a higher risk of infection than usual.

Your medical team might prescribe antibiotics or antiviral medicines to help reduce this risk.

“ *Blood counts are usually lowest around 7 to 10 days after chemotherapy so it’s particularly important to take steps to lower your risk of infection during this time. Avoid being around anyone who has an infection like a tummy bug or chicken pox. If you have any signs of infection, contact your medical team.*
Christine Coyle, Clinical Nurse Specialist

If you have neutropenia and you develop an infection, it can be very serious. This means you’ll need urgent treatment, usually in hospital.

Neutrophil levels usually return to normal without treatment. If your neutrophil count is very low, you might have treatment to help it recover faster.

Contact your medical team immediately if you have any signs of infection, including but not limited to:

- fever (temperature above 38°C/100.4°F)
- hypothermia (temperature below 35°C/95°F)
- shivering
- chills and sweating
- feeling generally unwell, confused or disoriented
- earache, cough, sore throat or sore mouth
- blocked nose
- cough, yellow or green phlegm or mucus (snot), difficulty breathing
- redness and swelling around skin sores, or injuries to intravenous (IV) chemotherapy lines
- diarrhoea or vomiting
- a burning or stinging sensation when you wee, or weeing more often than usual
- unusual genital discharge or itching
- unusual stiffness of the neck, and discomfort around bright lights
- any new pain.

Reducing your risk of infection

Although you can't completely rid your risk of infection, there are things you can do to help lower it. Note that if you have a sore mouth (oral mucositis, page 115), your risk of infection might be increased.

“

At first, I thought I couldn't go out or be around other people, but then I realised I could if I took precautions. I live near a café that's quite open-plan and doesn't get too busy, so I went there, which lifted my mood. I was careful to wash my hands well and to keep a distance from people.



Christy, diagnosed with Hodgkin lymphoma

- **Keep good hygiene**, this includes washing your hands well when you have been out, before preparing food and eating, and after using the toilet.
- **Stay away from people with infections** such as colds and flu.
- **Avoid public places at busy times** (for example, public transport during rush hour, swimming pools, gyms and cinemas), where infections can easily spread.
- **Protect your skin from cuts, grazes and scratches.** This lowers the risk of giving bacteria a way into your body. For example, use an electric shaver rather than having a wet shave, and take care while flossing. Wear gloves if you are gardening, and wear shoes outdoors.

If you cut, scratch or graze yourself, wash your hands and clean the wound with tap water. Pat the wound dry with a clean towel and place a clean (sterile) dressing on it. Avoid picking at scabs because this can increase the risk of infection.

Food safety guidelines

Food poisoning can happen if you eat or drink food that has a virus or harmful bacteria in it.

The World Health Organization (WHO) has five key steps to food safety, as shown opposite. For more detail about the WHO's advice, visit who.int and search 'food safety'.

Although it's best to avoid takeout foods and foods from buffets when you're neutropenic, this doesn't mean that you can't enjoy a treat. For example, you could have a well-cooked pizza. Many supermarkets now stock a range of international foods you could cook at home. Takeout drinks should be OK. However, doctors advise against having drinks from draft as the pumps can contain lots of bacteria. Instead, cans or bottles are generally considered to be safer.

You might have heard of a 'neutropenic diet' (sometimes called a 'clean', 'low-bacterial' or 'low microbial' diet). The aim is to cut out foods that are more likely to contain infection causing bacteria and fungi. However, there is limited scientific research supporting neutropenic diets, and advice varies between hospitals. Your medical team are best placed to advise you on any foods or drinks to avoid.

Step	How
Keep clean	<ul style="list-style-type: none"> • Wash your hands thoroughly. Make sure that food preparation surfaces and utensils are clean.
Separate	<ul style="list-style-type: none"> • Keep raw meat, raw poultry and raw seafood separate from other foods. • Use separate utensils to prepare food.
Cook food thoroughly	<ul style="list-style-type: none"> • Make sure that food is cooked through. This is especially important with meat, eggs and seafood. With meat, make sure that juices are clear, not pink. • Make sure that foods like soups or stews are warmed to at least 70°C. Reheat cooked food thoroughly.
Keep food at safe temperatures	<ul style="list-style-type: none"> • Generally, this means below 5°C for cold or perishable food temperatures and above 60°C for hot food. • Once food is cooked, put it in the fridge within 2 hours. However, don't leave it in there for too long.
Use safe water and raw ingredients	<ul style="list-style-type: none"> • Use clean water to wash fruit and vegetables before eating them. • Choose products that have been heat-treated (pasteurised) for safety, like pasteurised milk and eggs. • Do not eat or drink products that have passed their expiry date.

Thrombocytopenia

Thrombocytopenia means having fewer platelets than you should have. Platelets are fragments of blood cells that help your blood clot. People with lymphoma sometimes have thrombocytopenia because of the lymphoma itself or as a side effect of treatment.

Thrombocytopenia can increase your risk of bruising and bleeding. You might have nosebleeds, bleeding from your mouth or gums, blood in your urine or bleeding from your bowel. Women might also have heavier periods than usual. **Let your medical team know immediately if you develop any of these symptoms so that they can give you treatment if you need it.**

Tips to lower the risk of bruising and bleeding

- Avoid high-impact sports (such as running) and contact sports (such as rugby).
- Avoid blowing your nose hard.
- Wear protective gloves if you are gardening.
- Use a soft-bristled toothbrush, for example, a child's toothbrush, and avoid flossing your teeth if it causes your gums to bleed.

Peripheral neuropathy (PN)

Peripheral neuropathy (PN) is damage to the network of nerves outside of the brain and spinal cord nerves (peripheral nervous system). You can think of it a bit like a faulty wire, disrupting the signals between one part of your body to another.

Symptoms depend on which nerves are affected. It's fairly common to get 'pins and needles' (pricking, tingling or numbness of the skin), a burning sensation, pain and increased sensitivity to touch and temperature.

You might also have difficulty with tasks that are 'fiddly' and need fine movements, such as doing up buttons or tying shoelaces. Damage to your nerves can stop you from receiving all the signals (like pain and temperature) that you'd usually get. Without these, you might not realise you've hurt yourself.

If you drive, you must tell the Driver and Vehicle Licensing Agency (DVLA) if you have peripheral neuropathy. Find more information about how to do so on the UK government website. Search 'peripheral neuropathy and driving' at GOV.UK

Losing feeling in your toes can increase your risk of hurting yourself when you're cutting your toenails – you could ask your GP whether they can help you access a podiatrist (a health professional who deals with conditions of the feet) to help keep your feet in good health. This might be available on the NHS, or you could find one privately.

“ I developed peripheral neuropathy in my feet during chemo for non-Hodgkin lymphoma and it has continued post-treatment. I have a lack of feeling in the soles of my feet, which can cause balance difficulties, particularly on uneven ground. Regular walking reduces my symptoms and lessens the risk of falling. In addition, a physiotherapist at my local hospital has given me exercises to do daily, which are beneficial. Whilst peripheral neuropathy is a nuisance, it’s a small price to pay for successful treatment, which has given me 17 years of remission.



Mark, diagnosed with non-Hodgkin lymphoma

You can use the online search tool on the NHS website to find a podiatrist near to you at [nhs.uk/service-search/other-health-services/podiatrists-and-chiropractors](https://www.nhs.uk/service-search/other-health-services/podiatrists-and-chiropractors)

If you have pain with peripheral neuropathy, this can affect your quality of sleep. Speak to your medical team for advice on how to manage it.

Some people have asked whether CBD (that comes from chemicals produced by the cannabis plant) can be used to help control pain. At the moment, cannabis (page 80) and its related products are not licensed in the UK to treat pain.

“ *My medical team were able to offer me a different chemotherapy regimen to lessen the risk of peripheral neuropathy. I'm an ice skater and it would have broken my heart not to be able to ice skate as this is my escape and mental release.*



Penny, diagnosed with follicular lymphoma

Protect yourself by wearing gloves for activities and tasks such as washing up, using the oven and gardening. Reduce the risk of tripping over by wearing well-fitting flat or low-heeled shoes with covered toes, and try to keep the floors in your house clutter-free.

Usually, symptoms of PN go away once you finish treatment for lymphoma, although they can go on for longer. Your symptoms might improve in the year after treatment but further improvements after this time are less likely.

Tell your doctor if you have symptoms of PN so that they can:

- suggest how to manage your symptoms
- prescribe medication or refer you to a specialist if pain is a problem
- give you advice to help prevent further nerve damage
- make any necessary changes to your medication
- take your symptoms into account when planning any future treatment.

You might also be offered a referral to another health professional to help with problems related to peripheral neuropathy. For example, a physiotherapist could suggest exercises to help with muscle weakness and an occupational therapist could make recommendations about adaptations to make around your home or place of work.

Some people find that acupuncture helps with the symptoms of peripheral neuropathy. This involves having fine needles put into specific places in your body. If you're interested in finding out more, search 'acupuncture' at nhs.uk and speak to a member of your medical team to find out if it is safe and suitable for you.

Tips for coping with peripheral neuropathy

- Avoid alcohol as it can affect how well your nerves function.
- If your sense of temperature is affected, use a thermometer to make sure baths and washing up water are at a safe temperature.
- If your symptoms affect your fingers and toes, flex and stretch them for a few minutes throughout the day. You can also try gently massaging them.
- If cold weather makes your symptoms worse, wearing gloves and thick socks might help.
- Wear slip-on shoes, or ones with an easy fastening if tying shoelaces is difficult.
- Avoid putting pressure on parts of your body for too long. For example, don't sit with your legs crossed or lean on your elbows for lengthy stretches of time.

Skin problems

Some treatments for lymphoma can cause skin problems such as dryness, itching (pruritus), rash, soreness and sensitivity to sunlight (photosensitivity). Skin problems can also be a symptom of some types of lymphoma.

If your skin is dry, you could try using a coconut oil or an oat-based product in the bath. You could also ask your CNS if they can recommend a suitable moisturiser for you. See page 113 for more tips on coping with dry and itchy skin.

Skin problems usually clear up once you finish treatment. However, be aware that your skin might not return to how it was before you had lymphoma.

Sun safety

Use a high factor sun cream (ideally SPF50 but at least SPF30) when you're out in the sun. Avoid being out in strong sunlight. In the UK, this is between 11am and 3pm from mid-March to mid-October. It's also important to protect your head and scalp by wearing a wide-brimmed hat.

Contact your medical team if you develop severe sunburn after being in the sun. This is important because you might be at risk of heat exhaustion and sun stroke. In severe cases, you could develop burns that need medical treatment.

Search 'sun safety' at cancerresearch.org.uk for more information about sun safety.

Tips for coping with itchy or sensitive skin

- Wear loose-fitting clothes made from soft fabrics like cotton or bamboo.
- Use bedding that's made from 100% cotton.
- Soothe sore skin with a cold (but not freezing) compress.
- If you use cosmetics such as make-up, ask your doctor which products are suitable for you. 'Hypoallergenic' products are designed to minimise the risk of skin irritation and might be suitable for you if your skin isn't broken or damaged.
- Avoid shaving if you can, or use an electric razor rather than wet shaving in case you cut yourself.
- Avoid hair removal methods such as waxing, threading and removal (depilatory) creams.
- Avoid chlorinated swimming pools.



Search 'Your physical wellbeing' where you can watch a recording of a webinar we created in collaboration with Look Good Feel Better. It answers questions about skincare and make-up for people with lymphoma.

