



Alfie,
diagnosed
at 13



Ellie,
diagnosed
at 15

Young person's guide to lymphoma



Georgia M,
diagnosed
at 24



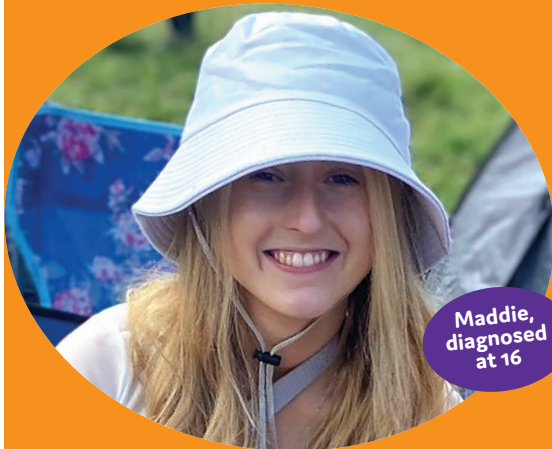
Lyle,
diagnosed
at 19



Aidan,
diagnosed
at 20



Harriet,
diagnosed
at 20



Maddie,
diagnosed
at 16



Dwayne,
diagnosed
at 25



Sophie,
whose partner
Lewis was
diagnosed
at 22

Who we are

We're Lymphoma Action, a UK charity that offers information and support to help people affected by lymphoma, including family and friends of someone who's been diagnosed. We hope to support you to live well, physically and emotionally, with and beyond lymphoma.

Our information is evidence-based, approved by experts and reviewed by users. We are also accredited by the Patient Information Forum (PIF) TICK, the UK's only assessed quality mark for health and care information. Search 'our approach to health information' on our website to find out more.

On our website,
lymphoma-action.org.uk, you'll
find lots of information and
resources to support you.



Lots of health professionals are involved in your treatment and care. There can be a lot of names, job titles and roles to remember. You can use the space below to help you remember who's who. You could include any important phone numbers or other contact details too.

Healthcare professional	Name and contact details
Key worker (often your clinical nurse specialist)	
Consultant	
Other doctors	
Dietitian	
Physiotherapist/ Occupational therapist	
Psychologist/Counsellor	
Social worker	
Out-of-hours emergency contact	

Around 500 young people (aged 15 to 24) develop lymphoma every year in the UK. If you, or someone close to you, is one of these people, we're here to support you.

My lymphoma type and stage

My key worker contact details

My treatment(s)



**Information
about my
lymphoma.**

How to use this book

Who's it for?

If you're a young person with lymphoma, this book is for you. Use it however you'd like to. Some people take it to appointments and make notes in it. You might also want to share it with friends and family, to help them understand a bit more about lymphoma.

What's it about?

In this book, we've tried to answer some of the questions you might have about lymphoma and its treatment. We also give tips to help you look after yourself and to live well, with and beyond lymphoma.

You don't have to read the whole book at once or in the order it's written. Some sections might not be relevant for the type of lymphoma you have; others might only be relevant at certain times, like after treatment. You can just pick the sections that are relevant to you at any given time.

What do the symbols and colours mean?

Each section has its own colour to make it easy to flip between them.



Notes

Tint boxes give you space to make notes.



Quotes from young people who have personal experience of lymphoma.



Top Tips

Top tips give ideas to help you cope with lymphoma and treatment.



More
information
is on page 8

Signposting circles tell you where you can find more information.



Website signposts direct you to further online information and resources.



Exclamation marks draw your attention to important points.



Wellbeing check-ins focus on helping you to live well.

What does that mean?

Words in **bold** purple are explained in the glossary section at the back of this book.

If you'd like this information in large print, please contact us – see back cover for details.

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About lymphoma



Lymphoma is the 5th most common type of cancer in the UK, but many people haven't heard of it before they are diagnosed.

If you've been diagnosed with lymphoma, you're not alone. There are other people your age who have had a diagnosis.

**Find out
how we can
support you
on page 187**

What's lymphoma?

Lymphoma is a type of blood cancer.

- It can affect both adults and children.
- Most types of lymphoma are treated effectively.

There are over 60 different types of lymphoma. Lymphomas are grouped into two main types: Hodgkin lymphomas and non-Hodgkin lymphomas (NHL).

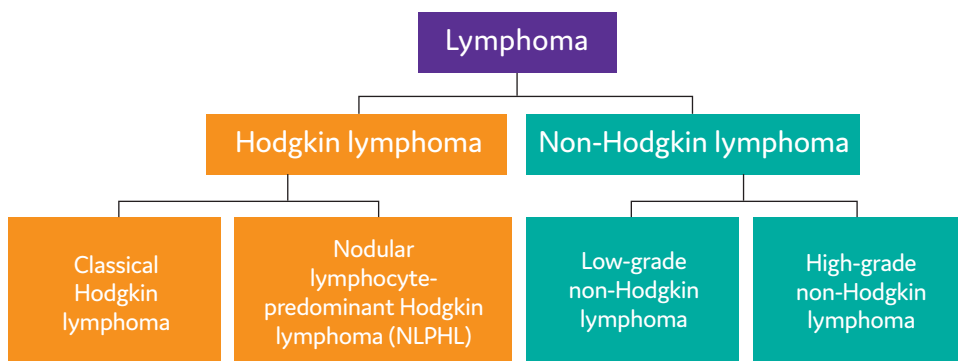
Treatments for lymphoma in young people are generally very successful.



“

I had not heard of lymphoma, although my parents had. It was when the doctor started talking about chemotherapy that it really hit me. I just wanted to start treatment straightaway.

Georgia M,
diagnosed at 24

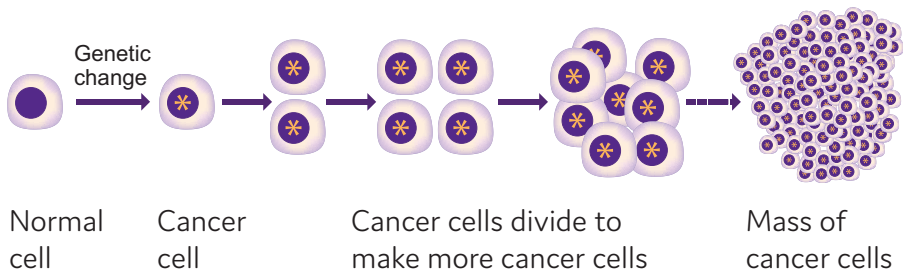


About lymphoma

How does cancer start?

Cancer happens when **cells** in your body grow out of control. They divide when they don't need to or don't die when they should. This can mean that abnormal cells build up and form a cancer.

The abnormal cells are 'malignant'. This means that they can spread to other parts of the body and start growing there too.



Search 'what is lymphoma' on our website to watch an animation that explains how lymphoma can start.



There are lots of different types of cells in your body, which is why there are lots of different types of cancer. In lymphoma, the cells that grow out of control are a type of white blood cell called a **lymphocyte**.

There are two main types of lymphocytes:

- B lymphocytes, also called 'B cells', make **antibodies** to fight infection.
- T lymphocytes, also called 'T cells', protect you from germs by attacking them directly.



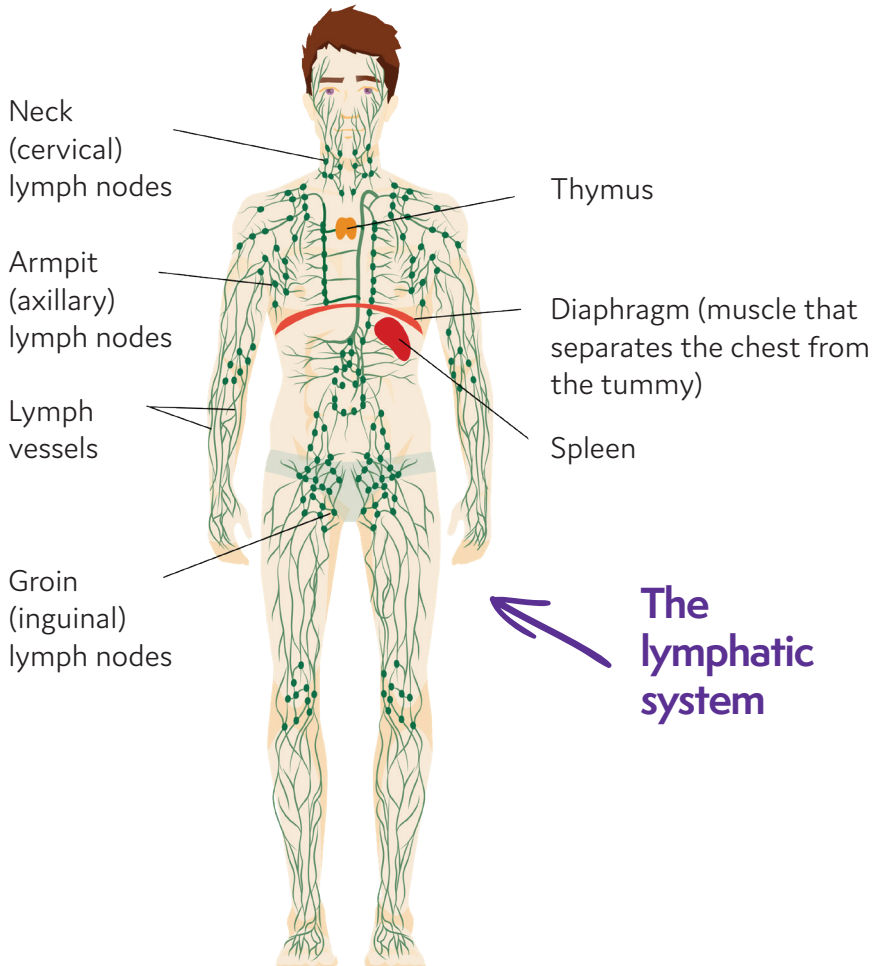
Most lymphomas develop from B cells. They are called 'B-cell lymphomas'. Some lymphomas develop from T cells, so they're called 'T-cell lymphomas'. Very rarely, lymphomas aren't typical of B cells or T cells.

What's the lymphatic system?

Your lymphatic system helps protect you from infection. It is a network of tubes (lymphatic vessels) and glands (**lymph nodes**) that run throughout your body. Lymphocytes travel around your body in your lymphatic system.

The lymphatic system includes your:

- **Thymus.** A gland where undeveloped (baby T cells) grow into fully working (adult) T cells.
- **Spleen.** An organ that helps fight infection. It filters your blood and destroys old and damaged blood cells.
- **Bone marrow.** The spongy material in the middle of your bones that makes all your blood cells.



Healthy lymphocytes travel around your lymphatic system in a fluid called lymph. They collect in your lymph nodes (glands), ready to fight infection and stop it from spreading around your body.

What happens in lymphoma?

If you have lymphoma, abnormal lymphocytes build up in your body, usually in your lymphatic system.

Symptoms

Many of the signs of lymphoma (symptoms) are also seen in other, less serious conditions, like common viruses. Even people who have the same type of lymphoma can have different symptoms. That's why lymphoma can be difficult to diagnose – it can easily be confused with something else.

In the past, when you've had a cold, sore throat or earache, you might have noticed that you had swollen glands (enlarged **lymph nodes**) in your neck. This is because lymphocytes were fighting the infection. This kind of swelling might have been painful but probably went down within a couple of weeks. In lymphoma, the swollen lymph nodes are **not** usually painful, and they **don't** shrink back down on their own.

The most common symptom of lymphoma is a painless, swollen lump or lumps that don't go down after a couple of weeks. Usually, swollen lymph nodes develop in the neck or just above the collar bones, but they can develop elsewhere, such as in the armpit or groin.



Swollen lymph nodes

“

I was getting ready to take my girlfriend out and noticed in the mirror that my neck looked bigger on one side. I could feel a big hard lump on the side of my neck.

Lyle, diagnosed with lymphoma at 19



If the lymphoma starts in a lymph node deep inside your body, you might get other symptoms. Lymphoma can grow outside your lymph nodes as well. This is called **extranodal** lymphoma ('extra' means that it is outside the lymph node).

If the lymphoma is growing in your lungs, you might have a cough or feel breathless. If it is growing in your tummy (abdomen), you might have a swollen tummy, which can be uncomfortable or painful.

Lymphoma can grow outside your lymph nodes as well.