Sore mouth (oral mucositis)

Some treatments for lymphoma can cause you to have a sore mouth. The inside of your mouth becomes swollen, red and painful. You might develop mouth ulcers.

Your medical team might prescribe treatments to help prevent or treat sore mouth. They might also prescribe a pain relief medication or mouthwash to soothe the pain.

“ *I struggled with mouth ulcers, which were miserable with nausea. This was managed with medication, taken shortly before I was due to eat.*

Colin, diagnosed with non-Hodgkin lymphoma



Sore mouth usually gets better once you finish your treatment and your blood counts return to their pretreatment levels. This is usually around 2 to 3 weeks after chemotherapy, and 6 to 8 weeks after radiotherapy. The timescales vary with different antibody treatments. Generally, they cause less damage and irritation to the lining of the mouth and gut, and less impact on the immune system.

Smoking and drinking alcohol can worsen a sore mouth. For tips on quitting smoking and lowering your alcohol intake, visit [nhs.uk/live-well](https://www.nhs.uk/live-well)

A sore mouth can increase your risk of infection. To help prevent infection:

- Rinse your mouth after eating. Use warm water or warm water mixed with salt.
- Clean your teeth twice a day using a soft-bristled brush. Change your toothbrush regularly (at least every 3 to 4 months). You could use children's toothpaste, which is milder than regular toothpaste.
- If you floss, do so gently, to avoid damage to your gums.

“ *If you develop a coating on your tongue, you can try cleaning it with a teaspoon of bicarbonate of soda mixed with a pint of warm water – dip a toothbrush into the solution and use it to clean your tongue. If this doesn't work, talk to your medical team – you might have mouth (oral) thrush, which needs treatment.*

Bev Wilson, Macmillan Lymphoma Clinical Nurse Specialist

Other mouth problems

Some treatments can cause you to get a white coating on your tongue. This usually goes away a couple of weeks after finishing treatment. Mouth (oral) thrush is a common infection that can develop during treatment. Thrush coats the tongue and the back of the throat in white patches. It can change your sense of taste and make eating uncomfortable. If you think you might have thrush, speak to your medical team so that they can offer you medication to treat it. You might be given medication to take during your lymphoma treatment to help prevent oral thrush if you are at an increased risk of developing it.

Eating and drinking with a sore mouth

If your mouth is sore, eat and drink foods that are not likely to be painful or cause injury to your mouth, for example, soft foods like mashed potatoes, scrambled eggs or soups. It might also help to eat these warm rather than hot.

Sucking an ice lolly or ice cube might also help to relieve a sore mouth. Another tip is to try rinsing your mouth every few hours throughout the day with a bland solution. For example, half a teaspoon of baking soda (bicarbonate of soda) mixed into a cup of water.

Avoid eating foods:

- with sharp edges, such as crisps and crusty bread
- that are spicy foods, like curry, jalapeño peppers and products marinated in sauces labelled as 'hot'
- that are acidic, like garlic, onions, vinegar, oranges and grapefruit.

If your mouth is dry, try sipping fluids, eating moist foods (like watermelon and jelly) and chewing gum or sucking a sweet. You could also ask your medical team about artificial saliva treatments, which might come as a gel, spray or lozenge.

See page 8 for more about diet and nutrition.

Fertility

Many people go on to start and complete a family without difficulty after treatment for lymphoma. They have healthy babies, and it seems that there is no long-term effect on them as they grow.

Fertility can, however, be affected by treatment for lymphoma. Usually, these effects are temporary. They can include:

- in men, low sperm count or no sperm
- in boys who haven't yet started puberty, damage to the cells that develop into sperm (germ cells)
- in women and girls, damage to eggs or a lower number of eggs
- in women and girls, periods stopping because of damage to the glands that store eggs (ovaries).

In girls and women, if chemotherapy reduces the number of eggs in the ovaries to a very low number, you might have premature ovarian insufficiency (POI), also called an early menopause (page 124). When this happens, there is no oestrogen production from your ovaries and you lose fertility.

Chemotherapy can cause fertility problems in men by damaging sperm production. It is unlikely to affect male hormone production though, as testosterone levels are generally normal.

In women who have pelvic radiotherapy, it might be possible to have the ovaries temporarily moved higher up into the tummy (abdominal) area, out of the way of radiation. However, this isn't suitable for all women and there is not yet enough data to know for certain whether it is helpful in preserving fertility.

If you have radiotherapy to the area just below your belly button (pelvic area), there is a possibility of temporary or permanent infertility in men and women.

If your treatment could affect your fertility and you might want to have a family in the future, tell your medical team. They can discuss options for preserving your fertility and might refer you to a fertility specialist.



If you are pregnant, you can read about treatment for lymphoma during pregnancy at lymphoma-action.org.uk/Pregnancy

“ Before starting treatment, I asked if we could talk about fertility. It was a slightly surreal experience as we had only just had our first baby, but we wanted the option of having more children in the future. We were referred to a fertility clinic, where we were asked a lot of very personal questions. I know my wife found it all very difficult but it was important to us to take this step. The procedure went well, and we have sperm banked for the future if needed, which feels good.



Christy, diagnosed with
Hodgkin lymphoma

Having a baby after treatment

Your medical team can give you advice specific to your individual circumstances about how long to wait after finishing treatment before trying to start a family.

Some people wait for at least 2 years after finishing treatment. This gives your body time to recover. Risk of your lymphoma coming back (relapsing) is also lower after this time.

If you are female, you might be advised not to wait too long if your treatment is likely to bring on early menopause (see page 124).

As a general guide, doctors generally recommend that men do not conceive within 3 months of finishing chemotherapy. As well as giving your body time to recover from treatment, it also helps to avoid starting a pregnancy using sperm that were being made while you were having chemotherapy. It takes around 3 months to make sperm, so waiting at least that long (and ideally a few extra months) after finishing treatment is recommended.

Generally, it's advised that you first try for a baby naturally. However, some women have fewer eggs, and some men have fewer sperm after chemotherapy. It's therefore a good idea to seek advice from a fertility specialist.

Some chemotherapy drugs can cause long-term damage to your heart or lungs. For women, pregnancy increases the strain on your body. Your medical team can advise you on whether to have your heart function and lung function tested before you try to conceive, and whether you should have additional monitoring during your pregnancy.

To listen to a podcast from Cancer Research UK, 'Will cancer make me infertile?', visit bit.ly/3S1Tdal

Fertility preservation options

Talk to your medical team about your options as soon as possible about fertility preservation. In many cases, options are more effective (and sometimes only possible) before you begin treatment for lymphoma.

For men, preservation options might include:

- Sperm banking (freezing) – collecting and storing semen (the fluid that contains sperm). The semen is preserved by freezing it and it is stored for you to use when you would like to have a baby if your sperm count stays very low after treatment.
- Testicular tissue freezing (testicular cryopreservation) – taking some tissue from your testicles (organs that make sperm) and freezing it to use when you would like to have a baby. This is still experimental and not yet in wide use.

There are also options for boys who have not yet started puberty.

For women, preservation options might include:

- Egg freezing – storing eggs to use when you would like to have a baby. This involves about 2 weeks of injections to stimulate your ovaries. The eggs are then removed (as with IVF treatment), frozen and stored.
- Embryo (which develops from a fertilised egg) storage. This also involves injections to stimulate your ovaries, and the eggs are then mixed with sperm from your partner (or occasionally a donor), making embryos. The embryos are frozen until you would like to use them to start a pregnancy. It's very important to know that if your partner later withdraws his consent to use the embryos, you cannot use them and they must be destroyed.
- Ovarian tissue freezing (ovarian cryopreservation) – this involves an operation to remove part of an ovary, which can then be frozen to store immature eggs. The ovarian tissue can later be thawed and put back into your body. In many cases, they start working again, making hormones and mature eggs, and it is possible to conceive naturally or by in-vitro fertilisation (IVF).

“ *I had a conversation about fertility before treatment began and it was explained that the ABVD chemotherapy regimen was more likely to preserve my fertility. Although I'm fairly sure I don't want children, I think it's an important discussion for someone my age to have.*

Hayley, diagnosed with Hodgkin lymphoma



- For information, search 'fertility' on our website
- You can find out about fertility preservation options, including IVF and to find a clinic, on the Human Fertilisation and Embryology and Authority (HFEA) website at hfea.gov.uk
- You can also find out more about fertility preservation options for women at the Cancer, Fertility and Me website: cancerfertilityandme.org.uk

Early menopause (premature ovarian insufficiency)

The menopause (last menstrual cycle or period) happens when the ovaries stop making the hormones that cause a woman's period. It also marks the end of a woman's fertility, although generally women will become infertile some years before the menopause.

For some women, treatment for lymphoma can cause early menopause. In the UK, most women reach the menopause between the ages of 45 and 55. If it occurs before the age of 40, it's called premature ovarian insufficiency (POI) or early menopause.

You are more likely to have an early menopause if you are near to the age of natural menopause when you have treatment. The risk also depends on what treatment you have. Your medical team should tell you if your treatment is likely to lead to early menopause. Speak to them about fertility preservation options (page 118) if you think you might like to have a child in the future.

Symptoms of early menopause

The symptoms of early menopause are the same as those of menopause. They can be uncomfortable and can affect your overall sense of wellbeing. Some are similar to symptoms of lymphoma, so you might worry that they are a sign of relapse. Seek advice from your GP or medical team if you're unsure.

The main thing you'll notice with menopause is that your periods stop or become irregular. You might also experience:

- hot flushes – feeling suddenly hot or cold in your face, neck and chest, which can make you dizzy
- night sweats and waking
- low mood, heightened anxiety and mood changes 'swings'
- problems with memory and concentration
- headaches
- dry and itchy skin
- muscle aching and stiffness
- repeated urinary tract infections (UTIs)
- loss of interest in sex, and vaginal dryness or irritation, which can make having sex painful.

Often, these symptoms can be reduced by taking hormone replacement treatment (HRT) as tablets, patches or gel you rub on your skin. Recurrent urinary tract infections and vaginal dryness or soreness can often be greatly improved by using vaginal oestrogen cream. Your medical team can advise about this or refer you to a specialist.

“ *If you're going through the menopause, particularly earlier than would usually be the case, this is difficult – especially on top of having lymphoma. I found that being straightforward and honest with people about it was helpful. People weren't judgemental; they just wanted to be supportive. I'm now 53, fit and well.*



Juliet, diagnosed with
Hodgkin lymphoma

Effects of early menopause

An early menopause can have long-term effects caused by low levels of the hormone oestrogen. These include an increased risk of developing other conditions:

- Thin, brittle bones (osteoporosis), which can mean it's easier to have a bone fracture. Search 'osteoporosis' at [nhs.uk](https://www.nhs.uk) for more information.
- Heart disease and stroke (cardiovascular diseases). Find out more about heart disease and menopause on the British Heart Foundation website at [bhf.org.uk](https://www.bhf.org.uk)

It might be possible to reduce these risks by replacing the missing oestrogen with hormone replacement therapy (HRT, page 125).

If you are going through menopause, it's especially important to eat a healthy diet with plenty of calcium to keep your bones healthy. Products that are high in calcium include milk, cheese, yoghurts and dark, leafy green vegetables such as broccoli and spinach.

- Watch our early menopause playlist at bit.ly/earlym_pause
- For tips to help manage menopause, search 'menopause things you can do' at [nhs.uk](https://www.nhs.uk)
- Find support, information and advice about menopause, visit [womens-health-concern.org](https://www.womens-health-concern.org)

If you experience symptoms of menopause, tell your medical team. They might offer you HRT if it is suitable for you. They can also suggest treatments to help relieve symptoms of menopause and might refer you to a health professional who specialises in menopause.

Going through early menopause can be physically and emotionally challenging. Ask your GP or clinical nurse specialist if they can signpost you to sources of support.

Daisy Network is a charity that offers information and support to women diagnosed with early menopause. Find their website at [daisynetwork.org](https://www.daisynetwork.org)

Our Live your Life programme

Our Live your Life programme is for people who have finished treatment or are on watch and wait (active monitoring). It aims to:

- connect you with other people who can relate to your experience
- allow you to ask questions in a safe environment
- empower you to develop coping strategies to live well, with and beyond lymphoma
- give you information to help you lead a healthy lifestyle
- help you find your 'new normal'.

The programme is led by people who have personal experience of lymphoma, and it's supported by clinical nurse specialists.

“ *Lymphoma Action’s Live your Life workshop provided a safe space for me to talk about my feelings with other people who understood how I was feeling and what I was going through with people who speak the ‘lymphoma language’. Most importantly for me was being able to recognise and accept those feelings. I could then move on to find a new normal.*

Dorothy, diagnosed with
follicular lymphoma



Find out more about our virtual and face-to-face Live your Life workshops on our website. Search ‘Live your life’.



“ *I feel as though my cancer days are long behind me, but I am still very mindful that all of the original advice is important and would seek help if I was worried about anything. I think I now lead a more healthy lifestyle and have a more positive mindset.*

John, diagnosed with Hodgkin lymphoma

Medical matters after treatment

Treatment summary	132
The recovery package	133
Follow-up appointments	133
If your lymphoma comes back (relapse)	136
Vaccinations	140
Safety precautions after steroids	140
Safety precautions after spleen removal or radiotherapy to the spleen	142
If you need a blood or platelet transfusion	143
Late effects	144
Keeping checks on your health	149

Treatment summary

At the end of treatment, your medical team complete a treatment summary, which outlines:

- treatment you've had
- possible side effects and late effects of your treatment
- possible signs that your lymphoma might be coming back (relapsing)
- your follow-up plan
- any lifestyle recommendations, for example about diet and exercise.

Your treatment summary should also tell you what symptoms you should look out for and who to contact if you notice them, including an out-of-hours number.

Your hospital should send a copy of your treatment summary to your GP and give you a copy. It should be added to your medical records and accessible via the NHS app, even if you are treated privately.

You should be given a treatment summary as a card or a letter; ask for it if you haven't been given one. Always carry it with you and keep copies in case you lose the original.

Anyone treating you in the future (for example, your dentist or a doctor giving you a general anaesthetic), needs to know that you've had lymphoma and what treatment you had. This is because certain treatments can cause problems if the person treating you doesn't know you've had them. Being

aware of your treatments means that they can take any necessary precautions to help prevent these problems.

The recovery package

Your medical team should offer you a personalised recovery package to help you adjust to living well with and beyond lymphoma. There are four parts to a recovery package:

- Holistic needs assessment (HNA), to consider any physical, practical, social, emotional and spiritual needs you might have (page 57).
- Treatment summary (page 132).
- Cancer care review, where you and your GP or a practice nurse check-in about any medical needs. It also gives an opportunity to talk about any points from your holistic needs assessment.
- Health and wellbeing events, designed to help people affected by cancer and their families live well. Our Live your Life sessions are an example (see page 128).

Ask your medical team about the recovery package if you haven't been offered one.

Follow-up appointments

Once you've finished treatment and you're in remission (no evidence of lymphoma), you'll have regular check-ups (follow-up). Follow-up gives you a chance to ask your doctor any questions you have and to discuss any concerns. Your medical team can see if there's anything else they could do to support your recovery.

As well as talking to your doctor, follow-up appointments might also involve:

- a physical examination, for example checking for swollen lymph nodes, your weight, blood pressure and heart function.
- blood tests, to give an overall picture of your health.

You might also have a scan to help your medical team see how well your lymphoma has responded to treatment. They might use this also to check for any signs of your lymphoma coming back (relapsing) and for late effects (page 144). However, scans aren't usually part of routine follow-up.

“ *How often and where you have follow-up after treatment will depend on your local services. Most people have a review every 3 to 4 months in the first year, and then less frequently. Some places offer a patient or symptom-initiated system instead. Your medical team can explain how your follow-up will be arranged.*

Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology

Supported self-management

You might be offered a self-management programme. This is where your health professionals help you to develop the skills, knowledge and confidence to monitor your health. For example, they can coach you to recognise the possible signs and symptoms of your lymphoma coming back (relapsing). You then book your own follow-up appointments as and when you need them.

Self-management **might** be suitable for you if you:

- are aged 18 or over
- are in long-term remission (disappearance or significant shrinkage of lymphoma)
- have long-term stable low-grade lymphoma
- have a low risk of your lymphoma coming back (relapsing).

Some people find the idea of self-management daunting at first. Other people prefer this approach – they find it more convenient to their lifestyle, as well as giving them a greater sense of independence and control.

“ *Treatment is so varied because there are so many types of lymphoma. Some people never need treatment; some people need strong treatment, but your medical team will support you to live well, with and beyond lymphoma.*

Wendy Osborne,
Consultant Haematologist

If you are interested in self-management, ask your clinical nurse specialist whether it is appropriate for you and whether your hospital can offer it.



Find out more by searching ‘self management’ on our website.

If your lymphoma comes back (relapse)

Usually, doctors say that lymphoma has relapsed if it returns after successful treatment. This means that you have had a remission (disappearance or significant shrinkage of lymphoma) that lasts for at least 6 months after treatment. If the lymphoma has returned in under 6 months following treatment, this is called ‘refractory’ lymphoma, rather than relapse. Your doctors can talk to you about treatment options if your lymphoma is refractory.

Relapsed lymphoma can cause the same symptoms as before, or you might have different symptoms. Ask your medical team what to look out for. Be aware of the most common symptoms.

“ Unfortunately, a PET scan three months after completion of treatment showed that my lymphoma had returned. Although I am facing more treatment, I feel confident in my body to handle whatever is to come.

Hayley, diagnosed with
Hodgkin lymphoma

Our podcast ‘understanding relapse in lymphoma’ explains what relapse means, treating and managing relapse, and gives tips for coping with concerns around relapse: lymphoma-action.org.uk/support-you/lymphoma-voices-podcasts#CharlotteBloodworth



Contact your medical team straightaway if you notice:

- **Swollen lymph nodes:** a lump or several lumps, often in the neck, armpit or groin. The lumps are usually painless.
- **Fatigue:** exhaustion for no obvious reason, or feeling washed out after doing very little.
- **Unexplained weight loss:** losing a lot of weight quickly without trying to.
- **Sweats:** sometimes described as ‘drenching’ when they happen at night because they can soak your nightclothes and bedsheets.
- **Itching (pruritus):** without a rash.
- **Fevers and infections:** some people get fevers (a temperature of over 38°C/100.4°F in adults). Fevers often come with night sweats and weight loss, but they can occur separately. Repeated or persistent infections (that are difficult to overcome) can also be a symptom of lymphoma.

“*It’s a good idea to know your nodes and what is normal for you. I usually suggest that people just run their hands along their neck, armpit and top of their legs (groin area). Remember that nodes are working organs. They expand when they’re responding to infection but usually go back down to their previous size within a couple of weeks.*

Charlotte Bloodworth, Advanced Nurse Practitioner



Our 'Know your nodes' video is for people who want to check their lymph nodes. It gives guidance on how to check and how often to do so. Ask your medical team how often they would advise that you check. While it is recommended to check regularly (around once a month), checking too frequently can be unhelpful as it can be harder to notice actual changes rather than day-to-day fluctuations, and can lead to increased anxiety.

“ Remember that symptoms don't necessarily mean relapse – a lot of potential symptoms of lymphoma can be symptoms of something else, like a cold. However, if you have any worries or just don't feel right in yourself, contact your medical team. Some people find it helpful to keep a diary of any symptoms to discuss with their health professionals.

Katherine Wight,
Lymphoma Nurse Specialist

Vaccinations

Take advice specific to your individual situation from your medical team. In general, most vaccinations are safe and recommended for people who've had lymphoma. However, as a general guide:

- You might need to wait 6 to 12 months after finishing treatment before having any vaccinations.
- You are recommended to have the winter flu vaccination each year if you have lymphoma.
- Ask your medical team or GP whether you should have any COVID-19 vaccinations available to you.
- If you've had your spleen (part of your immune system) removed or you've had a stem cell transplant, you'll need additional vaccines. Your medical team can give you advice about these.
- If you're going to another country, you might need other vaccinations (see page 30).

Vaccines made using living viruses or bacteria (live vaccines) can be unsuitable for people who have lymphoma or have recently been treated for lymphoma. Check with your doctor or specialist nurse before having a live vaccine.

Safety precautions after steroids

If you had steroids as part of your treatment, there is a possibility that your body might not make enough steroids of its own to help you recover – for example, from illness, an accident or an operation. This is quite rare.

Your doctor should tell you if you are not making enough natural steroids at the end of treatment. If appropriate, you can be given steroid replacements if you need them.

Steroid warning cards

Depending on your type of steroid medication and how long you are taking it for, you might be given a steroid treatment card or a steroid emergency card, or both.

- **A steroid treatment card** reminds you that you should not stop taking steroids suddenly, and what to do if you become unwell. It also tells health professionals the details of the steroids prescribed to you.
- **A steroid emergency card** is to help support the early recognition of a serious complication where you don't make enough of a type of steroid called 'cortisol' – this is known as adrenal crisis.

If you're given a warning card, carry it with you all the time you are on steroids and for some time after completing steroid treatment – this is usually 12 months, but take advice from your medical team.

If you have an operation or any dental work in the future, let the anaesthetist or dentist know beforehand that you've had steroid treatment and show them your warning card. They can then take any necessary precautions to ensure that you recover well.

Safety precautions after spleen removal or radiotherapy to the spleen

Your spleen is part of your immune system. If you've had your spleen removed (splenectomy), or you've had radiotherapy to your spleen, you won't be able to fight infections as well as you used to. For this reason, you'll need to take some precautions to lower the risk of infection. If you notice any signs of infection (see page 103), contact your medical team or your GP as soon as possible.

Antibiotics

- You'll probably need to take low-dose protective antibiotics every day for the rest of your life.
- Your doctor might also give you a course of antibiotics (rather than full-strength antibiotics) to keep at home in case you need them quickly.

Vaccinations

- You might need top-up (booster) vaccinations.
- You should also have the flu jab every year and a pneumococcal (pneumonia) vaccine booster every 5 years. You will also need to carry a warning card to show to anyone who treats you.

Travelling to another country

- If you travel to another country, you might need particular vaccinations. It's a good idea to consider this at least 8 weeks before your trip as some vaccinations need to be given well before you travel.
- For some parts of the world, you'll need to take precautions to avoid malaria (see page 29).

Always carry a card with your treatment summary (page 132). It's also a good idea to carry a card that lets people know you don't have a spleen in case of an emergency situation. Some people prefer to wear a piece of medical ID jewellery that has this information on. You could search online to find companies that supply these.