Other common symptoms:

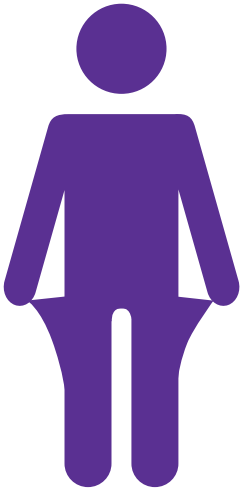
Fatigue

Fatigue means feeling exhausted for no obvious reason or feeling washed out after doing very little. It is different to normal tiredness.



Unexplained weight loss

Losing a lot of weight quite quickly without trying to.



Sweats

Sweats can happen at any time of the day with lymphoma. If they happen at night, they can make your nightclothes and bed sheets soaking wet and are often described as 'drenching'.

Itching

Itching (pruritus) with or without a rash can be a symptom of lymphoma. It can be very uncomfortable, particularly when you get hot.



Fever

Fevers (temperatures above 38°C), often come together with night sweats and weight loss, but they can happen separately. They can also be a sign of infection.

Your doctors might say that you have **B symptoms** if you have one or more of the following:

- **fever:** a high temperature (above 38°C) that might come and go
- **drenching sweats:** especially at night
- **unexplained weight loss:** losing weight quickly without trying to.

Doctors consider whether you have B symptoms when they plan your treatment.

“

Over about 12 months, Lewis repeatedly became unwell with a series of nasty chest infections. They began with cold-like symptoms but turned into more serious infections; green phlegm, a dry, recurring cough and feeling so unwell that he missed repeated weeks of work, each time taking longer to recover. He also experienced drenching night sweats, lost his appetite and became breathless and fatigued.

Sophie, whose partner Lewis was diagnosed at 22



Why did I get lymphoma?

In most cases, the cause of lymphoma is unknown.

- **Nothing you did or didn't do** caused your lymphoma – there's also no evidence that stress or the amount of exercise you do causes lymphoma.
- **You can't 'catch' lymphoma** or pass it onto anyone.
- **Lymphoma isn't inherited** (something you get) from your parents.
- **If you have lymphoma, it's very unlikely that any brothers or sisters you have will get it**, but there's a slightly increased risk with some types of lymphoma.

Some people with health problems that affect their **immune system**, or who have had certain viruses (such as Epstein–Barr virus, or 'EBV') **might** have a higher risk of developing lymphoma. However, in most cases, no one can say why you have developed lymphoma.

There's information about possible causes and risk factors of lymphoma on our website. Search 'causes' at lymphoma-action.org.uk



“

For a long time, I felt to blame for my diagnosis or looked for a reason why this had happened to me. I can now see that I was just trying to process and understand what was going on and make sense of it all.

Mila, diagnosed at 19

We're here to support you (page 187)

About lymphoma

Tests you might have

Some tests are only done for certain types of lymphoma. Your doctors will choose the best tests for you, so you might want to read only about these ones.

You're likely to have a **biopsy** to confirm your diagnosis (see page 22)

“

Before you have tests and scans, you should be given information about them and a chance to ask any questions you might have. No matter how often you have appointments, if you have any concerns before your next one, get in touch with your medical team.



Dr Naomi Cornish,
Doctor specialising in
haematology.



Before treatment

Tests before treatment might include those that help your doctors to:

- Find out as much as possible about your lymphoma, for example, what type it is and where it is in your body. This is called **staging** (see page 43).
- Check how well your liver and kidneys are working. This information can help to decide the best treatment for you.
- Check for any viruses you might have, in case they need treating before you begin your treatment for lymphoma.



During treatment

During treatment, your doctors test:

- whether treatment is having the expected effect on your lymphoma
- how well your body is coping with treatment.

After treatment

After treatment, your doctors might do further tests to check:

- your physical and emotional recovery
- for any side effects or **late effects** of treatment (health problems that can develop months or years after treatment) – see page 177
- for any signs of the lymphoma coming back (**relapsing**).

Tests you
might have

Biopsy

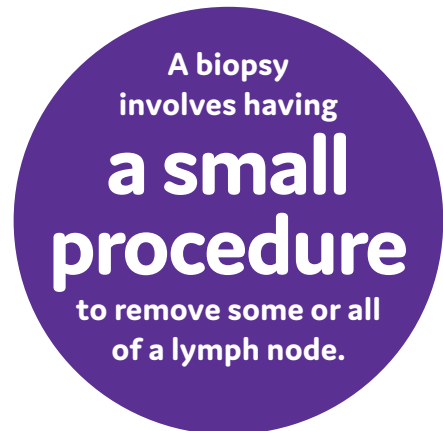
A **biopsy** is a procedure that removes all or part of a **lymph node** to look at under a microscope.

It's the test that's usually used to check whether or not you have lymphoma.

A biopsy can also give further information about the type of lymphoma you have and how fast it's growing.

What happens?

Having a biopsy involves a small procedure. Usually, two or three small samples (cores) from an enlarged lymph node are removed during a biopsy. Occasionally, it is necessary to remove the whole lymph node to be sure of the diagnosis.



You will have a local or general **anaesthetic** for the biopsy procedure:

- If the lymph node is near the surface of your skin, you will usually have a local anaesthetic to numb **only** this area.
- If the lymph node is deeper inside your body, or if it is necessary to remove the whole lymph node, you might have a general anaesthetic, which puts you into a sleep-like state.

Whichever type of anaesthetic you have, you won't feel the biopsy needle going in or the lymph node tissue being taken out.



After I'd had a biopsy, I was told that it was stage 2 Hodgkin lymphoma. After I was told that, my life changed so quickly. However, the first thing I did when I was told was I named my tumour 'Terry the Tumour'. Naming it and trying to make it humorous felt like the best way I could deal with it.

Harriet, diagnosed at 20



Tests you
might have

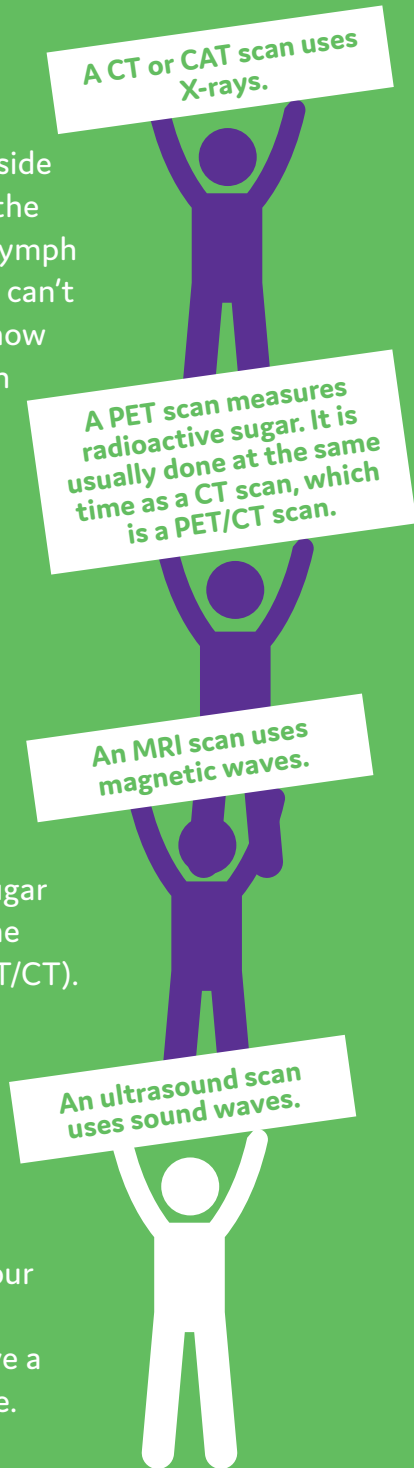
Scans

A scan is a way of looking at what's inside you – it's a bit like taking a picture of the inside of your body. There are lots of lymph nodes deep inside your body that you can't see from the outside. Scans help to show which lymph nodes are affected and in which parts of your body.

There are different types of scan that build up pictures in different ways. There's information about these in this section, and you can find out more on our website. Search 'tests, diagnosis and staging'.

- A **CT or CAT scan** uses X-rays (page 27).
- A **PET scan** measures radioactive sugar (see page 27). It is usually done at the same time as a CT scan (called a PET/CT).
- An **MRI scan** uses magnetic waves (page 29).
- An **ultrasound scan** uses sound waves (page 32).

Some scans are better than others at seeing different parts of your body. Your doctor decides which type of scan is best for you, so don't worry if you have a different type of scan to someone else.



A CT or CAT scan uses X-rays.

A PET scan measures radioactive sugar. It is usually done at the same time as a CT scan, which is a PET/CT scan.

An MRI scan uses magnetic waves.

An ultrasound scan uses sound waves.

What happens?

You usually have scans as an outpatient, which means you don't have to stay in hospital overnight.

Having a scan doesn't hurt, but you need to lie very still while you're having your scan. Some scanning rooms need to be kept cool for the machines to work properly. You could ask for a blanket if you feel cold.

Having a scan isn't something most people are used to. They might not like the loud noise some machines make, or worry about feeling closed in. Talk to the hospital staff if you feel worried – they can give you information about what to expect and will do all they can to help you to feel comfortable and calm. You could also ask if you'd like a family member to be able to talk to you from outside the room through an intercom.

Scans
don't hurt,
but you need to lie
very still while you're
having your scan.

Tests you
might have

If you are worried about having your scan, talk to hospital staff before the day – this gives them a chance to help you feel more relaxed about it.

Follow any instructions your medical team give you about preparing for your scan, including about what to wear and if you'll need to take off any metal, such as jewellery.

If you'd like to, ask if you can listen to something like music or a podcast during the scan. The staff in the scanning department can usually help with this. For safety reasons, there might be certain requirements for the types of headphones you can use.

Ask if you can listen to something during the scan.



CT/CAT scan

CT stands for 'computed tomography' and CAT stands for 'computed axial tomography'. They are different names for the same type of scan. You might be given a special dye (contrast agent) before your scan to make it easier to see the insides of your body clearly. You have a contrast agent as a drink or as an injection into a vein. How you have it depends on which areas of your body your doctors need to look at.

When you have a CT scan, you lie on a bench that moves slowly into a ring-shaped machine.

**The machine is open at both ends.
It takes lots of pictures from
different angles to build up a
3D image of the inside of your body.**

A CT scan
takes about
15 to 45
minutes.

PET scan

PET stands for 'positron-emission tomography'. This type of scan helps doctors to see where in your body the lymphoma is growing.

You'll be given information about how to prepare for your scan. This might include being asked:

- to 'fast', which means that you can't eat or drink for a while before your scan – usually, you can have only water in the 6 hours beforehand
- not to do any strenuous physical activity (that gets your heart rate up) in the 24 hours before your scan.

Tests you
might have

If you take any other medication, your medical team will let you know whether it's OK to take this as usual on the day of your scan.

When you go for the scan, you have an injection of a radioactive sugar (radiotracer). This helps to show how active the **cells** in your body are. Lymphoma cells take up more of the sugary radiotracer than healthy cells and show as 'hot spots' on the scan image.

You then wait for about an hour for your cells to take up the sugar.

You might be asked to stay still or sit quietly after you've had the radiotracer and before your PET scan so that your muscles don't absorb the radiotracer.

If you think you might find this difficult, talk to your medical team before the day of your scan. They can offer suggestions to help you stay as comfortable as possible – such as using support pillows during the scan or taking pain relief medication beforehand.



PET/CT scan

Most people have a CT scan and a PET scan in the same appointment – this is known as a PET/CT scan. Having both types of scan can help give doctors a clearer idea of what is happening inside your body.



You might have very low levels of radioactivity in your body for around 6 hours after a PET or a PET/CT scan.

Try to stay away from pregnant women, babies and young children during this time. Ask your medical team for advice if you think this could be difficult.

A PET or PET/CT scan takes
30 to 60 mins
but you have to be
at the hospital for 2 to 3
hours in total to have
the radioactive
sugar.

MRI scan

MRI stands for 'magnetic resonance imaging'. An MRI machine makes a 3D picture of the inside of your body by measuring changes in magnetic waves as they pass through you. You lie on a bench that moves into a cylinder that's open at one end.

Tests you
might have

For various reasons (including safety reasons and to ensure a high-quality scan image), you'll need to:

- Take off anything with metal in it, like a bra and metal jewellery. Some nail polishes also contain metal fragments so should be removed if they'll be within the scanning field.
- Leave your mobile phone and any other electronic devices in a different room.
- Make sure you don't have any cards with a magnetic strip, such as bank cards, in your pockets, as the machine can damage them.