There are lots of companies that supply medical alert jewellery. One of these is MedicAlert: [medicalert.org.uk](https://www.medicalert.org.uk)

If you need to have a blood or platelet transfusion

Some people treated for lymphoma need irradiated blood if they ever have a blood transfusion. Irradiated blood is blood treated with X-rays to destroy any donor white blood cells that might attack your own cells.

You might need irradiated blood products in the future if:

- you've had Hodgkin lymphoma
- you were treated with certain chemotherapy drugs, such as purine analogues (like fludarabine) or purine antagonists (like bendamustine)
- you've had a stem cell or bone marrow transplant.

If you ever need a blood transfusion, the hospital where you had treatment will know that you need irradiated blood, but other hospitals won't.

Your doctor will tell you if you need irradiated blood and you will be given a card that says so. Keep your card with you at all times.

Late effects

Late effects are health problems that can develop weeks, months or years after treatment. Your medical team should tell you about the possible late effects of your treatment. We list some of the more common late effects in the next few pages, but this doesn't mean that you will necessarily experience them.

Not everyone gets late effects. However, it's important to know any signs to look out for – often, health problems are more manageable if you seek medical attention sooner rather than later.

Other ('second') cancers

Being treated for lymphoma increases your risk of developing a different type of ('second') cancer. However, most people who are treated for lymphoma don't go on to develop another cancer.

Second cancers that have been linked to chemotherapy treatment include leukaemia, lung cancer and skin cancer. With radiotherapy, the type of second cancer you are most at risk of depends on the area of your body treated.

Ask your medical team what cancers you might be at a higher risk of developing. Make sure you know the symptoms of these because cancer is usually more treatable if it's diagnosed early. You can also ask your clinical nurse specialist or your GP about cancer screening programmes, which are designed to find cancers early.

Cancer Research UK has information about cancer, including common signs and symptoms of different types. Search their website at: [cancerresearchuk.org](https://www.cancerresearchuk.org)

Heart problems

Some treatments can affect how well your heart pumps blood around the body. This includes:

- anthracyclines – the risk increases with higher doses or more courses of anthracycline treatment.
- after radiotherapy to the chest
- after a stem cell transplant.

Heart problems become more common 10 years or more after your treatment but can develop sooner.

If you're at risk of heart problems, you might be advised against certain activities that put a strain on your heart. This can include lifting heavy weights and diving.

Look after your heart by eating a healthy diet, taking regular exercise, limiting your alcohol intake and not smoking. Find out more on the British Heart Foundation website at bhf.org.uk

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with:

- radiotherapy to the chest
- the chemotherapy drug bleomycin, which is sometimes used to treat Hodgkin lymphoma as part of the ABVD and BEACOPP regimen (combination of drugs).
- the targeted drug brentuximab vedotin, which could contribute to lung problems.

Mild scarring might not cause any symptoms. However, if the damage is more severe, you could become short of breath more easily than before treatment. For this reason, you might be advised against certain types of exercise.

If you've had treatment that increases your risk of lung problems, it's particularly important to follow a healthy lifestyle and not to smoke. See pages 8 to 20 for more about healthy living.

If you experience lung problems:

- If you need surgery in the future, tell the anaesthetist, so that they can take any necessary precautions.
- Ask your medical team about any activities you should avoid – they are likely to recommend that you do not dive. This is because of the high levels of oxygen that you're exposed to.

Hormone problems

Treatment for lymphoma can affect the glands that make chemical messengers (hormones) in your body. This can cause problems, such as with thyroid function and fertility (page 118). In children, it could affect growth.

Thyroid problems

The thyroid gland produces a hormone called thyroxine, which controls how your body uses energy.

If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid (hypothyroidism).

If this happens, your thyroid gland doesn't make as much thyroxine as it should. It can make you:

- feel tired
- sensitive to the cold
- constipated
- gain weight easily.

Hypothyroidism is easily treated with thyroxine tablets.

The risk of developing hypothyroidism is at its highest in the first 5 years after treatment. However, it stays increased after this time compared to if you had not ever had treatment for lymphoma.

Doctors diagnose hypothyroidism with a blood test. You might be offered regular blood tests to keep checks on your thyroid functioning.

If you think you might be affected by thyroid problems and you're no longer having follow-up appointments, speak to your GP. Tell any doctors treating you that you have had treatment for lymphoma so that they are aware of your increased risk of thyroid problems.

British Thyroid Foundation have a guide to hypothyroidism that you can find on their website. Search 'hypothyroidism' at btf-thyroid.org

Eye problems

Eye problems are a less common late effect of treatment for lymphoma. They can include:

- dryness
- cloudy patches in the lens of your eye that reduce your vision (cataracts)
- high pressure inside your eye (glaucoma), which can affect your vision – this can sometimes happen after steroid treatment.

Have regular check-ups with your optician and tell them what lymphoma treatment you've had.

Dental problems

Radiotherapy to the head and neck increases your risk of tooth decay. Have regular check-ups with your dentist. Follow their advice to keep your teeth healthy.

Keeping checks on your health

Taking good care of your physical and emotional health can help you to live well after treatment. It can also better prepare you if you do need further treatment in the future.

Tips to stay well after treatment

- Lead a healthy lifestyle (pages 8-20).
- Take advice from your medical team – this includes about any risks you might have and any safety precautions to take.
- Find out what symptoms you should look out for and what to do if you notice them.
- Know your nodes. (See page 51).
- Be aware of any signs of infection (page 103) and who to contact if you notice any.
- Go to any follow-up appointments you're invited to. These allow doctors to monitor your health and increase the chances of finding any problems early, including possible signs of late effects.
- Go to any health screening programmes you're invited to. In the UK, these might include screening for breast, cervical, bowel and prostate cancer. The NHS has more information about screening.
Visit [nhs.uk/conditions/nhs-screening](https://www.nhs.uk/conditions/nhs-screening)



“ *A month before I didn't even know there was something wrong with me, and now I am diagnosed with a stage 3 cancer. How does that work? I found it difficult to come to terms with the treatment plan. However, within a couple of days, I had information from Lymphoma Action that helped me to understand more about my treatment. I also found it very beneficial to connect with others at a support group.*

Andy, in remission from follicular lymphoma

Feelings and emotions

Adapting to a diagnosis of lymphoma	152
Shock and disbelief	154
Anger	155
Fear and worry	157
Anxiety	159
Low mood	162
Adapting to life with lymphoma	168

Lymphoma can have a significant impact on your emotional wellbeing. Although it can take time, many people adapt well to a diagnosis and live well, with and beyond lymphoma.

“ *We recognise that being affected by lymphoma can feel overwhelming, with a lot of new information to process and many questions to ask. It can affect every part of life: physical, emotional, financial, social and spiritual. We are here for everyone affected by lymphoma, from diagnosis and beyond.*

Dallas Pounds, Director of Services



Adapting to a diagnosis of lymphoma

Finding out that you, or someone you're close to, has lymphoma is likely to bring many thoughts and emotions.

There's no right or wrong way to feel, and there is support available, however you're feeling.

In this chapter, we outline some of the thoughts and feelings people often share with us as they go through their lymphoma experience. We give some ideas of how to cope with these. You'll find more about emotional wellbeing in the next chapter.

“ *Reactions from people who contact the Helpline team having just received a diagnosis are almost never the same. Some people are trying to come to terms with the variety of different emotions they're feeling. Others are looking for support in coping with the practical aspects of their life after diagnosis. We're here to listen, to try to answer any questions, and to support people throughout this time.*

Neil, Lymphoma Action
Helpline team member

Your medical team should help you to adjust to your diagnosis by looking at your holistic needs – this means helping to address any physical, practical, social, spiritual and emotional needs you might have (see page 57).

Shock and disbelief

A lymphoma diagnosis is a lot to take in. You might feel shocked or 'numb', especially if the lymphoma was discovered during tests for something else.

Some people think the diagnosis can't really be true and that the doctors have made a mistake. This way of coping is known as 'denial'. As long as it doesn't continue for too long, it can give you time to adjust to the reality of a distressing situation. You might need to go over the news a number of times before it starts to feel real.

“ *The nurse took me into a private room with my sister. I told her I hadn't even heard of lymphoma. She explained more about it, but in truth a lot of it didn't sink in at the time.*

Cornita, diagnosed with low-grade non-Hodgkin lymphoma



“ *When I went back for the results of the biopsy, I was stunned to hear that I had stage 4 classical Hodgkin lymphoma. It was a bolt out of the blue. Everything went blank and I simply couldn't take anything in. My wife was with me and she asked about 20 questions, but I can't remember one of them.*



Neil, diagnosed with Hodgkin lymphoma

Anger

You might feel confused, angry and upset after being diagnosed with lymphoma.

For example, some people feel angry at the unfairness of the situation because there's nothing they did or didn't do to develop lymphoma. They feel jealous of people who don't have lymphoma, including family and friends, who seem to be having an easier time. Some people describe a general sense of anger directed 'at the world'.

Some people feel angry towards the cancer for disrupting their life and future plans, or at the health professionals who told them their diagnosis.

“ *I felt angry that lymphoma had taken everything away from me but I also realised there was help and support out there. I’ve only recently accepted that it is OK to be angry.*



Hayley, diagnosed with
Hodgkin lymphoma

If you are on watch and wait (active monitoring), you might feel negatively towards your medical team for suggesting that you don’t need treatment at the moment.



Watch and wait can be a difficult approach to understand – we have more information on our website and in our book: *Active monitoring (watch and wait) for lymphoma*.

Anger can disguise feelings of emotional vulnerability (being able to acknowledge your emotions, particularly difficult ones), pain, fear, panic, frustration, anxiety and a sense of helplessness. It can sometimes be more comfortable to show anger than to feel and show other difficult emotions.

Fear and worry

After the initial shock and disbelief of a lymphoma diagnosis, we often hear people say they feel scared and worried. It might feel as though you've been thrown into an unfamiliar world of medical information and hospital appointments.

“ *There can be a rollercoaster of emotions, many of which can be difficult, Over time, familiarity with the situation can help to diminish fear.*

Michael, diagnosed with non-Hodgkin lymphoma

For many people, the thought of treatment can be extremely daunting. You might be fearful about the possible symptoms or side effects you might experience. This is a completely natural response. Your medical team are there to talk you through what to expect and offer ways of coping.

Our Helpline team are also here to support you with any emotions and fears you might be experiencing throughout your lymphoma experience.

“

Hearing the words ‘you have cancer’ is the most terrifying thing anyone can ever say to you. Asking a doctor if I’m going to die was the most frightening thing, but I just wish I could go back to that time of diagnosis and show myself this journey isn’t as scary as I thought it was going to be. It’s a crazy journey with ups and downs but knowing the treatment I’m having means I can continue my life cancer-free makes it all worth it – even on the tough days.

Faye, diagnosed with Hodgkin lymphoma



There might be times when your level of fear and worry is high, such as before you go for a treatment session or while waiting for a scan. Many people also worry about their finances, work and family life, particularly if they need to change their working arrangements. We cover day-to-day practicalities in the first chapter of this book (page 8).

There are very effective treatments for lymphoma. Nonetheless, troubling thoughts can arise. For example, that you will die, or that you’ll not be around to see your children or grandchildren grow up.

Living with uncertainty and the unknown can be very difficult – see page 161 for tips on adapting to uncertainty.

Fear is a natural emotion. However, it can feel overwhelming, particularly if you're trying to cope with it alone. If you'd like to talk to someone about how you're feeling, call our Helpline Team on 0808 808 5555. Finding out a bit about lymphoma and treatment can also help you to feel more in control – see page 178 for tips.

Anxiety

Anxiety is a powerful sense of unease. It can be a reaction to the unknown and to uncertainty. For example, you might feel anxious while waiting for treatment and test results, or if you are on watch and wait (active monitoring).

Media stories can also trigger anxiety. You might feel unsettled by something you see, hear or read – for example, on TV, in a magazine article or on social media, not necessarily about lymphoma but perhaps about health in general.

Common signs of anxiety include:

- tiredness, but difficulty sleeping
- feeling worried or irritable
- difficulty concentrating
- feeling unable to do your day-to-day tasks
- tense muscles
- a fast heartbeat, fluttering or pounding heart (palpitations)
- feeling sick or dizzy
- quick breathing.

Many people feel anxious about the outcome of their lymphoma. The doctors treating you are best placed to advise you on how effective treatment is likely to be. They base this on factors such as the type of lymphoma you have, how fast it's growing (whether it's high-grade or low-grade) and how well you respond to the treatment. They also consider your general health, and any other conditions you might have.

Even with all of the information your medical team have about your lymphoma, nobody can say for sure how long someone will live. Some people find it helps to take a day at a time. Show yourself kindness and patience. If there are days you don't feel like doing much, try to allow yourself that without feeling guilty. Try to value the day-to-day things too – taking a walk, meeting up with friends, enjoying a film or planning what you'd like to plant in the garden, for example, can help to give a sense of normality and time away from thoughts of lymphoma.

Sometimes, anxiety can lead to 'if only' thoughts. For example: 'If only I'd gone to the doctor sooner, I wouldn't be in this situation'. These thoughts can be a way of trying to take control of a situation that is, ultimately, beyond anybody's control.

Although it might not be a quick or easy process, it can be helpful to learn to live with uncertainty. The following tips are based on those from [HelpGuide.org](https://www.helpguide.org). You can find more on their website, as well as a meditation to listen to on coping with uncertainty. Search 'uncertainty' at [HelpGuide.org](https://www.helpguide.org)

Tips for managing uncertainty

- **Notice triggers that worsen your uncertainty** – such as ‘negative’ or alarming new stories or social media related to lymphoma. Limit your time looking at these.
- **Take note of when you start to feel uncertain** – you might notice physical signs such as muscle tension or shortness of breath. Try to ‘pause’ and re-balance. You could try breathing exercises, meditation or mindfulness (page 200). You could also speak to someone about how you feel.
- **Let yourself feel the uncertainty** – although it is uncomfortable, the feeling usually starts to fade over time. If your level of discomfort is high, you might find it helps to focus on your breathing (see page 198).
- **Make a plan for the things that you have some control over** – for example, you could think about short-term changes you might make to your day-to-day routine if you’re likely to experience side effects such as fatigue (see page 65). However, accepting that nobody can control everything in life can lower the pressure you might put on yourself.
- **Focus on now (the present moment)** – there are lots of things that could happen in life. Many people spend a lot of time thinking about possible negative outcomes without considering alternatives. This can lead to low mood and feelings of helplessness. Try to pay attention to the ‘here and now’. This can help slow your mind down from racing thoughts, which can become overwhelming. Though it takes practice, it can help you to enjoy what is happening now, rather than worrying about what might be to come.
- **Manage stress and anxiety** – find ways to manage the stress and anxiety that can come with uncertainty (see page 192).

Low mood

It can take a while to process all the changes that are happening in your life, and it's natural to feel low from time to time.

You might feel a sense of loss for the life you had before you were unwell, or for plans you'd made that you are now reconsidering. These feelings are a type of grief. For some people, they might trigger memories of other past losses. You might also feel sad for your family and friends, knowing that they, too, are coping with difficult feelings.

The diagnosis can also challenge your sense of control. It might seem that you no longer have influence over things that are happening in your life. For example, if you have lots of appointments that tell you when and where you need to be. This can lead to feeling restricted, and to hopelessness and low mood.

If your low mood goes on for more than a couple of weeks and it affects your day-to-day life, it could be a sign of depression.

Depression can affect people in different ways. For example, you might feel:

- anxious, sad, or 'empty' or emotionally 'lost'
- hopeless, helpless and pessimistic
- guilty or worthless
- a loss of interest in activities you once enjoyed
- unable to concentrate or remember things

- difficulty in making decisions
- as though you want to harm yourself, which could include thoughts of ending your life.

You might experience physical symptoms such as aches, pains, constipation, a change in appetite, sleeping more or less than usual, slow movement and speech, or loss of sex drive (libido).

Speak to your clinical nurse specialist or GP if you think you might be affected by depression. Seeking help early can help to lessen the risk of going on to develop more severe depression. For more information about depression, including symptoms and self-care and possible treatments, visit mind.org.uk/Depression

Feeling vulnerable or emotionally fragile

Many of us have a feeling that nothing can go very wrong with our body and that serious illness or injury only really happens to other people. Being diagnosed with cancer can shatter this belief and leave you feeling uncertain about the future. Some people lose trust in their body and worry about developing other illnesses. All of this can leave you feeling emotionally fragile and unable to cope well.

“ Like many people, I thought I was invincible. I never thought anything could be seriously wrong. So I was totally shocked when I was told I had a slow growing type of lymphoma. It took a while to sink in that I had cancer.



Adam, diagnosed with nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

Loneliness and isolation

It might feel as though there is a separation between you and those around you, and that other people don't really understand what you're going through. It can be hard to see their lives going on as usual.

If you need to take time out of some of your usual activities, you could feel distanced from your everyday world. You might miss day-to-day things, like spending time with work colleagues, or even saying 'hello' to a familiar face in the supermarket.

Even when you're with other people, you might feel lonely and isolated. Friendships might feel different. Maybe you

see your friends less often than before you were diagnosed. Some relationships might generally feel strained – for example, if people around you seem to feel nervous about ‘saying the wrong thing’.

Remember that the people close to you might be struggling with their own emotions. They might have their own fears, sad memories and anxieties about cancer, and not want to show that they are upset in front of you.

Similarly, you might hide how you feel from other people. This could be because you want to protect them from hearing something they are not comfortable with, or a feeling that you don’t want to ‘burden’ them. It might also feel too painful to talk about how you really feel.

See chapter 2 (page 33) for more on relationships, family and friends.

Although you might not want to answer questions about your lymphoma, it can be helpful to think about what you **could** say, both to the people you know and plan to see, and those that you might ‘bump’ into, by chance. Being prepared can stop you from avoiding other people through feeling uncomfortable about such conversations.

You could say something very brief, for example: ‘I’ve been unwell but I’m having treatment and I’m doing OK’. Or you might want to give a bit more detail, for example: ‘I’ve had a really tough few months going through treatment for lymphoma. I’ve been feeling stressed and low. I lost some of my hair because of the treatment I’m having, which is why I look a bit different to usual.’

“ I find that people often struggle more, mentally, after treatment. Sometimes they’ve not really had time to get their head around treatment before they have it. They’ve also become used to seeing their medical team a lot and then go home, knowing that they won’t see us again for another six weeks and think, ‘What now?’ As Clinical Nurse Specialists, we’re here to support you – for example, by helping you to access a counsellor. ”
Christine Coyle, Clinical Nurse Specialist

Life after treatment can also bring a sense of loneliness. Lots of people say they find this difficult because they have become used to seeing the health professionals who have been taking care of them. They feel ‘lost’ and uncertain no longer seeing them so frequently. You might also feel isolated if friends and family expect you to quickly go ‘back to normal’, or assume you’ll want to celebrate, without realising that this is still a difficult time for you.

You might be interested in our Live your Life self-management programme, designed for people who have just completed treatment or who are on active monitoring. See page 128 for more information.

Supportive relationships can be very beneficial to emotional wellbeing. Although it can be difficult, honesty can be helpful. There might be times that you just want some time away from friends and family and to be alone with your thoughts for a while. Let them know, but try not to withdraw from them completely. See page 39 for tips on effective communication.

Determination

People sometimes tell us they feel a sense of determination to get through their treatment. This can be empowering and motivating and bring a sense of energy and control. However, even the most determined of people have times when their motivation dips. You might, for example, feel less motivated when your physical energy is low, or if you have a setback. This is natural. You are human and no one can keep their motivation high all the time.

“ *I used to use the phrase ‘eyes on the prize’. For most people, the objective of treatment is to get well, or at least to alleviate symptoms. For me, determination felt like a big part of that.*

Michael, diagnosed with non-Hodgkin lymphoma

Unhelpful questioning and blame

You might give yourself a hard time, thinking that there must have been something you did, or didn't do, to get lymphoma. You might blame yourself for not seeing the doctor sooner. You might feel guilty that your friends and family are having a difficult time too.

Guilt can be irrational yet powerful. Give yourself permission and time to process difficult feelings. This is an important part of managing your emotions and adapting to life with lymphoma.

It's human nature to look for someone or something to blame, or at least to explain things. Unfortunately, most of the time, no one can say why lymphoma develops. You can read more about possible causes on our website. Search 'causes' at lymphoma-action.org.uk

Adapting to life with lymphoma

It can take time to adapt to living with lymphoma. In some ways, your life might never be the same as it was before you were diagnosed. However, over time, most people adjust to these changes. Staying involved in your life can help you adjust to your new situation. For example, continuing with activities and hobbies when you can, and keeping up with friendships. You can also let your medical team know if you'd like to take an active role in conversations and decisions about your health and care options and ask them to support you in this. However, if you'd prefer not to know much detail, that's OK too.

“ *I slowly came to terms with the fact that I am facing a condition that is manageable but not curable. It has taken me some time to adjust to this being my new life; my new normal.*

Nicola, diagnosed with follicular lymphoma



Positive life changes

Many people go on to experience positive life changes after a diagnosis of lymphoma. These can take time to come, but examples include having:

- a healthier lifestyle
- closer relationships with family and friends
- better connections with yourself and the world
- new priorities and a greater appreciation for life
- a feeling that life has more meaning
- more ability to live in the present moment
- greater resilience, acceptance and gratitude
- the opportunity to explore new possibilities in life.

'Post-traumatic growth' is the term sometimes used to describe these kinds of positive changes that can happen after a traumatic life event, such as being diagnosed with cancer. Expressing your emotions, managing stress, and feeling supported by family and friends can increase the likelihood of developing these positive life changes.

“

I see my experience as a second chance at things; almost like a warning shot. I am re-evaluating what is important and focussing on things that make me and my family happy. It has also been a time of really appreciating what I have in life, like a wonderful family and amazing parents.

Neil, diagnosed with Hodgkin lymphoma





Notes



“ *From the moment of diagnosis, I found that there is so much to take in, ask and anticipate. The prospect of treatment can be so overwhelming. I found it invaluable to recognise that there are times when it is useful to think and plan ahead, and others when it is better to just choose to think about things one day at a time. This approach has helped me to live my life with and beyond treatment.*

Mila, diagnosed with Hodgkin lymphoma

Emotional wellbeing

Managing emotions	174
Dealing with worries and concerns	181
Challenging unhelpful ways of thinking	183
Self-confidence and self-esteem	189
Managing stress and anxiety	193
Complementary therapies	203

Managing emotions

People find different ways of coping. While none of these can take away a difficult situation, they can help to make it more manageable. It's important to consider what helps **you**, regardless of what works for other people. We outline a few ideas in this chapter. See also the next chapter on feelings and emotions for tips to improve wellbeing, for example, on how to challenge unhelpful thoughts (page 183).