An MRI scan usually takes up to an hour. The machine can be very noisy. You might be able to wear earplugs or listen to music or a podcast – ask the medical staff before the day of your scan as the headphones need to be safe to use with the machine.

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I had been experiencing a lot of bad back pain and I was referred for an MRI scan. The next day, I had an appointment where I was told that I needed further investigations to find out if I had cancer. At this point, I just wanted any tests and scans I needed to find out as much as possible.



Maddie, diagnosed at 16

“

I was so scared of going for my first MRI, but by the end of my first treatment, I'd had so many MRI scans that I felt fine about it. I even fell asleep during my last one! My hospital staff gave me the option of listening to music or watching a film during the scan. A friend also suggested making beats in my head to go along with the MRI noises, which I found worked as a fun distraction. Remember – you can stop the scan or talk to someone at any point.



Georgia M, diagnosed at 24

Tests you
might have

Ultrasound scan


Ultrasound scans use sound waves to create an image.

During an ultrasound scan, you lie down on a couch and have some gel put onto your skin. The gel might feel cold and can be sticky but it wipes off easily afterwards.

A health professional called a 'sonographer' moves the gel around your skin using a tool (transducer or probe). As it moves around, it makes high-energy sound waves.

These are too high-pitched for humans to hear.

The waves travel through your body. They bounce off tissues and organs inside your body. This makes echoes, which build up an image of the inside of your body.



An ultrasound
takes about
15 to 30
minutes.

Bone marrow biopsy

A bone marrow biopsy (sometimes called a 'trephine' biopsy) can help doctors check whether there is lymphoma in your **bone marrow**. In some cases, this test can also help to diagnose the type of lymphoma you have.

What happens?

You're given a general anaesthetic or a local anaesthetic to numb the area. Usually, you're also given a **sedative** to relax you – if you're not given one and you'd like one to help you feel calmer, ask for one.

Usually, the small sample of bone marrow is taken from your hip. You lie on your side while a doctor inserts a needle through your skin into the back of your hip (pelvic) bone. You'll feel some pressure as the needle goes into the bone and you might feel sore afterwards.

Pain should settle within 48 hours – pain relief medication (like paracetamol) can be helpful during this time. If the pain does not ease or continues over time, seek medical advice.

Tell your medical team if you develop any of the following:

fever (temperature above 38°C)

pain where the sample was taken that gets worse or that lasts more than a few days

redness or swelling where the needles went in

bleeding that doesn't stop when you apply pressure.

These might be signs of infection that need treatment.



Lumbar puncture

You might have a lumbar puncture as part of staging if you have non-Hodgkin lymphoma.

In a lumbar puncture, a doctor takes a sample of the fluid that surrounds your brain and spinal cord (which is called '**cerebrospinal fluid**' or '**CSF**') and looks at it under a microscope.

Lymphoma in the brain or spinal cord (**central nervous system** or **CNS**) is uncommon. However, if your doctors think you might have lymphoma in your CNS, they might do a lumbar puncture to help confirm this. They can then plan the best treatment for you.

What happens?

You have a local or general anaesthetic. If you're having a local anaesthetic and you feel very anxious, ask your medical team before the day if you can have a sedative.

You lie on your side with your knees bent up towards your chest. A doctor puts a needle into a gap between the bones in your lower back and removes a few drops of CSF. You need to stay very still while the CSF is collected.

A lumbar puncture takes about 30 minutes. If you're having **chemotherapy** drugs given into your CSF at the same time, it can take a couple of minutes longer.

You need to lie flat for a while afterwards, usually for about 30 minutes to an hour. This helps to lower the chances of getting a painful headache.

If you get a headache after a lumbar puncture, drink plenty of water. Your medical team can advise you on which painkillers are best for you.

Headaches after a lumbar puncture usually get better within about a week – speak to a member of your medical team if they go on for longer.

Blood tests

You have blood tests as part of your diagnosis, and frequently throughout your treatment and follow-up.

Blood tests can help give doctors an idea of your general health. They can show how many of each type of blood cell you have. This is known as **blood count**.

Blood samples can be taken in various ways: from a vein in your arm, from a finger prick or from your **central line** (a hollow tube inserted into a vein deep inside you) if you have one fitted.

You might have blood tests **before treatment**, for example to:

- find out more about the type of lymphoma you have
- see where lymphoma is in your body and if it's affecting your liver, kidneys or bone marrow.



Drink plenty of
water.

See page
102 for
information
on blood
counts

Tests you
might have

During treatment, to:

- check how well your body is coping with treatment
- make sure you've recovered enough from one round of treatment before starting the next.

Find out
about late
effects on
page 177

After treatment, to:

- monitor your recovery after treatment
- check for late effects
- look for any signs that your lymphoma might have come back (**relapsed**) – though it's usually the person who's had lymphoma who notices this first, and it is very rare for relapse to be obvious from a routine blood test.

Some people feel very nervous about having blood tests. Talk to your medical team if this is the case. They're used to helping people who feel anxious or squeamish about needles.

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: guyandstthomas.nhs.uk



Other tests

In some cases, your doctors might recommend other tests, for example:

- **Echocardiogram**, which uses echo (ultrasound, page 32) to look at your heart. This helps to give doctors an idea of how your heart is working, whether it's damaged and whether it is affected by lymphoma.

- **Lung functioning tests**, which measure how well you are able to take in oxygen and hold air in your lungs. These tests are sometimes needed before some types of treatment that can affect your lungs.

Waiting for test results

Your medical team should give you an idea of how long it'll take for you to get your test results. The waiting time depends on the type of test you had. In most cases, results take around a couple of weeks. With a biopsy, they can take a few weeks.

While you're waiting for your test results, your doctors are gathering important information to find out all they need to know about the type of lymphoma you have. This allows them to offer the most suitable treatment for you.

Waiting for test results can be hard. If you'd like support, our Helpline Services are here for you.

Talk to a member of your medical team if you're waiting for your results for longer than you expect. They can explain why this might be and when you are likely to find out more.

Search 'waiting for test results' on our website to watch a short video where Lymphoma Nurse Specialist Lucy Whiteman explains why test results can take a while to come back.



Tests you might have

Types of lymphoma

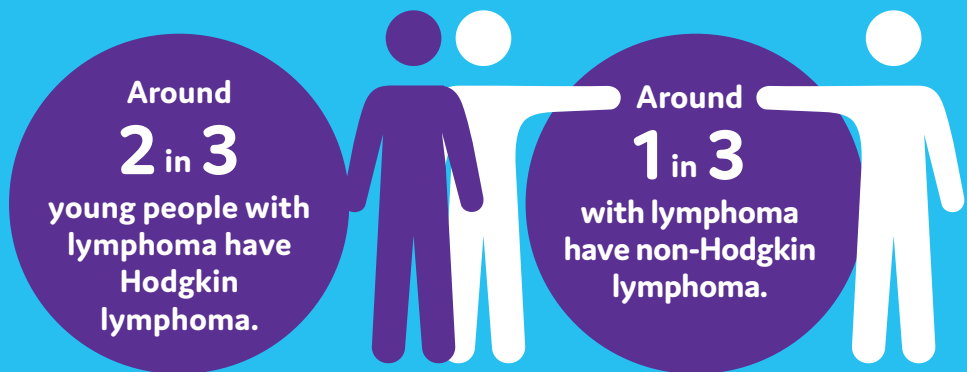
Your doctor or nurse will talk to you about your diagnosis when all your test results are back. They tell you:

- the type of lymphoma you have
- where it is in your body (its stage)
- which treatments might be suitable for you.

You can take someone with you to your appointments if you would like to.

What types of lymphoma are there?

There are two main groups of lymphomas: Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). Within these groups, there are lots of different subtypes (see page 40).



What's the difference between Hodgkin lymphoma and non-Hodgkin lymphoma?

There is a difference in how the cancer **cells** in Hodgkin lymphoma and non-Hodgkin lymphoma look under a microscope.

Doctors look at your **biopsy** sample and check for Reed-Sternberg cells. These cells are large and look different to healthy cells under a microscope.

Lymphoma is diagnosed as Hodgkin lymphoma if there are Reed-Sternberg cells present. Non-Hodgkin lymphoma (NHL) is any type of lymphoma that doesn't contain these cells.

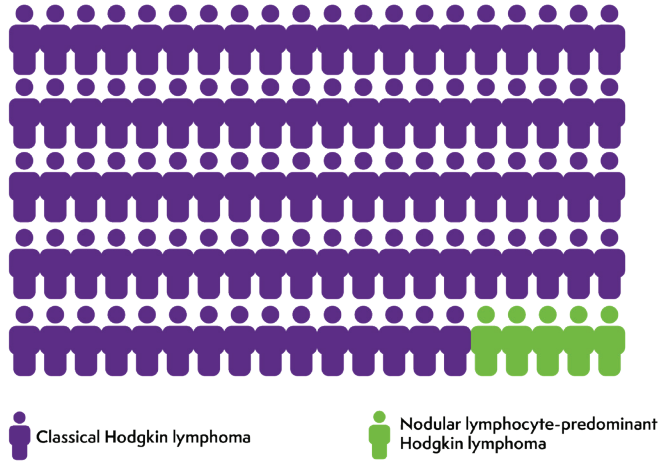
You might be interested in our animation that outlines how lymphoma develops. Search 'what is lymphoma?' on our website.



Types of Hodgkin lymphoma

There are two main types of Hodgkin lymphoma.

- The most common type is **classical Hodgkin lymphoma**, which makes up about 90% of cases.
- There is a rarer type called **nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)**, which is slower-growing.



There are four subtypes of classical Hodgkin lymphoma: nodular sclerosing (NS), which is the most common subtype in young people, mixed cellularity (MC), lymphocyte-rich (LR) and lymphocyte-depleted (LD). Usually, however, they're generally referred to just as classical Hodgkin lymphoma. They are all treated in the same way and have similar outcomes.

NLPHL behaves differently to classical Hodgkin lymphoma and usually needs less treatment.

Types of non-Hodgkin lymphoma

There are many different types of NHL.

NHL can be classed as fast-growing (high-grade) or slow-growing (low-grade) lymphomas.

High-grade lymphomas

Most young people have a high-grade lymphoma. High-grade lymphomas are generally more responsive to treatment and more likely to go into long-term **remission** (disappearance or significant shrinkage of lymphoma) than low-grade lymphomas.

Low-grade lymphomas

Low-grade lymphomas usually respond well to treatment, but they can be harder than high-grade lymphomas to get rid of completely. Treatments for low-grade lymphoma usually control it for a while, often up to many years. After this time, the lymphoma tends to come back (**relapse**) and need more treatment. For this reason, people often think of these types of lymphoma as a long-term (chronic) condition that needs treatment from time to time.

The most common types of NHL in young people are all fast-growing:

- **Diffuse large B-cell lymphoma** (DLBCL) is a B-cell lymphoma that can develop in **lymph nodes** or in **extranodal** places (sites), such as the chest and tummy.
- **Burkitt lymphoma** is a B-cell lymphoma that often involves lymph nodes in the tummy or bowel (intestine), head and neck.
- **Lymphoblastic lymphoma** is a T-cell lymphoma that most often causes swelling of lymph nodes around the heart.
- **Anaplastic large cell lymphoma (ALCL)** is a T-cell lymphoma that can develop anywhere in the body, either in the lymph nodes or in extranodal sites.

Different types of lymphoma need different treatment.

We have more information about types of lymphoma at lymphoma-action.org.uk/Types



There's space at the start of this book (page 4) to write down information about the type and stage of your lymphoma.



I decided straightaway that a positive attitude was important for me when dealing with this and although obviously shocked, I was also relieved to have any diagnosis. This meant my treatment could start, ultimately improving my health at a faster rate.

Ellie, diagnosed at 15



Staging

Staging means working out which parts of your body are affected by lymphoma. This information helps doctors plan the best treatment for you.

The same staging system is used for everyone with Hodgkin lymphoma.

With NHL, there are different staging systems for people who are under 18 and those who are over 18. Lymphoma in people aged over 18 is described as 'advanced' or 'not advanced'.

In children and young people, it's becoming more common for doctors to talk about 'early' or 'advanced' stage lymphoma rather than using the numbers.

The descriptions below apply to both Hodgkin lymphoma and non-Hodgkin lymphoma.