Your medical team should also help you to live well with lymphoma. As part of this, they should offer you a holistic needs assessment (HNA), which helps to address any physical, practical, social, emotional and spiritual needs you might have (see page 57).

Express yourself

Expressing how you feel can help to make emotions more manageable.

Some people find it hard to talk about their feelings, particularly those about cancer. Although it might feel difficult, try not to ignore them. If you prefer, you could find another outlet, such as:

- **doing something creative**, like writing, drawing, painting, keeping a journal or playing music or singing
- **through physical activity**, like walking or doing yoga
- **releasing built-up emotions**, by allowing yourself to cry, or letting out anger and frustration by squeezing or punching a pillow.

Some people use music, art or drama to relax, express themselves or to take them away, mentally, from a difficult situation. For example, music might help to distract you if you need time away from your thoughts.

“ *The chemotherapy treatment initially didn't work, which was a huge blow. I turned to writing about my experiences, which felt freeing, empowering, private and cathartic.*

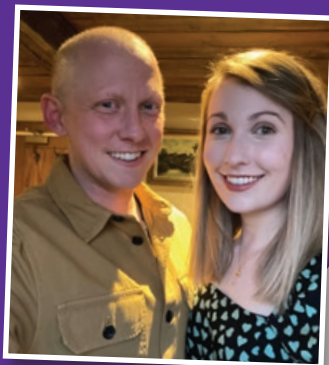
Sarah, diagnosed with
Hodgkin lymphoma

Letting out your thoughts and emotions can help you to feel less overwhelmed. Be aware, however, that focussing on them can bring intense emotions to the front of your mind. It can be helpful to set aside a limited amount of time in one go to reflect. Think, too, about how you'll take care of yourself afterwards. For example, by catching up with a friend or going for a walk or listening to music.

Connect with other people

It is common to withdraw from other people when you feel low. It can feel overwhelming to cope with emotions – your own and those of the people around you. You might find their attention or sadness overbearing. Keep in mind that they care. Try to find ways of letting them know when you'd like to be alone, but reconnect again afterwards.

“ *My treatment started a couple of weeks after my diagnosis where, following a round of fertility preservation, I received 12 courses of chemotherapy. I started writing a weekly blog and sharing photos on my social media account to help me retain control of the story.*



Ben, diagnosed with Hodgkin lymphoma

Being in contact with other people who can relate to your experience can provide an opportunity for mutual support, sharing thoughts, emotions, experiences, tips and ideas. You could connect with people affected by lymphoma through our Online Support Groups or Buddy Service. See page 207 for more about how we can support you.

You might also like to connect with people in ways that aren't connected to your lymphoma experience – for example, through a choir or reading group. Simply being around other people in a shared activity can bring a greater sense of wellbeing.

Find out about lymphoma

For some people, finding out about lymphoma and its treatment can be empowering, helping to take away some of the fear of the unknown.

“ *I found speaking to people who have also been through a similar experience really helped. Lymphoma Action offer lots of ways to connect you with other people living with lymphoma.*



Paris, diagnosed with Hodgkin lymphoma

Take care to go at a pace that feels right, though, so as not to overwhelm yourself with too much detail too quickly.

Remember that some questions have no answers. There are many types of lymphoma, and even the same type can affect different people in different ways. Some types behave more like long-term conditions, so treatment is more focussed on controlling the lymphoma and helping you to live well with it.

Tips for finding out about lymphoma

- We have lots of information on our website and in our books. You can also speak to our Helpline team.
- Talk to your health professionals. Your clinical nurse specialist (CNS) or key worker is often a good first point of contact.
- If you feel daunted at the thought of finding out about lymphoma, you could ask a friend or family member to do it for you.
- Prepare questions to ask your medical team and note down the answers you get. It's OK to say if you don't understand something or need to go over it. Ask for information to be repeated or explained in a different way if this might be helpful.



Search 'questions to ask' on our website for some suggestions of things you might like to ask your medical team.

“ *Having a diagnosis meant that I could now do some research. I made sure I only looked at trusted sites, like Lymphoma Action and the NHS.*
Hayley, diagnosed with Hodgkin lymphoma

Consider what you can and can't control

Having lymphoma can take away your sense of control. Look for what you can influence to help you regain your independence. For example, think about:

- the level of detail you want to know about your lymphoma and treatment at any given time
- how little or much you tell people about your lymphoma
- which activities to prioritise at times when your energy is low.

It can also be helpful to recognise that there are things that are beyond your control. In time, this can help to bring a calmer mindset as you start to 'let go' of the worry and pressure that can come with trying to control things that you are unable to.

Tips to help regain a sense of control

- Do the things that are important to you, such as spending time doing a hobby or with people you care about.
- Keep some structure in your life. For example, have a daily or weekly routine.
- Think about what information you're comfortable sharing with other people. Some people might ask lots of questions, but that doesn't mean you have to answer all of them or share a lot of detail – see page 41 for ideas on what you might say.

Keep a sense of 'you' and normality

Keep a sense of 'you' by continuing to do the things that matter to you, when you can. It's also important to take time out for yourself. You can do this by having things planned to look forward to in the short, medium and longer-term. You could talk to your medical team about when might be a good time to plan certain activities or a holiday. They might suggest, for example, waiting for a certain number of days after having treatment.

“ *Having a routine helped me to focus on something other than being ill and having treatment. I think it really helped me to see friends and family, and to go to my pilates class when I could.*

Corrin, diagnosed with lymphoma



Think about how others could help you

Having lymphoma takes a great deal of physical, mental and emotional energy. It's very likely that you'll need some help, in various ways, from the people around you.

It can be hard to ask for help, especially if you like to do things for yourself. Know that accepting help isn't forever. It might be, for example, just while you're recovering from treatment.

Accepting help might prevent you from becoming overly tired. It can also help you to save your energy for the tasks and activities that matter most to you.

Tips for asking for and accepting help

- Think about tasks other people could help with, such as preparing meals or cutting the grass.
- Keep in mind that people often want to help – they'll appreciate being given an idea on how they can support you.
- Have a rota for friends and family to help. For example, if you've got lots of appointments in one week, each person could help with one journey to and from the hospital.

Dealing with worries and concerns

Worries can feel overwhelming if they keep going round in your mind. Getting your thoughts down on paper can take away some of their power and bring a sense of release. Writing down or talking about your worries might also help you notice any links between them and think about how you could address them.

Make a plan

Think about what underlies your worry – try to break down problems into more manageable pieces. Think about which aspects you can do something about so that you can come up with a plan for how to address them. We give some examples over the page:

The worry	What could help	Possible resources
<p>I won't be able to get the children to school when I'm going through treatment if I get nausea and fatigue.</p>	<ul style="list-style-type: none"> • Finding ways to cope with side effects of treatment (see pages 65 to 129). • Finding out who could help with the school drop-offs if I'm feeling too unwell. • Explain the plan to my children. 	<ul style="list-style-type: none"> • My medical team for help with managing side effects. • Family, friends and classmates' families for help with school practicalities.
<p>Treatment might not work.</p>	<ul style="list-style-type: none"> • Talking to my medical team about what to expect from treatment. • Finding ways to manage my anxiety (see page 192). 	<ul style="list-style-type: none"> • My medical team for information about my lymphoma and its treatment. • Wellbeing resources (see our website for examples).

You might also find it helpful to consider the worst case and how you'd deal with it if it became a reality. This can help you to realise that you could cope with such eventualities. It also gives you an opportunity to think about the support you might need. Even without an answer to the worst case, just thinking about it can help to remove some of the power that a niggling thought can have.

Box (contain) your worries

Some people try to 'box' or compartmentalise their worries, setting aside fixed time to worry. For example, you might sit down at 5 o'clock each evening and spend 15 to 20 minutes thinking about the things that are troubling you.

At other times of the day, you could write down any worries as they come to you. Try to put them aside, knowing that you have allocated 'worry time'. When you come back to them during this time, you can look at which ones you can do something about and make a plan to deal with them (page 181). For those that are beyond your control, try to develop ways of relieving stress and anxiety (page 192).

This strategy takes practice and doesn't work for everyone. However, by learning to set aside your worries, you can free up space in your mind for other things. Some people realise they have more control over their thoughts than they had realised.

Challenging unhelpful ways of thinking

During our lives, we develop ways of thinking – sometimes known as 'thinking patterns'. For example, you might be someone who often sees the risk in situations, or someone who is generally optimistic. You might think that you should always be positive, or hide challenging feelings from those around you.

There is no evidence to suggest that thinking positively affects the development or outcome of cancer. Putting pressure on yourself to think or feel a certain way can have a negative impact on your emotional wellbeing. Your quality of life might, however, be improved by finding ways to live well with your lymphoma.

If unhelpful thinking patterns (or 'thought traps') affect your emotional wellbeing, try to find ways to challenge these. Doing so can help to manage stress and anxiety. It can give you more space in your mind, as well as mental energy, to find helpful ways of dealing with your situation.

It can be very difficult to break thinking patterns. Often, they develop over many years and become a 'default' or habitual way of thinking. However, with awareness, you can start to challenge your thinking patterns and consider other, more balanced ways of thinking. You might like to get the help of a counsellor with this (page 201).

On the next few pages, we outline some common thinking patterns and possible ways of challenging them. You'll also find tips to help challenge negative self-judgements on page 188.

Assuming the worst (catastrophising)

Assuming that the worst will happen, even with limited information to suggest that this is realistic.

Example: 'I'm tired and my body aches today.'

- Catastrophised thought: 'This must mean my lymphoma is growing.'
- More balanced thought: 'I did a lot of walking yesterday and went to bed late, which might be why I feel achy. There is a possibility the way I feel is related to the lymphoma. I can talk to my clinical nurse specialist about this.'

Emotional thinking

Being so heavily influenced by your emotions that you see them as fact.

Example: 'I feel so worried about treatment and how I'll get through it.'

- Catastrophised thought: I just **know** that I'll feel terrible during treatment and will probably experience all of the possible side effects.
- More balanced thought: I can find out from my medical team which side effects they expect me to experience. I can find out from them how to cope with these.'

Applying a conclusion too broadly (overgeneralising)

Thinking that something negative will happen again because it has happened before.

Example: 'I didn't recognise the symptoms of lymphoma.'

- Overgeneralising: 'so I'll probably also not notice them if they come back.'
- More balanced thought: 'I've got more information now. I know what symptoms to check for and how to contact my medical team if I'm concerned.'

'Shoulds', 'oughts' and 'musts'

Putting yourself under pressure to feel or act in certain ways.

Example: 'I should stay on top of the housework.'

- Thinking in ways that put you under pressure: 'I must start on the cleaning. The whole place is a mess!'
- More balanced thought: 'The house isn't as clean and tidy as I'd like it to be. I don't have the energy to clean today and it isn't a priority. I could clean one room when I feel less tired. I can ask a friend or family member to help too.'

Overlooking (discounting) positives

Ignoring positives, which you might recognise as ‘yes but...’

Example: ‘My clinical nurse specialist told me that the treatment I’m having is generally very successful.’

- Discounting the positives: ‘but she probably only said that to make me feel better. I doubt it’ll work for me.’
- More balanced thought: ‘She has a duty to be honest. I can ask her how and when we’ll know if I’ve responded to treatment and what the next steps are if it’s not as good as expected.’

Labelling

Applying critical labels about behaviours or characteristics to the whole person in general.

Example: ‘I didn’t get through half of the things I had planned to yesterday.’

- Labelling: ‘I’m useless. What a complete waste of a day!’
- More balanced thought: ‘I spent a few hours resting because I was fatigued. This is what my body needed so it was a sensible thing to do. I still washed the dishes and had a phone conversation with a friend in the morning. I can do more when my energy levels are higher.’

Assuming that other people are making negative judgements (mind reading)

Assuming that other people are thinking negative things about you without checking the reality.

Example: 'It's not a good idea to tell friends how I'm really feeling'.

- Mind reading: 'Friends will think I'm such a burden and bore if I tell them how I feel.'
- More balanced thought: 'They are likely to want to support me. I know I would if a friend was in my situation. I could start by talking my feelings through with Lymphoma Action's Helpline team and then tell a close friend a bit about how I'm feeling.'

You can find free, downloadable resources to help you identify and challenge thinking patterns on the [Getselfhelp.co.uk](https://www.getselfhelp.co.uk) website

If you find it difficult to adapt your thinking patterns, you could ask your GP if they can refer you to a cognitive behavioural therapist (a professional who specialises in working with unhelpful thinking patterns).

Self confidence and self-esteem

Lymphoma can affect how you think and feel about yourself.

- Self-confidence is about your belief in your abilities.
- Self-esteem is about your feelings towards yourself.

Give yourself time to think about these challenges. You could talk them through with a close friend or a counsellor (page 201) to help you adjust to the unknown and to changes in your life.

Body image

Lymphoma and its treatment can affect the way you look. Even if you're prepared for this, it can still be a shock. You might feel bad about some aspects of your physical appearance. For example, you might experience a change in weight, hair loss, or look more tired than usual. If your body image is negatively affected, it can have a knock-on effect on your self-confidence and self-esteem. You might feel uncertain about social and sexual relationships or your capabilities in your work.

“ *After the first chemotherapy, my long, dark hair just blew out. For me, it really is a major part of my identity, and emotionally, I found this really difficult. It was a very clear indication of what I was going through – to myself and also to my family.*

Surinder, diagnosed with non-Hodgkin lymphoma

Be kind to yourself

It's human nature to make judgements, including towards oneself. However, you might notice that your self-judgements are often negative, for example, 'I didn't achieve a single thing today' or 'no one finds me attractive'. You might think of these as the voice of your inner critic – an unhelpful voice inside your head.

Pay attention to your inner voice. Does it say kind and helpful things, or is it self-critical? With awareness, you can start to respond to it.

To bring some distance between you and your inner critic, you could write down these messages.

- First, use 'I' – for example 'I'm boring' or 'I'm not interesting'.
- Then change your thoughts to 'you' – for example 'you're boring' or 'no one finds you interesting'.

Once you have written down your inner critic's messages, have a go at challenging them. Respond to each with something kind and compassionate that a friend might say to you.

For example, in response to 'you're boring', you might say: 'My friends invited me for coffee so obviously they don't find me boring. One of them also shared something confidential with me afterwards, which shows that they trust me.'

With practice, you can become more aware of your inner critic. Instead of absorbing the critical messages and accepting them as the truth, you're likely to be more able to respond with balance and compassion.

Tips to help with how you feel about yourself

- Think about what you have instead of what you haven't done – you could do this at the end of each day.
- Spend time with the people who are supportive.
- Keep up with your day-to-day activities as much as you can.
- Set goals so that you have something to focus on and achieve.
- Challenge unhelpful thinking patterns (see page 183).

“ *The weight gain caused by the steroids affected my self-esteem and made me feel quite insecure. When I looked in the mirror, I didn't recognise myself. Over time, I learnt to be kinder to myself by remembering that my body is going through aggressive treatment and needed to be fuelled by honouring hunger cues.*

Mila, diagnosed with Hodgkin lymphoma

Managing stress and anxiety

Stress and anxiety are natural responses to worrying situations. However, if they continue in high levels over time, this can have a major impact on your emotional wellbeing. If your stress levels are high, you might be more likely to feel overwhelmed and unable to cope well.

There's no scientific evidence to support the idea that stress and anxiety cause or worsen cancer. However, finding ways to manage stress can benefit your overall physical and emotional wellbeing. By managing your stress levels, you're less likely to feel hopeless and helpless, which, in turn increases your likelihood of taking good self-care and seeking medical attention when you need to.

Finding ways to prevent high levels of stress and anxiety can also reduce the risk of:

- using unhealthy ways of trying to cope, such as drinking alcohol, smoking or using recreational drugs
- high blood pressure (hypertension), which can lead to serious health conditions such as kidney disease and problems with your heart
- activating other health conditions that can be linked to stress, such as asthma attacks, psoriasis and shingles.

We outline some of the ways that you can try to help manage stress and anxiety. You'll find more ideas in page 193.

You might also find the NHS website's list of wellbeing apps helpful:

[england.nhs.uk/support-now/wellbeing-apps](https://www.england.nhs.uk/support-now/wellbeing-apps)

“ *My life slowed down to just concentrating on getting through each moment; drug to drug, endless exams, needles, biopsies and tubes. A meditative focus on the small things that mattered really helped. I found a great deal of comfort in talking to those in hospital who had had similar experiences and spending time with family and friends.*

Carly, diagnosed with Hodgkin lymphoma

Make time for yourself

At times, living with lymphoma might feel as though your life is filled with medical appointments, treatments, tests and medications. It can be hard to make time for yourself but it's important that you try to prioritise it.

You could list things that help you relieve stress and try to build them into your day-to-day life.

For example:

- doing something active, like walking, gardening, going to a local park or painting
- doing something social, for example, meeting friends or catching up with a relative on the phone
- doing something to relax, for example, taking a bath or listening to soothing music – some people find complementary therapies help to relax (see page 203)
- doing something to distract or entertain you, like watching a film or reading a book.

Talk about your experience and how you feel

Talking to other people who can relate to your experience can be very beneficial. Some people find it easier to talk openly to people who have personal experience of lymphoma than to family and friends. Others prefer to speak with a trained counsellor (page 201). You might also be interested in our support services including our support groups and Buddy Service (see page 207).

Get restful sleep

It can be difficult to get a restful night's sleep if you have lymphoma. Symptoms of lymphoma (such as sweats and itching) and side effects of treatment can lower the quality of your sleep. Heightened stress and anxiety can also make it hard to rest.

Better sleep can improve your overall sense of wellbeing. We offer some tips below to help with sleep. If you have ongoing difficulties, ask a member of your medical team for advice specific to your situation.

Remember that some medications (for example steroids) could affect your sleep. Talk to your medical team if you think this could apply to you – they might suggest staggering or reducing doses, and taking it earlier in the day.

Some herbs and supplements are marketed as helping with sleep. If you are thinking of taking any, speak to a member of your medical team to find out if they're safe for you.

Tips to help your sleep

To help set your body (internal) clock:

- Get some natural light during the day.
- Stick to a set bedtime and time that you get up each day.

Close to bedtime:

- Do something to relax. For example, have a bath, read a book or listen to music.
- Avoid alcohol and foods and drinks that temporarily increase how alert you feel (stimulants) like those that are high in sugar, or high in caffeine, like coffee and tea.

Make your bedroom into a 'sleep-ready' environment:

- Have it at a comfortable temperature.
- Keep it dark. You could use blackout curtains or blinds, or wear an eyemask.
- Minimise 'blue light' from mobile phones, laptops and tablets. Most devices have a filter you can set to lower the amount of blue light they give off.
- Filter out noise that prevents you from sleeping. For example, use ear plugs or try playing soft music.
- Keep a pen and paper nearby to write down any thoughts that are going around in your head – see page 181 for dealing with worries and concerns.
- You'll find more tips on our website – search 'top tips for difficulty sleeping' to find out what the members of our closed Facebook group have shared.
- Read a guide on how to sleep better from Mental Health foundation – search 'sleep' at mentalhealth.org.uk

Spend time in nature

Nature can help to manage stress and anxiety by giving you a sense of belonging in the world. This can include being in a garden, park, at the beach or in a forest. If you spend time with other people in nature, it can also provide an opportunity to socialise.

Some people find gardening helps how they feel mentally. As well as giving you time outside in nature, it can be a means of physical exercise. It can also be a social activity. Many people enjoy the focus and sense of satisfaction gardening can offer, for example, if you see something you've planted growing. If you don't have a garden, you could volunteer or join a community gardening group.

Take care to avoid injury and infection – for example, wear protective gloves, wash your hands afterwards, and make sure that you take care of your skin in the sun (page 113).

- You can find out more about how gardening could benefit you on the Grow Places website at growplaces.org.uk/evidencebase
- The RHS has an online search tool to help you find a community gardening group near you: rhs.org.uk/findacommunitygroup

Forest bathing

Forest bathing originated in Japan. It means spending time among trees, taking note of your natural surroundings, and breathing deeply. The idea is that this can help to bring a sense of calm, and lower stress.

- Forestry England UK has tips on forest bathing for beginners. Search 'forest bathing' at forestryengland.uk
- Forestry and Land Scotland has information about forest bathing in Scotland. Search 'Forest bathing' at forestryandland.gov.scot

Relaxation techniques

There are a lot of techniques you could try to relax your body and to encourage a calmer state of mind. We outline some of these on the next few pages. See pages 194-197 for information about sleep and spending time in nature, both of which can help with relaxation.

Breathing exercises

Breathing techniques can be helpful in tense and stressful situations. Some people say they help them to feel calmer and more in control, allowing them to think more clearly.

It can be helpful to practise breathing exercises when you feel calm, so that you can use them more easily when you are starting to feel anxious or stressed. You could try a breathing technique to help if you feel uneasy – for example, about having chemotherapy, waiting for scan results or being on 'watch and wait' (active monitoring).



On our website, you'll find resources, information, tips and techniques to help improve your emotional wellbeing.

7/11 breathing

There are lots of breathing exercises that can help bring about a sense of calm. One that many people find helpful and simple to learn to do is '7/11 breathing'. It can slow the rate you take oxygen in and, in turn, helps your body stop preparing for 'fight or flight'. Counting can also take your attention away from immediate worries that might feel overwhelming.

- Find a comfortable position, either sitting, standing or lying.
- Breathe in through your nose while counting silently to 7.
- Breathe out through your mouth while counting silently to 11.
- Repeat until you feel calmer. A few minutes is often enough.

The main thing is to breathe out for longer than you breathe in – don't worry if you can't breathe in for the count of 7 and out for the count of 11 at first.

Progressive muscle relaxation (PMR)

Progressive muscle relaxation (PMR) aims to help you release tension in your body. It involves tightening (tensing) and relaxing different muscles and noticing the difference in feeling between tensing and relaxing.

PMR exercises can help you relax before bed, or before, during or after something you find stressful.

- Find a comfortable sitting or lying position.
- Clench your fists tightly for 5 seconds, then let go.
- Shrug your shoulders up towards your ears. Hold them here tightly for 5 seconds, then release.
- Pull your chin towards your chest. Clench your teeth and frown. Hold for 5 seconds then move your chin back to its natural position and relax the muscles in your face.
- Close your eyes tightly. Hold for 5 seconds, then gradually let them open.
- Clench your buttocks. Hold for 5 seconds, then release the tension.