Early stage lymphoma (stage 1 or 2)

Your lymphoma is in just one place or a few places that are on the same side of your diaphragm – this is the sheet of muscle across the bottom of your ribcage that separates your chest and heart from your tummy.

There are four main stages of lymphoma:

1 to 4

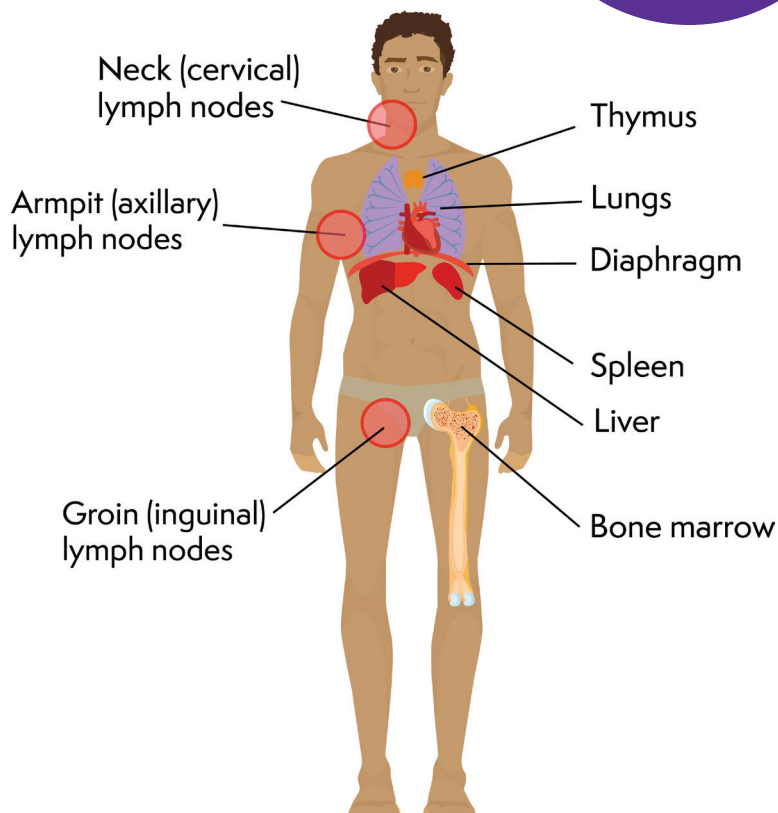
These are sometimes written in Roman numerals (I, II, III and IV).

Advanced stage lymphoma (stage 3 or 4)

Your lymphoma might be both above and below your diaphragm, or it might have spread to other places like your lungs, bones, **bone marrow** or **central nervous system (CNS)**.

Your **lymphatic system** is all over your body, so it is not uncommon for lymphoma to be at an advanced stage when it is diagnosed. There are effective treatments for all stages.

There are
**effective
treatments**
for all stages.



What do the letters mean?

As well as a number, your doctor might use a letter after your stage. For example, you might have stage 2A, or stage 3E.

Stage letter	What it means
A	You haven't had any B symptoms (you might hear the word 'asymptomatic' which means 'no symptoms').
B	You've had one or more B symptoms: unexplained weight loss, night sweats or fevers. See page 18 for more about B symptoms.
E	'Extranodal', which means that the lymphoma started outside of the lymphatic system.
S	There is lymphoma in your spleen (part of the lymphatic system).

If the lymphoma measures above a certain size (depending on its type), it might be called 'large' or 'bulky'.

Ask your doctor to explain what they mean if you're not sure about any of the terms they use. You could also ask them to write things down to help you remember them.

We have more information about staging at lymphoma-action.org.uk/Staging



Finding out about lymphoma

Your medical team are best-placed to answer any questions you might have about your lymphoma. They plan the most suitable treatment for you based on your individual situation. There is a lot of health information available, particularly online, and it can vary in quality.

Treatment outcomes in young people are generally much better than in older people. Advances in science and medicine also mean that these continue to improve as time goes on.

It's up to you how much you would like to know about your lymphoma. It might feel daunting to find out about your lymphoma and what the next steps are. However, it can help to have some understanding of what's happening, so that you can feel more in control of your situation and make informed decisions about your treatment and care.

- **Go at your own pace**, and recognise that you might need different amounts of information at different times.
- **Talk things through with your doctors and nurses**, so that they can answer any questions you have. You can talk to them about the side effects you might get from treatment, as well as about managing other areas of your life, such as school, work and your social life.
- **Check that any sources of information you use are reliable and up-to-date.** One easy way is to look for the PIF TICK quality mark (shown on the back cover of this book). The PIF TICK website at piftick.org.uk has more information about finding trustworthy health information.

We've got more suggested questions to ask your medical team on our website. Search 'questions to ask' at lymphoma-action.org.uk



Your feelings after a diagnosis of lymphoma

There is no 'normal' way to react to finding out you have lymphoma. You might have lots of different emotions, even within a single day. People often experience a mixture of feelings when they are first diagnosed.

Among many others, you might also feel some, or all, of the following:

- **Fear and anxiety** about the unknown.
- **Helplessness and loss of control**, for example, because you have so many medical appointments.
- **Anger and irritation**, that lymphoma has caused disruption to your life and plans.
- **Loss and sorrow**, for example, grieving for your good health, or for your day-to-day life as you've lived it up until now.

- **Sadness** – for what you, and those close to you are going through.
- **A sense of pressure** – some people feel they need to be, or pretend to be, positive, for the people close to them.
- **Guilt** – wondering if you could have done something to prevent the lymphoma, or for having an impact on those around you.
- **Withdrawal or loneliness** – feeling that those around you don't understand what you are experiencing.
- **Relief** – that your doctors have planned your treatment and that you have a schedule of appointments to focus on.

How you cope with your diagnosis is very personal. You might want to talk about it, or you might just want to be alone for a while. Some people choose to find out as much as they can about lymphoma; others prefer to have far less information.

Whatever your approach, remember that there are people who can help you.

We're here to support you (see page 187)

“

I felt isolated, both at home and in hospital. My friends all got to go out at weekends and to go to college. I asked my friends to carry on talking to me about 'normal' things and I prioritised giving my energy to my social life.

Maddie, diagnosed at 16

About treatment

Your medical team will make treatment recommendations **personal** to you.



Some young people are treated for **lymphoma** using options recommended for children. Some young people are treated using options recommended for adults.

Who makes decisions about my treatment?

Your medical team will offer you the best treatment. They should help you to understand your lymphoma and treatment options, so that you can be involved in decisions about your care.

Find out more information about treatment options on page 68

Many children and young people have their treatment as part of a clinical trial (page 65). Whichever treatment you have, you'll be given information about possible side effects of treatment and what to do if you have any problems or concerns.

It's up to you how much you want to know. You might just want to know basic information about your lymphoma and treatment options, or you might want to know lots of detail.

If you choose to take someone with you to your appointments (like your mum or dad, a carer, sibling or partner), it can be helpful to talk beforehand about the approach you'd like to take. Think about whether you'd like them to be actively involved in the discussion, or if you'd prefer them to come along to support you while you lead the conversation. You could also ask them to help by noting down the key points.

Search 'getting the best from appointments' at lymphoma-action.org.uk for more tips.



“

For me, it helped to ask questions, such as about treatment plans, to keep me in the know about what was happening to my own body.

Ellie, diagnosed at 15

About
treatment


Will treatment be successful?

Treatment for lymphoma in young people is generally very successful. After treatment, most young people go into **remission** and stay in remission.

Occasionally, there are some lymphomas that need different, more intensive treatment to send the lymphoma into remission.

Some health professionals prefer not to use the word 'cure', at least not until a while (often around 5 years) after you have stayed in complete remission. Talk to your lymphoma doctor or nurse about the likelihood of remission – they are best-placed to advise you based on your lymphoma type, its stage, and your individual circumstances.

It can be very difficult to deal with not knowing for certain what the outcome of treatment will be.



See page 126 for tips to help you cope with uncertainty

Who gives consent for me to have treatment?

You can only have treatment if you, or an adult who is responsible for you (a parent, guardian or carer) agrees to it by signing a consent form. **If you are 16 or over**, you are considered able to decide on your own medical treatment, unless there is significant evidence to suggest otherwise. You can sign your own consent form and no treatment can be given without your agreement.

If you are under 16, you might be able to sign your own consent form if your doctors think it is appropriate. Your parents or carers will also need to sign it. If your doctors think it is not appropriate for you to sign your own consent form, your parents or carers sign it for you.

Search 'consent' on the NHS website at www.nhs.uk for more information.

Getting ready for treatment (prehabilitation)

Your doctors might suggest ways of getting ready for treatment, mentally and physically – this is called 'prehabilitation'. It includes eating well, doing physical activity and managing stress. It might also include getting help to stop smoking or to reduce your alcohol intake, as well as managing any other health conditions you have.

Prehabilitation can help in lots of ways. For example, it might mean:

- a shorter stay in hospital
- fewer side effects of treatment
- faster recovery
- fewer complications after treatment
- better overall physical and mental wellbeing.



About treatment

Your doctors can give guidance on how to get you into the best condition for treatment. This might include putting together a personalised prehabilitation care plan (PPCP) to suit your needs.

Where will I be treated?

Children and young people with cancer are treated in Principal Treatment Centres (PTCs) or Teenage and Young Adult (TYA) designated hospitals. In some cases, there is the option of having a combination of these, known as a 'joint' or 'shared care' arrangement (page 55).

Your medical team will talk to you about your options. Together, you decide the best place to have your treatment.

Principal Treatment Centres (PTCs)

PTCs are hospitals that have specialist facilities for diagnosing and treating children and young people with lymphoma. Most PTCs in the UK are within large teaching hospitals. There are fewer PTCs than regular hospitals so you might need to have your treatment away from where you live.

Children's Cancer and Leukaemia Group (CCLG) lists PTCs in the UK on their website: [cclg.org.uk/In-hospital/Specialist-hospitals](https://www.cclg.org.uk/In-hospital/Specialist-hospitals)



Teenagers and Young Adult designated hospitals (TYAs)

Some hospitals have cancer units designed specifically for teenagers and young adults (TYA) within their adult services. This means that you can spend time with, and get support from, other young people. You might have a TYA that is closer to you than your nearest PTC.



I was treated in a TYA ward as the medical team thought I'd benefit from being with other people my age. It was really helpful to talk to others who had already had six rounds of chemotherapy; they helped prepare me for what to expect.

Georgia M, diagnosed at 24



Joint or shared care

If you are under 19 years old, it might be possible for you to have a 'joint' or 'shared' care arrangement. This means that your care and treatment is split between two places (the PTC and the designated hospital). You can then have some of your appointments, for example blood tests, closer to home. With this arrangement, the local hospital is called a Paediatric Oncology Shared Care Unit (POSCU).

About
treatment

If you are 16 to 18 years old, you are treated at the PTC on the TYA unit. However, you might be able to have supportive care (such as blood tests) locally at designated hospitals.



I was treated mainly in children's wards. The hospital environment can seem mundane or like no one understands, so it helps to meet and connect with people in similar situations. This may be through hospital directly, like a support group or social event on a teenage cancer ward, or through a different organisation, like Lymphoma Action.



Ellie, diagnosed at 15

Young adults aged 19 to 24

If you are a young adult, you can choose whether you would like to be treated in a:

- TYA unit or an adult ward at a PTC.
- Teenage and young adult-friendly part of an adult ward at your local TYA designated hospital – these are often private rooms or shared with other TYA patients only. You have access to facilities like games consoles.
- Joint care arrangement, with some parts of your treatment at your PTC and others at your TYA designated hospital.

Talk to your medical team about your options. You might want to think about how much time they expect you will spend in hospital and how close each available option is to your home.

“

I was given the option of moving to a hospital with a Principal Treatment Centre for teenagers and young adults. However, I decided to stay at the hospital I was diagnosed in for two reasons. Firstly, and most importantly, I felt confident in my doctor, but also it was far easier for me to get to. I was the youngest on the ward by far, but I really appreciated the banter and support from everyone.

Natalia,
diagnosed
at 20



“

I chose TYA for my treatment because I felt more comfortable being around young people of a similar age to me and I liked how colourful and welcoming the floor was. I saw young people sitting with their parents and friends during infusions or doing some art activities.

Mila, diagnosed at 19

Do I have to stay in hospital?

Generally, you won't need to stay in hospital overnight, although it depends on the treatment you have and on how far away from your home you're being treated.

About
treatment

Ask how long you'll be at the hospital for each time you have to go in. You can usually take someone with you for support and company.

If you're having chemo, you might have the option of having treatment at home – this is called 'ambulatory **chemotherapy**'. You go to the hospital each day for check-ups and to have your treatment set up in a special pump. You wear the pump in a backpack or bumbag so that you can have the treatment at home but you can contact the hospital at any time if you have any problems. Whether you can have ambulatory chemo depends on if it's suitable for the specific type of treatment you need, and on whether your hospital is able to offer it.



Think about what you might like to bring for something to do – ask if you can use your

phone or
tablet.

When might I need to stay in hospital overnight?

You might have to have some of your treatment as an inpatient, which means you need to stay in hospital overnight. You might also have to stay in hospital if you have any serious side effects or develop an infection. If you are under 19 and you're being treated in a TYA unit at a PTC, someone can usually stay with you overnight if you want them to.

When you are an inpatient, it doesn't mean you have to stay in bed all the time; it just means that your treatment continues for several days so you need to stay in hospital to have it. Ask what facilities are available at your hospital, like common rooms, games rooms or a kitchen. You should be able to have a look round before you go into hospital.

Questions you might like to ask about hospital:

Where am I being treated?

What should I take with me to hospital?

Is there WiFi? Can I use my phone/tablet/laptop?

Is there a TV?

Is there a games room or common room?

Is there a fridge or a kitchen where I can make a snack?

Can someone stay with me?

When can my friends and family visit me?

Is there anywhere my friends and family can stay?



Top tips for staying in hospital

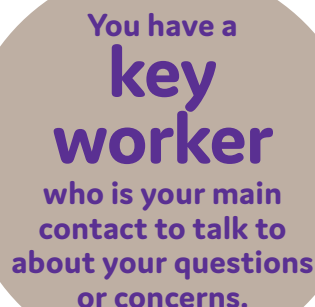
- Ask if you can visit the unit beforehand so that you can familiarise yourself with it before your stay.
- Think about ways you can keep updated with what's going on at school, college or work.
- Bring things from home to make your space friendly and comfortable, like photos and bedding.
- Get dressed whenever you can.
- Find out when visiting hours are so that friends and family can spend time with you.
- Bring something to stop you from getting bored, such as books, music, magazines, your phone/tablet. You could also download your phone or tablet with apps, music and films.
- Find out how things are arranged at the hospital where you'll be treated and what facilities there are.



Who looks after me during my treatment?

You see lots of different health professionals during your treatment. They all have different roles in your care. This is called a 'multidisciplinary team' (MDT). The hospital should also keep your GP informed about your treatment.

You have a 'key worker' who is your main contact to talk to about any questions or concerns. Your key worker is often a clinical nurse specialist (CNS), or sometimes a teenage and young adult (TYA) nurse specialist.



You have a
**key
worker**
who is your main
contact to talk to
about your questions
or concerns.

Who is my doctor?

You have a consultant or specialist who takes the lead in planning your treatment, checking your progress, and offering you follow-up appointments after your finish your treatment. This is often a haematologist (specialist in blood conditions) or an oncologist (specialist in cancer).

Who else is involved in my care?

You might also meet a:

- **counsellor or psychologist**, who can help you with your feelings about your diagnosis and treatment.
- **dietitian**, who gives advice about eating and drinking during your treatment
- **occupational therapist**, who can organise equipment to help with day-to-day things like showering and getting from one place to another
- **physiotherapist**, who helps you to keep fit and active, sometimes to help prepare you for treatment

- **radiographer**, who carries out X-rays and scans
- **research nurse**, who supports you in taking part in a clinical trial, if you participate in one
- **social worker**, who can help to address social, emotional and practical needs, for example, to do with money and education or work
- **young people's community worker**, who can help you to build connections in the community, helping you with social, educational and employment issues

“

My social worker was a great support. I met with her every few weeks and she was someone out of my social circle that I could talk to about lots of different things. She also helped me to write a series of letters to my GP to help me express my feelings.



Maddie, diagnosed at 16

There might be other people involved in your care too. There's space on page 3 to note down any names and important contact details. Ask as many questions as you would like to. You could also ask for information to be repeated if this is helpful.

Top tips for asking questions

- If you have a question, don't hesitate to ask it. Even if you think it's silly, ask it anyway. The doctors and nurses have heard it all before and it's important that you understand what is happening.
- If you don't know exactly what your question is but you feel generally unsure about something, talk to your medical team about this too.
- Write your questions down to help you remember them.
- Write down answers or ask someone to take notes for you.
- If you don't understand the answer, ask your medical team to explain it in a different way.
- If you forget the answer, don't be embarrassed to ask your question again – there can be lots to remember and take in.



You might want to look at our suggested questions – search 'questions to ask your medical team' on our website.



You could use this space to note down any questions you want to remember to ask your doctor.



Clinical trials

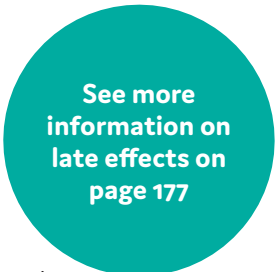
Doctors are always trying to improve treatments for lymphoma in young people.

A clinical trial is experimental in some way. It can test new drugs or new ways of giving tried-and-tested drugs.

Sometimes, a trial compares a new treatment to the best current treatment (sometimes called the 'gold standard'). Sometimes, a trial compares current treatments to each other.

Clinical trials are very important for lots of reasons. They can:

- test whether less intensive treatment can reduce side effects, especially **late effects**
- test how well existing treatments work, if it is unclear
- find ways to work out which people might need more intensive or different treatments
- test whether newer treatments could be safer and more effective than the current best treatments.



See more information on late effects on page 177

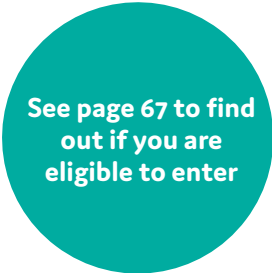
Clinical trials are designed to be safe and fair.

If you take part in a trial, doctors will keep careful checks on you at every stage of treatment and during follow-up. You should also be given an opportunity to ask any questions you might have at any time.

Will I be offered a clinical trial?

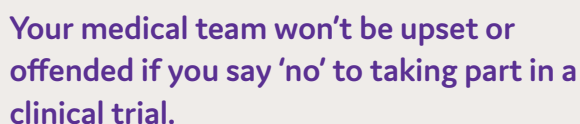
Your doctor will make their treatment recommendations for you based on your individual situation. You'll be offered treatment either:

- according to the national guidelines, or
- as part of a clinical trial, if there is one available for your type of lymphoma and you are eligible to enter.



See page 67 to find out if you are eligible to enter

If your doctor suggests a trial, they should give you information about it. You should have time to think about it and then to ask any questions you might have. There are lots of people you could talk your decision through with – a research nurse, friends, family or your GP.



Your medical team won't be upset or offended if you say 'no' to taking part in a clinical trial.



What happens if I say 'no' to a clinical trial?

It is your decision whether you take part in a trial. You should only take part if you want to. Your medical team won't be upset or offended if you say 'no'.

If you decide not to take part, or if you decide to take part and then change your mind, you will get the best available standard treatment. In many cases, this is very similar to the treatment in trial.

How do doctors decide which treatment I get?

Clinical trials usually compare two or more treatments. The treatment you get is often allocated by a computer ('randomised'), so neither you or your doctor can decide which one you have.

Usually, you're told which treatment you are having and given information about it. Sometimes the trial is 'blinded', which means you don't know exactly what treatment you are having. This is because your expectations about a treatment could influence the results of the trial without you meaning them to. If your trial is blinded, you are given information about the different treatments you might be on.

What if there's not a trial for me?

Clinical trials have 'eligibility criteria' that people taking part have to meet. This is an important part of making the trial safe and fair. Although it might feel disappointing if there isn't a trial for you, you'll still get the best available treatment.

Not all hospitals run clinical trials. If your hospital isn't running a trial that's suitable for you, you might be able to be referred to a hospital that is.

Find out more about clinical trials at lymphoma-action.org.uk/about-clinical-trials



About
treatment

Treatments for lymphoma

Your treatment is planned for you as an individual. Your medical team takes lots of factors into account, including the type and stage of your lymphoma, your age and general health.

As a general guide:

- most people have chemotherapy
- some people might also have radiotherapy (for example, some people with Hodgkin lymphoma)
- some people with non-Hodgkin lymphoma (NHL) have antibody therapy (a type of targeted treatment) as well as chemotherapy.

Less commonly in young people, doctors might recommend active monitoring, or 'watch and wait'. This is where you have regular appointments to check on your lymphoma and monitor your health to see how the lymphoma is affecting you. You don't start treatment unless the lymphoma begins to cause significant health problems.



Search
**'active
monitoring'**
on our website to
find out more.

You might want to read only the sections about the types of treatment you are having.

Chemotherapy (chemo)

Chemotherapy is treatment with drugs that are designed to destroy cancer **cells**. The drugs work on cells that are in the process of dividing and they don't have much effect on cells that are not dividing. Chemotherapy works in one or both of the following ways:

- stopping lymphoma cells from dividing so that they die off
- triggering lymphoma cells to die.

Search 'how chemo works' on our website to watch an animation explaining how this type of treatment works.



Why do I have more than one chemotherapy drug?

You usually have more than one chemo drug, given together in a **regimen**. Each drug destroys cancer in a slightly different way. Having several together helps destroy as many cancer cells as possible in one go.

Regimens are often known by abbreviations of the names of drugs they include. Each letter stands for the name of one of the drugs. Examples include ABVD, ESHAP, R-CHOP, OEPA, COPDAC, CODOX-M or DA-EPOCH.

“

After the diagnosis I was referred for 6 rounds of chemotherapy. It was tough but with the support of my team and my family I managed to get through it.

Tiff, diagnosed at 24

“

I met my consultant for the results of my PET scan. He told me I had stage 3 Hodgkin lymphoma. When he told me about the success rate of the chemotherapy treatment I would have, I felt positive.

Katie, diagnosed at 22



You'll probably have a type of **steroid** called a 'corticosteroid' as part of your chemo regimen too. Steroids help to reduce the size of lymphoma and can help with some of the side effects of chemo.

Search 'regimens' on our website to find out more about chemotherapy regimens.



What are chemo cycles?

A cycle is a block of treatment that is given over a number of days. You then have a break – usually a few weeks without treatment. This is to let your body recover because chemo destroys healthy cells that are dividing quickly (such as your hair cells) as well as lymphoma cells.

Each cycle is usually 2 to 3 weeks long. A whole course of treatment is made up of a number of cycles.

Your medical team check how well your body is coping throughout your treatment. If your body needs more time to recover, the next cycle of chemo might need to be delayed for a short while until it is safe for you to have more.

“

I had chemo from November through until May. I felt OK during treatment but very tired a few months later. I also experienced hypomania with my steroids, which meant that I felt euphoric and full of energy, which really took its toll on me once it wore off.



Maddie, diagnosed at 16

The length of your whole course of chemo depends on what treatment you're having, how many cycles you need and how your body responds to it. It can take anything from a few weeks to 2 years to complete. Your medical team should tell you how long they expect it to take but it might be longer if any of your cycles need to be delayed for a little while.

“

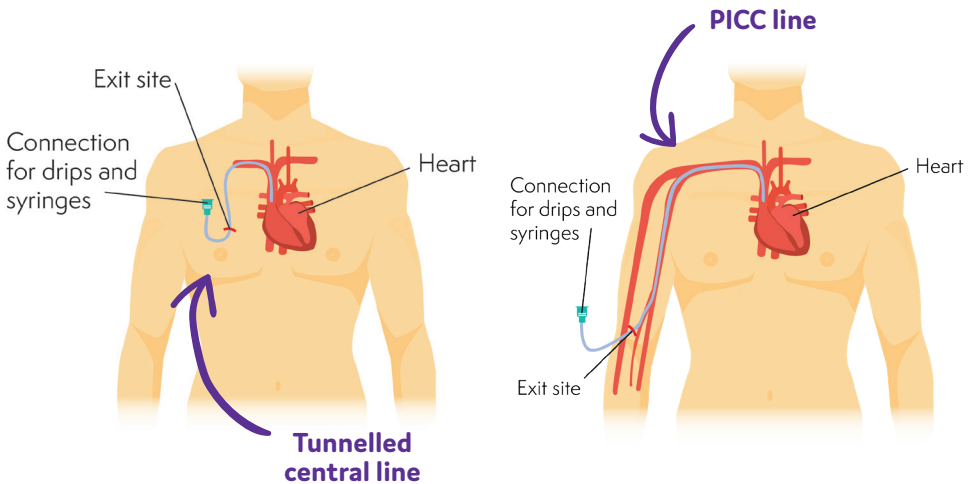
I was scared. I didn't know how I'd respond to treatment or what the future would hold. Support staff in the hospital gave me activities to distract me during my chemo, until I was ready to talk about my feelings. Occupational therapists also helped me to start doing some of the activities I'd enjoyed before I was diagnosed. I started to feel more like myself and enjoyed my days again.