At the end of the exercise, pay attention to the feeling of release. Breathe out, get up slowly and gently stretch.

- The no panic website has more information about PMR at nopanic.org.uk/relaxation-technique
- On the Selfhelp.org website, you can find a podcast that guides you through PMR. Search 'muscle relaxation' at helpguide.org

Meditation

There are many different types of meditation. Many of them involve being still and quiet. Some include movement to help you relax.

Meditation can be helpful in managing stress and anxiety, and in improving overall mental wellbeing. It might also help with sleep, tiredness, pain and feeling sick (nausea).

Mindfulness

Mindfulness is a type of meditation that encourages you to slow down and pay attention to the present moment (the here and now). This includes noticing your breathing and other physical sensations, such as the feel of your feet on the ground, the breeze against your skin, the temperature of the air, and any sounds you hear.

Many people use mindfulness to feel calmer, to help take control of their thoughts, and to prevent worries from taking over their mind. Although mindfulness takes practice, even doing it for a short time each day can be helpful.

Mindfulness-based stress reduction (MBSR) is an 8-week programme that includes mindfulness and yoga (which focusses on poses, postures and breathing). Some hospitals offer it to people with cancer to help improve mental wellbeing, reduce fatigue, pain, stress and anxiety. Ask your medical team if you are interested in MBSR.

The NHS every mind matters website has information about meditation. You'll also find resources for beginners if you are new to meditation: [nhs.uk/every-mind-matters/mental-wellbeing-tips/how-to-meditate-for-beginners](https://www.nhs.uk/every-mind-matters/mental-wellbeing-tips/how-to-meditate-for-beginners)

Yoga

Yoga is a type of meditation. It is often described as a ‘mind–body’ exercise, combining breathing with stretches and controlled movements. Many people say that yoga improves their overall mental wellbeing. Some research suggests that it might help people cope with symptoms of cancer and side effects of treatment, including anxiety, fatigue, quality of sleep and mood. Search ‘yoga’ at cancerresearchuk.org to find out more.

Visualisation (guided imagery)

Visualisation is where you imagine something to help you feel calmer. For example, you might picture a beach or woodland, or you might think about a recent activity where you felt happy. Imagine it in as much detail as possible, including what you might see, smell, hear and feel if you were actually experiencing it now.

You can work with a therapist to guide you through visualisation, or you can use resources such as podcasts and apps. Some studies suggest that visualisation might improve mood and sleep quality in people with cancer. Search on Cancer Research UK’s website for more information.

Support from a counsellor or other therapist

There are many different types of therapy that aim to support your emotional wellbeing. Many of these involve talking to a trained professional such as a counsellor. However, there are alternatives to talking. For example, you could consider working with an artistic or creative therapist to do something like drawing, painting, sculpting or using music to explore your feelings. See page 75 for information about cognitive behavioural therapy (CBT).

Therapists aim to offer you an emotionally safe and confidential space to help you think about:

- your thoughts and feelings, which might include how lymphoma affects your life
- what's important to you in your life
- how you usually respond to people and situations
- your feelings of safety, resilience and ability to cope
- ideas and ways of addressing challenges.

The relationship between you and your therapist is extremely important – if you can trust them with how you feel, you are more likely to find your time together beneficial.

If you would like support in adjusting to living with lymphoma, speak to your GP or a member of your medical team. They might be able to refer you on the NHS, or they might know of other wellbeing and counselling services in your local area.



- On our website's useful organisations webpage, you can find a section on emotional wellbeing. This includes organisations that offer or signpost to therapists.
- Search 'how to find therapy or counselling' on the Mind website at mind.org.uk for more information about accessing these services for free or at a reduced cost.
- Search 'types of talking therapy' on the Mind website to find out about different types of talking therapy.

Complementary therapies

Complementary therapies don't treat or cure your lymphoma, but some types might improve your mental and physical wellbeing. Studies suggest that complementary therapies might help people who are living with cancer. For example, acupuncture could help to reduce sickness (nausea), pain and symptoms of nerve damage (peripheral neuropathy).

“ *During treatment, I started to feel disconnected from my body and I couldn't talk. A doctor explained that this was a form of disassociation, as a result of facing a life-threatening illness. I had to stop work and couldn't see people because of risk of infection, causing me an enormous amount of stress. I had regular sessions with a psychologist, and we tried several types of complementary therapy, but I gradually managed to cope and changed my mindset. I put trust in my medical team and, mentally, my perspective on life changed. I now try to the best of my ability.*

Colin, diagnosed with non-Hodgkin lymphoma



Massage

Massage might help reduce pain, fatigue and anxiety. Many people find it relaxing.

We're sometimes asked whether massage could spread lymphoma around the body. There's no evidence to suggest that this can happen. However, people with lymphoma should avoid deep tissue massage. This is particularly the case if you bruise or bleed easily. A gentler massage might be more suitable for you.

There are many different types of complementary therapies, such as aromatherapy, reflexology and massage. Many people find them relaxing and use them to manage stress and anxiety. Find out more by searching 'complementary therapy' at cancerresearchuk.org

Speak to your medical team if you're interested in trying a complementary therapy so that they can offer advice. They can:

- Tell you anything to avoid – for example, if a complementary therapy could interact with another treatment you're having.
- Advise you on anything you should tell a complementary therapist before having treatment. For example, if you have a low platelet count, you might bruise easily, so your medical team might suggest asking your therapist to use a gentle touch.
- Tell you about any reputable, local services. Some local charities and hospitals offer complementary therapies free of charge to people affected by cancer.

Many hospices offer complementary therapies without charge. Find your local hospice at: hospiceuk.org/hospice-care-finder

If you've had radiotherapy, remember that the skin on areas of your body treated might be more sensitive than usual. Plain (carrier) oils are made from plants. These are likely to be more suitable than other types of oils.

Tips for choosing a complementary therapist

- Check the therapist's qualifications and professional organisation membership. This is usually in their leaflets or on their website. You could also ask to see training certificates.
- Find out about their experience – how long have they been practising and have they treated people with cancer?
- Check they have appropriate insurance. Does it cover them to treat people with lymphoma?
- Search 'useful orgs' on our website – you'll find a section on complementary therapies that includes resources to help you search for a reputable therapist in your area.

Other organisations

We list organisations below that you might find helpful. Search online for the name of the organisation to find their websites. If you don't find what you're looking for, please contact our Helpline team (page 207).

Cancer Research UK has information on cancer, a database of clinical trials and a nurse-led helpline: 0808 800 4040.

Macmillan Cancer Support provides support to people affected by cancer and their family and friends.

Maggie's Centres gives support to people with cancer and their family and friends.

Mental Health Foundation have podcasts designed to give you skills to help improve your mental wellbeing.

NHS website has information and resources to help you live well, as well as about services in England. NHS Direct Wales is for people living in Wales, and NHS Inform is for people living in Scotland.



Visit [lymphoma-action.org.uk/Useful-Organisations](https://www.lymphoma-action.org.uk/Useful-Organisations) for a list of other organisations you might find helpful.

Information and support

If you or someone you love is affected by lymphoma, we're here to support you.



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website.



Find an **Online Support Meeting** at lymphoma-action.org.uk/OSM



Join our **Closed Facebook Group** at facebook.com/groups/LymphomaActionSupportUK



Our **Buddy Service** can connect you with someone in a similar situation to you. Call our Helpline for details.



Visit lymphoma-action.org.uk/TrialsLink to search for clinical trials that might be suitable for you.

See our website for full details of our services. For our latest news and updates, follow us on social media:



@lymphomaaction



lymphoma_action

More information

If you're interested in finding out more about any of the topics covered in this book, we have lots more information on our website. We also produce a number of books, which are available free of charge, including:

- *Hodgkin lymphoma*
- *High-grade non-Hodgkin lymphoma*
- *Low-grade non-Hodgkin lymphoma*
- *Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL)*
- *Active monitoring (watch and wait) for lymphoma*
- *Young person's guide to lymphoma*
- *A book for family and friends: When someone close to you has lymphoma*

Find our full range of books and information at lymphoma-action.org.uk/Books or call us on 0808 808 5555.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo



How you can help us

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.

Lymphoma Action is a charity and relies on the generosity of its supporters. If you or your family would like to get involved with some of our fundraising activities, visit lymphoma-action.org.uk/GetInvolved

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

Disclaimer

Although we make reasonable efforts to ensure the content of our publications is accurate and up-to-date at the time of going to press, we make no representations, warranties or guarantees, whether express or implied, that the content is accurate, complete or up-to-date, particularly in relation to medical research which is constantly changing.

The content of this publication has been developed for people living in the UK and is provided for general information only and primarily for personal and educational use. It is not intended to amount to advice on which you should rely. You must obtain professional, medical or specialist advice before taking, or refraining from, any action on the basis of the content of this publication. Lymphoma Action cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information referenced in it.

©Lymphoma Action 2023. All rights reserved. No part of this publication may be reproduced or transmitted without permission. Go to lymphoma-action.org.uk/Legal for permitted use and reproduction of this book.

Funding

With thanks to Abbvie, Bristol Myers Squibb, BTG (part of SERB Pharmaceuticals), Eli Lilly & Company, Roche Products Ltd, Sobi and Takeda UK Ltd for funding this book. As per our policy, they have no influence over our content.

Acknowledgements

We would like to acknowledge the continued support of our Medical Advisory Panel and other expert advisers as well as our Reader Panel. In particular we would like to thank:

- Professor Richard Anderson, The Medical Research Council Centre for Reproductive Health, Edinburgh.
- Charlotte Bloodworth, Advanced Nurse Practitioner, University Hospital of Wales, Cardiff.
- Bev Wilson, Macmillan Lymphoma Clinical Nurse Specialist, St George's University Hospital NHS Foundation Trust, London.

With special thanks to Adam, Andy, Ben, Callum, Carly, Christy, Colin, Cornita, Corrin, Doreen, Dorothy, Faye, Geoff, Hayley, Jacqueline, Jean, John, Juliet, Mark, Michael, Mila, Natasha, Neil, Nicola, Paris, Penny, Sarah and Surinder for sharing their experiences. Quotations from their stories are featured throughout the book. To read some of their stories and those of others affected by lymphoma visit lymphoma-action.org.uk/stories

We would like to thank professionals Charlotte Bloodworth, Christine Coyle, Dr Wendy Osborne, Sandra Richardson, Katherine Wight and Bev Wilson for sharing their thoughts. Thanks also to Lymphoma Action Director of Services Dallas Pounds and Support Team member Neil.

This book gives tips to help you manage the physical, practical and emotional aspects of living with and beyond lymphoma.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years.

We're here for you.



Freephone helpline **0808 808 5555**
(Mon to Fri, 10am to 3pm)



information@lymphoma-action.org.uk



www.lymphoma-action.org.uk



Live Chat via our website
(Mon to Fri, 10am to 3pm)

Inform | Support | Connect

Lymphoma Action
Unit 3, Bell Business Park
Smeaton Close, Aylesbury
Bucks HP19 8JR
General enquiries 01296 619400

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



This book is 100% recyclable

Company Registration No 03518755
Charity Registration (England and Wales) No 1068395
(Scotland) No SC045850

© Lymphoma Action 2023
7th edition produced December 2023
Next revision due December 2026
LYM0060LivingLymphBk2023ed7
ISBN 978-1-914948-10-7