Mila, diagnosed at 19

Treatments for
lymphoma

How do I have chemo?

In most cases, chemotherapy is given through a drip into a vein (intravenously, or by 'IV'), although you might have some drugs by mouth (orally), usually as tablets. You might have a **central line** fitted, so you don't need to have a needle put into your vein every time you need treatment.



A central line is a thin, soft tube that stays in your vein throughout your treatment. The line is inserted either through a vein in your arm or your chest. It is called a 'central' line because the end of the tube goes into a central vein just above your heart.

You can have lots of different types of treatment through a central line. You can also have blood taken through it. You don't have to have a central line if you don't want to.

You have a small operation under general or local **anaesthetic** to put a line in. The line shouldn't hurt once it is in place. Your medical team will show you how to look after the line.

When you finish your treatment, you have a small operation to have your central line taken out.

Some people also have chemo given into their **cerebrospinal fluid (CSF)** so that the chemo reaches their brain and spinal cord (**central nervous system**). This is called intrathecal chemotherapy. It is given during a lumbar puncture (page 34).

“

I had a PICC line inserted to save a cannula being inserted each day of chemo. The nurses could also take blood from my PICC line.

Katie, diagnosed at 22

Search 'intravenous chemotherapy' at cancerresearchuk.org for more about the different ways of having drugs intravenously.



Different types of lines

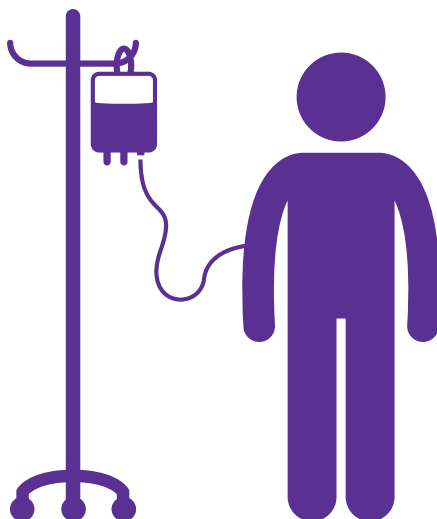
Different types of lines have different advantages and disadvantages. Your medical team will decide which type is best for you.

Central lines like a Hickman® or Groshong® line go into your chest. The end of the line that's outside your body splits into smaller tubes (lumens) that can connect to drips or syringes.

A **PICC line** goes into a vein in your arm. The end of the line outside your body also ends in smaller tubes (lumens). This is easier to fit than a Hickman® line or a portacath. It is usually used for short-term treatment or until you have one of the longer-lasting lines fitted, if you need one.

A **portacath** or 'port' is a line that ends in a reservoir or chamber (port) just under the skin on your chest. The port is a small disc that goes just under the skin. A special needle goes through your skin into the port each time you have treatment.

You'll be given clear guidance on how to look after your line. Make sure you know who to call if you have any problems with it. You can note down any important contact details on page 3 of this book.



Top tips for lines



- Ask what signs of infection to look for and who to contact if you notice any.
- If you have any type of line other than a portacath, it's important not to get your line wet. Your nurse should give you information about how to protect your line when you shower.
- Your nurse should 'flush' your line to keep it clean. This means injecting fluids through it every week (or every 4 weeks if you have a portacath) and every time it's used. Ask your nurse if you think this is due.
- Keep your arm active to avoid the risk of clots.
- Recognise how much of the line is hanging out of your arm. If it gets longer, it may mean the line is no longer in the correct place. If this happens, it is important to contact your medical team.
- Don't let the tips of your line rest in water. You could use a special cuff (available on prescription) to cover the line if taking a shower or bath.
- Keep your line covered to avoid it becoming dislodged. If it does get dislodged, tell your medical team immediately so that they can push it back in or replace it.

What side effects from chemo might I have?

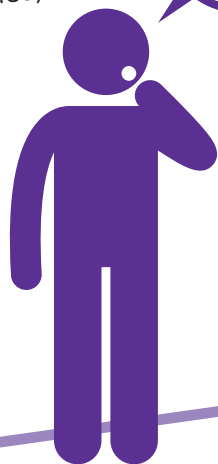
Chemo works by destroying cells that are dividing.

Unfortunately, this means it affects healthy cells that are in the process of dividing too – especially those that divide rapidly, like blood cells, hair cells and the cells that line your gut. The damage to healthy cells causes many of the unwanted side effects of chemo.

Most people treated with chemo get some of the side effects listed below during their treatment. However, you might get different side effects, or none at all – ask your medical team what to expect.

Common side effects of chemotherapy include:

- extreme tiredness (fatigue)
- feeling or being sick (this is often well controlled with anti-sickness medicines)
- hair loss
- low **blood counts: neutropenia, anaemia and thrombocytopenia**
- sore mouth and throat
- weight loss or weight gain
- constipation or diarrhoea
- peripheral neuropathy (nerve damage, often noticeable as tingling in your hands and feet).



Your medical team should give you information about any side effects specific to the drugs in your chemo. They should also tell you about any possible **late effects** – side effects that can develop months or years after your treatment.

For info on side effects and coping with them, see page 92

Radiotherapy

Some young people with Hodgkin lymphoma have radiotherapy. Radiotherapy is rarely used for non-Hodgkin lymphoma.

How does radiotherapy work?

Radiotherapy uses powerful X-rays directed at the lymphoma cells to destroy them. The type of radiotherapy used in lymphoma treatment doesn't make you radioactive so won't harm anyone else by being close to them after your treatment.

Your treatment is planned so that you have the lowest possible dose of X-rays. This helps to reduce the chances of long-term side effects and late effects.

How long does radiotherapy take?

Usually, you have radiotherapy Monday to Friday for a few days or weeks. The treatment itself only lasts a few minutes but it can take a while to position the X-ray beam so it hits all the lymphoma cells but as few of your healthy cells as possible.

You have tiny permanent ink marks or tattoos on your skin to make sure the **same area** is treated every time.

You have to keep very still during the treatment.

Treatments for lymphoma

“

I found the five sessions of radiotherapy went OK; they involved a fair amount of waiting around, and then me lying down while a large machine zapped me through a hole in the plate that was made for me.

Dwayne, diagnosed at 25

What side effects from radiotherapy might I have?

Many people treated with radiotherapy have sore skin in the area of their body treated. Other side effects depend on where the radiotherapy goes to. For example, if you have radiotherapy to your head, neck or upper chest you might have a sore mouth or throat. Your medical team should tell you what side effects to expect from your treatment.

See page 92 for more on side effects



Targeted drugs

Targeted drugs are treatments that work on certain cells without affecting others.

They do this by targeting specific **proteins** that lymphoma cells have, but that most healthy cells don't have.

Lots of targeted drugs are used to treat lymphoma and many more are being developed. They're often used to treat adults, but some might be used for under 18s.

See page 65 for more on clinical trials

If you're under 18, you might have a targeted drug as part of a clinical trial (see page 65).

The most common targeted drugs for lymphoma include:

- **Rituximab** – an **antibody** therapy that sticks to B cells and acts like a flag to attract other immune cells. This helps your **immune system** fight the lymphoma. Rituximab is used with **chemo** to treat some types of B-cell lymphoma, including Burkitt lymphoma, diffuse large B-cell lymphoma (DLBCL) and rare forms of B-cell Hodgkin lymphoma.
- **Brentuximab vedotin** – an antibody joined to a chemo drug. This takes the drug directly to lymphoma cells. Brentuximab vedotin is sometimes used to treat adults with Hodgkin lymphoma or anaplastic large cell lymphoma that didn't respond (**refractory**) or came back (**relapsed**) after initial treatment.
- **Nivolumab or pembrolizumab** – drugs that block the proteins lymphoma cells use to turn off your immune cells. Nivolumab or pembrolizumab are sometimes used to treat adults with Hodgkin lymphoma that didn't respond (refractory) or came back (relapsed) after other treatments.
- **CAR T-cell therapy** – treatment where your own T cells are genetically modified in a lab to recognise and kill lymphoma cells. CAR T-cell therapy is sometimes used to treat people over 18 who have DLBCL or primary mediastinal B-cell lymphoma (PMBL) that didn't respond (refractory) or came back (relapsed) after other treatments. It's only available in a few hospitals in the UK.



Search 'targeted treatments' on our website for more information.



Treatments for
lymphoma

Treatment during pregnancy



Generally, you're advised not to start a pregnancy if you are having or will soon start treatment for lymphoma.

This applies to males as well as females. Some treatments could carry a risk of abnormalities or serious harm to your unborn baby. Less is known about the effects of antibody therapy and targeted drugs on an unborn baby. Your medical team might advise you against having this type of treatment if you are pregnant.

Waiting for a while after treatment before beginning a pregnancy also allows your body time to recover from treatment.

If you're already pregnant when you are diagnosed, your medical team will take this into account when planning your treatment. Depending on the stage of your pregnancy, your medical team might advise you to delay treatment until after your baby is born.

If you need treatment straightaway, or you are in the first trimester of your pregnancy (when risks to your baby could be higher), your medical team might be able to make some changes to your treatment plan. They will discuss the risks and benefits of different treatment options with you.

In some cases, your medical team might suggest that you do not continue with your pregnancy. This can be extremely difficult to deal with. There is support available, for example counselling, support groups and online forums. Ask your medical team to signpost you.

Pregnancy Choices Directory offer a range of support services, including counselling centres across the UK at pregnancychoicesdirectory.com



How do I know my treatment has worked?

You have tests at the end of treatment to see whether your lymphoma is in **remission**. Most people have scans during treatment to see how their lymphoma is responding. You usually also have a scan after your planned course of treatment is finished. Your doctor plans any follow-up scans you need.

Most young people are in remission at the end of treatment.

You can find out more about what happens if your first treatment wasn't successful or your lymphoma has come back (relapsed) on page 85.

Treatment and care to help you live well

Treatment and care to help improve your quality of life is known as 'palliative care'.

A common belief is that palliative care applies only to people who are nearing the end of life. **In reality, it can be used alongside active treatment for lymphoma and your medical team can offer it to you from the point of diagnosis, throughout treatment and during follow-up.** The purpose of it is to help you to live well, with and beyond lymphoma.

Your medical team should help you to address any needs you have. For example:

- **physical wellbeing needs** might include managing side effects of chemo
- **practical support needs** might include helping you to access financial support
- **psychological wellbeing needs** might include supporting your emotional wellbeing by helping you to make sense of what's happening or offering a complementary therapy.

See page 83
for more on
complementary
therapy



You might also hear about 'enhanced supportive care'. This focuses on preventing and managing the physical and psychological effects of cancer and its treatment. In many parts of the UK, palliative care specialists are involved in the delivery of enhanced supportive care. This can be offered to people who are having active treatment to put their lymphoma into remission.

Search 'enhanced supportive care' on our website to listen to a podcast with Palliative Care Consultant, Dr Dan Monnery.

Complementary therapy

Complementary therapies can improve your overall wellbeing. They are sometimes used alongside palliative care and supportive care. Some research suggests that they might help to:

- control symptoms such as feeling sick (nausea), pain and extreme tiredness (fatigue)
- lessen feelings of anxiety and improve your overall wellbeing.

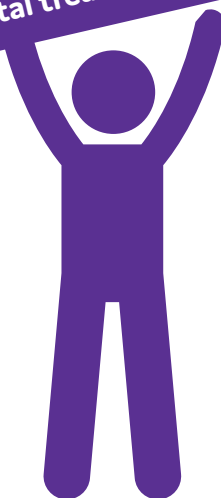
Examples of complementary therapies include massage, acupuncture, aromatherapy, art therapy, reflexology and meditation. Before having any type of complementary therapy, speak to your medical team to check it is safe for you.

If you're interested in trying a complementary therapy, your key worker is a good person to ask about local services available to you. You might be able to get some types of complementary therapy free of charge at your hospital. You might also be able to access them through cancer support centres, hospices and charities.

'Alternative' therapies are not the same as 'complementary' therapies. Examples of alternative therapies include dietary supplements, herbal remedies and homeopathy. Alternative therapies are used instead of mainstream hospital treatments. There is no evidence that they are effective at treating lymphoma. Be wary of any claims that they can cure cancer.



Speak to your doctor if you are considering any alternative therapies; some can interfere with hospital treatment.



If my treatment doesn't work or my lymphoma comes back

Most people go into **remission** and stay in remission after their first treatment – so you might want to skip this section if it doesn't apply to you. For some people, the first treatment isn't enough to put their lymphoma into remission. If your lymphoma doesn't seem to respond to treatment, it is called **refractory** lymphoma, and you will probably need a stronger treatment.

“

The PET scan results after the first two cycles showed that my chest was still affected by Hodgkin lymphoma. I needed to change to a more toxic chemotherapy.

Natalia, diagnosed at 20



Treatments for
lymphoma

If lymphoma comes back (relapses)

Most people stay in remission once they are in remission. However, sometimes lymphoma comes back. This is called **relapse**. If your lymphoma relapses, you need different treatment.

Can I have more treatment?

Most young people can have more treatment if they need it. You might have:

- a different, probably stronger, chemo regimen
- high-dose treatment and a **stem cell** transplant
- a targeted drug (page 78), usually through a clinical trial
- CAR T-cell therapy (page 79), usually through a clinical trial.

High-dose treatment and stem cell transplants

Your body replaces your blood cells when they naturally get worn out and die – this is an ongoing process.

New blood cells are made from stem cells, which live in your **bone marrow** (spongy tissue inside your bones). A stem cell is an undeveloped blood cell that can grow into all the different types of blood cell your body needs.

What's a stem cell transplant?

Some people need high-dose therapy to treat their lymphoma. This is usually **chemo**, but occasionally you might have radiotherapy as well.

High-dose therapy is more likely to destroy lymphoma cells than standard treatment, but it also damages healthy stem cells. When this happens, your body can't make the blood cells it needs. A stem cell transplant gives you healthy stem cells after your high-dose treatment so that you can start to make new blood cells again.



A stem cell
transplant gives you
**healthy
stem cells**
after your high-dose
treatment so that you
can start to make new
blood cells again.

Will I have a stem cell transplant?

Most people with lymphoma do not need a stem cell transplant. You might need one if you still have lymphoma after chemo, or if your lymphoma comes back after treatment. Your medical team will talk to you about having a stem cell transplant if they think you need one.

Most people with lymphoma who need a stem cell transplant have one that uses their own stem cells. This is called an autologous stem cell transplant.

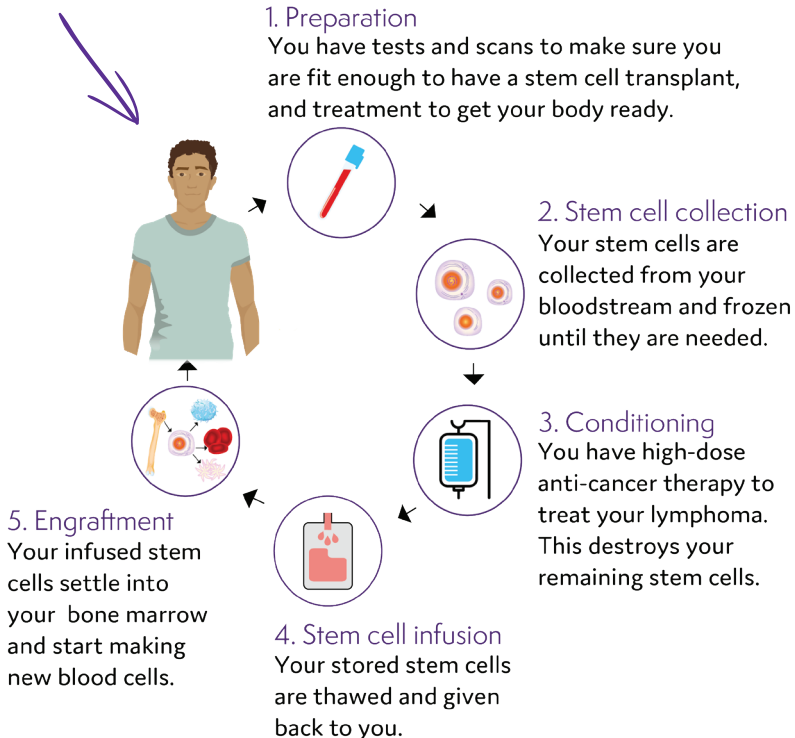
Very rarely, people with lymphoma might need an allogeneic stem cell transplant, which uses donor stem cells instead of your own stem cells.

How does it work?

You have treatment to help your body make stem cells and move them into your bloodstream. The cells are collected from your blood. They are frozen and stored until they are needed. You then have your high-dose treatment.

After your high-dose treatment, the stem cells are put back into your bloodstream through a drip (infusion). They find their way back to your bone marrow where they can start making new blood cells.

The autologous stem cell transplant process



How are stem cells collected from the blood?

You have a drug called granulocyte-colony stimulating factor (G-CSF). This encourages your stem cells to move out of your bone marrow and into your blood. When you have enough stem cells in your blood, you go into hospital to have your stem cells collected. It takes a few hours to collect the cells.

You have blood taken from a vein, usually in your arm. The blood passes through a machine that separates and collects the stem cells and returns the rest of the blood to your body. If there aren't enough stem cells, you might have to have more treatment and go back to hospital for a few days in a row for more collections.

What happens next?

The next step is the high-dose treatment, which aims to kill any lymphoma cells left after your previous treatment.

After treatment, the stem cells are given back to you, usually through your central line. You can expect to stay in hospital for at least 3 weeks after having the stem cells.

Depending on your hospital's policy, you might have to stay in an isolation room. This is to protect you from infections until the treatment is over and your bone marrow is working properly again. During this time some of your family and friends can come to see you.



The collected stem cells are
frozen and stored.

Very rarely, people with lymphoma might need an allogeneic stem cell transplant, which uses donor stem cells instead of your own stem cells.

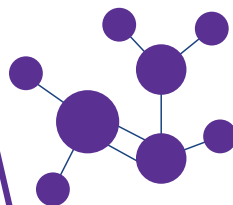
Learn more about stem cell transplants at lymphoma-action.org.uk/SCT or visit lymphoma-action.org.uk/Books to download our book on autologous stem cell transplants.



Newer drugs and clinical trials

If your lymphoma has come back (relapsed) or didn't respond to the treatment you've been given (refractory), you might be offered a new drug as part of a clinical trial.

There are lots of new drugs in development for lymphoma. Many of these are 'targeted therapies' (page 78). Most are only available in clinical trials at the time of writing.



Read about clinical trials on page 65



Wellbeing check-in



You might feel relieved to have a treatment plan, but the thought of treatment can still be daunting.

You might also feel OK about it at first and then more nervous as the date of your first treatment session gets nearer. Or you might feel overwhelmed at first, but then feel more settled as times goes on.

There can be a lot of information to get your head around. Also, going for treatment can be tiring. Think about what might help you to prepare mentally for treatment – for example, breathing exercises (page 125) or giving yourself mini markers or ‘checkpoints’, like something to look forward to after your first round of treatment.

Everyone's experience is different, however you might want to read about others' experiences of treatment through the personal stories on our website at lymphoma-action.org.uk/stories or ask our Helpline Team if they can put you in touch with someone else who's experienced treatment through our Buddy Service.

If you're over 18, find peer support through Teenage Cancer Trust's digital support programme. Search 'peer support' at www.teenagecancertrust.org

Side effects of treatment



Treatment can damage healthy cells as well as destroying lymphoma cells, causing unwanted side effects.

These are usually temporary and get better once you finish treatment. Each treatment has its own set of possible side effects. However, even with the same treatment, different people can react differently to the same treatment.

Macmillan Cancer Support has an online search tool that tells you about different treatments and their possible side effects. Search 'treatments and drugs' at macmillan.org.uk



This section outlines the most common side effects of treatment and gives tips to help you cope with them. You might want to read about these now, to help prepare yourself, or you might want to wait and see how your treatment affects you.

Ask your medical team what side effects you're likely to experience. They are experienced in helping people with all sorts of side effects.

Health problems known as 'late effects' (see page 177) can develop months or years after treatment.

Hair loss

Many people treated for cancer worry about losing their hair. While some treatments can cause hair loss, this doesn't always happen.

For many people, hair is part of their identity. Even if you're told that your hair will grow back, hair loss can be very difficult to cope with. You might be worried about how you'll look and what people will think.



“

I went through 6 rounds of chemotherapy. I lost my hair after the second session, which I found really tough. It came out in clumps so I decided to shave it off to save me from getting upset time and time again. Losing my hair really did affect my self-esteem and it still does to this day, which is about 7 months post-treatment. I still wear bandanas while my hair is slowly growing back.



Tiff, diagnosed at 24

Side effects of
treatment

“

As a 20 year-old girl, the last thing I wanted to hear was 'you will lose your hair'. Even though it was the most heartbreaking experience, as that's when it hit me that it was all real, I started buying different wigs and playing around with them. I went to the hairdresser to pick up my real hair wig from the little princess trust and I didn't wear it for a few months as I didn't know how to really wear it. However, when I put it on and started wearing it I felt like me again.

Harriet, diagnosed at 20

Will I lose my hair?

Most young people who have chemo lose their hair, but not everyone does. You are likely to lose all the hair on your head including facial hair, but you might only lose some of it. It might become thinner, dry or curly. Rarely, it might become slightly yellow in colour. Hair elsewhere on your body could fall out too.

With **radiotherapy**, hair is only affected on the part of your body treated.

Targeted treatments are less likely to cause hair loss. However, some might cause changes to the hair on your head – for example, it might become thinner, dry, curly or go a yellowish colour. You might also experience changes to the growth of hair on your face (including to your eyelashes and eyebrows) – it might grow more quickly and thickly, or the rate of growth might slow down.

When does hair start to fall out?

Most people start losing hair a couple of weeks after starting chemo. With radiotherapy, hair loss tends to happen gradually, towards the end of treatment.



The hardest part of life after treatment was showing people my hair. I wore a hat for the whole time, and wouldn't let anyone see me without it. Even when my hair started growing back, I refused to take it off. I was so sure that everyone would make fun of me or think I looked ugly. However, when I finally took it off, no one said anything at all. I realised it wasn't as big a deal as I'd thought. My friends still wanted to hang out with me – all that worrying was for nothing.


Georgia M, diagnosed at 24

When will it grow back?

Your hair will usually start growing back when you've finished treatment, although it might take between a few months to a year to fully recover. Your hair might not be the same as before – it could grow back thicker, straighter, curlier or even a slightly different colour. For most people, changes are for just a short while. If they are longer-lasting, you might be offered a referral to a dermatologist (doctor who specialises in problems related to the skin, hair and nails). They can help you to manage it.

What can I do about hair loss?

Some people try out shorter hairstyles to get used to having less hair before it starts to fall out.



See page 98 for more tips on looking after your head



Side effects of treatment

Ask your hospital if the NHS or a charity can help you with funding for a wig.

You might want to embrace your hair loss. Just remember to keep your head warm in winter and to protect your scalp from the sun in summer by wearing a hat.



You can also consider accessories. There are lots you could try out to see what looks and feels best for you:

- try a wig, headscarf, turban or bandana
- experiment with different styles of hats.

Search 'tie a headscarf' on our website for a video demonstration of three different ways to tie a headscarf.



Can I dye my hair?

If you want to dye your hair, wait until it has grown back all over your head. 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 vegetable-based hair dye that you wash out is suitable for you.

Natural, temporary hair dyes

might be better than permanent chemical products. Check with your clinical nurse specialist.



I found the prospect of losing my hair quite upsetting but I decided to take back some power by shaving my hair into a buzz cut before it fell out and donating it to a charity. This made me feel good because I could be helping someone else. I had a wig fitted and styled which I really love wearing. It helps me at times when I want to fit in and when I miss having my long hair. I chose to have it in a different colour to my natural hair because before diagnosis I liked changing my hairstyle and colour as things changed in my life. I chose my new wig colour to signify this new stage in my life. I was given advice about how to look after my bald scalp. I like wearing bandanas or beanie hats to keep my head warm.



Mila, diagnosed at 19

Side effects of treatment

Top tips for looking after your head

- **If you want to shave your head before chemo, do it before you start treatment. Avoid shaving your head during chemo as small cuts could get infected.**
- **Be gentle with your hair before it falls out and when it's growing back – don't use heated styling tools like hairdryers or straighteners.**
- **Let your hairdresser know that you have had treatment for lymphoma, so that they can take any necessary safety precautions when styling your hair.**
- **Use soft hairbrushes or wide-toothed combs and gentle products, like baby shampoo.**
- **Moisturise your scalp using gentle, unperfumed products.**
- **Protect your head from the sun, wind and cold. Cover it with a hat or turban, or wear a high factor sunscreen (SPF 50).**

Fatigue



Fatigue is extreme tiredness. It can affect how you feel emotionally, as well as your physical energy levels.

Most people with lymphoma feel fatigue at some point. You might feel drained and unable to carry on with your day-to-day tasks. Fatigue can happen because of your lymphoma, the treatment, or both, particularly if you have side effects like **anaemia** (shortage of red blood **cells**). The emotional impact of lymphoma can add to exhaustion. You are likely to have good days and more challenging days during treatment.

Keep a diary to see if you can see a pattern.

Plan to do things on days when you think you are likely to have more energy. You might find it helpful to use a fatigue diary to help with this – search ‘fatigue diary’ on our website for a downloadable resource. You can also search online for free fatigue management apps.

Fatigue can be difficult to understand if you’ve never experienced it. Some people feel that others might not appreciate quite how exhausted they are. This can be frustrating if friends and family seem not to understand how you feel. You could compare your energy levels to a bank with a fixed amount of money to spend, or a car with a limited amount of fuel to use.

Side effects of
treatment

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I found the fatigue from my chemotherapy to be cumulative; the more infusions I had the more exhausted and washed out I felt. The physio emphasised the importance of trying to stay active to combat fatigue. This felt counterintuitive as the fatigue made me feel capable of doing very little. I found, however, that when I managed to go for a short walk or do some stretches (even in bed), I felt more energised for the rest of the day. Going outside for fresh air also really helped me feel more relaxed.



Mila, diagnosed at 19

Search 'spoon theory' at butyoudontlooksick.com to read Christine Miserandino's experience of illness-related fatigue and how she explained it to friends and family.



Top tips for coping with fatigue

- **Pace yourself – be active when you can and use your energy for the things that are most important to you.**
- **Build rests into your day-to-day life – although you might want to ‘keep going’, this can make you feel more tired later.**
- **Get some regular, light exercise – just going for a short walk can help.**
- **Relax when you can – listen to music, take a bath or try meditation techniques like mindfulness.**
- **Follow a healthy lifestyle – this includes eating well, managing stress and getting enough good quality sleep.**
- **Ask your clinical nurse specialist if they can offer a referral to an occupational therapist for tailored guidance to help manage your fatigue.**



Download the Untire app for tips on reducing fatigue and exercises to help improve your energy levels.



Low blood counts

Treatment can affect the numbers of blood cells you have (your '**blood counts**'). This can happen with chemo, which destroys healthy blood cells as well as lymphoma cells. It can also happen with some targeted drugs, and with radiotherapy focused on large bones (as these contain **bone marrow**).

Follow any advice from your medical team carefully if you have low blood counts. There is more about reducing the risk of infection in the next section.

Your doctors keep careful checks on your blood counts so that they can make changes to your treatment as necessary.

The different types of blood cells do different jobs. The table below explains what they are and what low levels might mean.

	White cells	Red cells	Platelets
Medical name	Neutrophils and lymphocytes	Not applicable	Platelets
What do they do?	Fight infection	Carry oxygen	Stop bleeding
What's the shortage called?	Neutropenia and lymphopenia	Anaemia	Thrombocytopenia
What are the symptoms?	More infections and difficulty getting rid of them	Pale skin, feeling tired, breathless, cold, dizzy	Bruising easily, bleeding longer
What happens if I have a shortage?	Delay lymphoma treatment and take antibiotics if you have an infection.	Delay lymphoma treatment and have a red cell transfusion if needed.	Delay lymphoma treatment and have a platelet transfusion if needed.

Infection



Infections can be very serious when you're having and recovering from treatment for lymphoma. Your medical team can give you advice to help lower your risk of infection.

However careful you are, you can't prevent all infections. You can get infections from things in your everyday life like your surroundings, your food and other people. You can even get them from germs that live in your body. These germs are important in making your body work properly. They don't usually cause problems but might if your blood counts are low.

Neutropenia

If you have a low white cell count (**neutropenia**), you have a much higher risk of infection than you'd usually have. Your risk is at its highest when your neutrophil count is at its lowest (which is about 7 to 10 days after chemo). From then on, your bone marrow starts to recover and make blood cells again.

Search '**neutropenia**' on our website for more information.



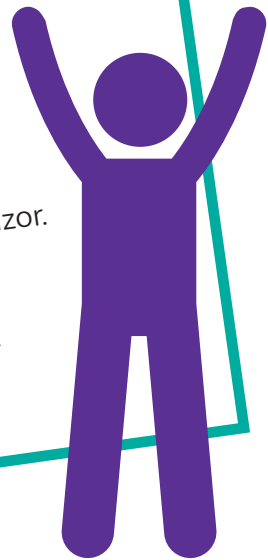
Side effects of
treatment

Lowering your risk of infection

There are lots of ways to reduce your risk of infection:

- Take care to follow all advice from your medical team about what is safe to do and what you should avoid.
- Stay clean. Wash your hands before meals and after using the toilet. Brush your teeth at least twice a day.
- Stay away from crowded places like cinemas, busy shops and public transport.
- Ask your medical team if it is safe for you to go to school, college or work.
- Avoid people who have a contagious illness, for example a cold, flu, diarrhoea, vomiting or chickenpox.
- If you have pets, ask someone else to clean up after them. Wash your hands after touching pets.
- Be careful with anything sharp, like knives, scissors and gardening tools. Use an electric shaver instead of a razor.
- Clean any cuts or grazes with soap, warm water and an antiseptic.
- Follow food safety advice. Ask your doctors what food to avoid.

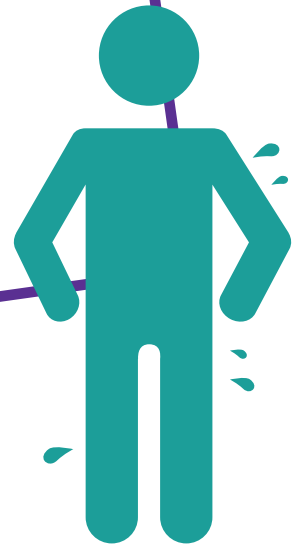
**Reduce
your risk**



Contact your medical team immediately if you have any of the following symptoms:

- fever (temperature above 38°C)
- shivering
- chills and sweating
- feeling generally unwell, confused or disoriented
- earache, cough, sore throat or mouth
- redness and swelling around skin sores, or injuries to intravenous lines
- diarrhoea
- a burning or stinging sensation when you wee
- unusual genital discharge or itching
- stiffness of the neck and discomfort around bright light.

Only take medicines your doctor tells you to.



Side effects of
treatment

Feeling and being sick



Nausea is feeling sick. Vomiting is being sick. Sickness can happen as a side effect of treatment. It can be worsened by stress and anxiety.

Some people feel nauseous before (in anticipation of) treatment. This is known as anticipatory nausea and sometimes happens if you've had sickness after treatment in the past – your brain can make links between having treatment and feeling sick. You can then start to feel sick when you even think about going for treatment.

Will I be sick?

Chemo makes lots of people feel sick, but not everyone. Radiotherapy to the tummy (abdomen) can make you feel sick too. Some targeted drugs can also cause sickness.

If you experience sickness, it usually starts soon after treatment and lasts a

day or two.

What can I do about it?

There are lots of different anti-sickness drugs (antiemetics) available. Tell your medical team if you felt sick after your last treatment so that they can offer you one. If one type doesn't work for you, you can ask to try another one.

If you have anticipatory nausea, antiemetics are less likely to be effective. Instead, your medical team can help you by offering non-drug approaches, such as a complementary therapy. You might also be offered behavioural strategies to try, such as distraction, guided imagery, relaxation and cognitive restructuring (where you aim to change distressing thoughts, feelings and beliefs about treatment).

See page 83 for more information on complementary therapy

If your nausea causes problems with eating and drinking, speak to your medical team for advice.

Side effects of treatment

Top tips

for eating
and drinking
with nausea

- Eat food you like, though you might want to avoid your favourites, in case you start to link them in your mind with sickness and start to enjoy them less.
- If you notice a pattern to your sickness, plan your meals and snacks so that you eat when you're less likely to feel or be sick.
- Don't skip meals or snacks, as hunger can worsen sickness.
- If full meals feel overwhelming, try having five or six smaller ones throughout the day.
- Choose plain-tasting carbohydrates, such as toast, crackers, breadsticks, pretzels, rice, pasta, potatoes or noodles as they might be less likely to make you feel sick than greasy or very flavourful foods.
- Don't force yourself to eat anything that makes you feel sick.
- Eat a cracker or a dry biscuit before you get up if you feel sick in the mornings.
- Drink water or cool, citrus flavoured, fizzy drinks.
- Suck ice cubes or sweets.
- Try adding ginger to your diet as this might help to alleviate sickness – for example, ginger beer, ginger tea, ginger biscuits, ginger cake or root ginger.
- Limit food smells that might worsen your nausea – you could ask someone else to prepare it. For foods that can be cooked in a microwave rather than a standard oven, this can also help to lower food smells.

Digestion problems



Lots of people get diarrhoea (looser, more frequent poo) or constipation (difficulty going for a poo) during treatment.

Tell your medical team if this happens to you – it could be caused by an infection, or it might be a side effect of your treatment. Your doctors might offer medicines to help. Although there are some over-the-counter medicines available, don't take any without checking with your doctor first.

What can I do about diarrhoea?

While you have diarrhoea, it might help to make some temporary changes to your diet. Your medical team or GP can give you guidance about how to manage diarrhoea. This might include to:

- drink plenty of plain water or weak squash
- avoid milk and fizzy drinks
- avoid foods that are high in fat or sugar

Drink plenty of
**water or
weak
squash.**

Side effects of
treatment

- avoid citrus fruits (like lemons and oranges) and onions
- eat low-fibre foods such as white bread, poppadoms, white rice, white pasta and noodles
- cut down on raw fruit and veg for a while
- eat foods that are rich in potassium to help replace that lost through diarrhoea – these include bananas, nuts, broccoli, fish and chicken.

If your bottom is sore, wash it clean instead of wiping it. Have a warm bath and use a simple barrier cream or soothing cream (like one that's used for haemorrhoids or 'piles'). Wash your hands carefully to help reduce the risk of infection.

The Bladder and Bowel Community produce a 'Just can't wait' toilet card. You can get this as a physical card or as a digital version that you can display on your phone. The card can help you to quickly and easily let people know that you have a medical condition and that you need to use a toilet quickly. The digital version can also help you to locate your nearest toilet facilities.

Search 'just can't wait' at bladderandbowel.org to get your free digital card. If you prefer, you can apply for a physical card although note postage charges apply.



What can I do about constipation?

- Drink plenty – water and fruit juice can be good options.
- Build some physical activity into your everyday life.
- Try to get into a routine and go for a poo at around the same time each day, such as in the morning or half an hour after a meal. Don't strain when trying to poo, though.
- Eat high-fibre food like fresh fruit and veg, and cereals.
- Ask your pharmacist or GP about laxatives (medication to help treat constipation), but don't take any without seeking medical advice.



Changes in taste and other difficulties with eating and drinking

Treatment for lymphoma can affect your eating and drinking. For example, you might feel sick, or food might taste different. If you have a sore mouth, it can make eating and drinking painful. Stress and anxiety can worsen difficulties with eating.

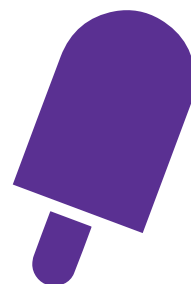
If you have a sore mouth...

Tell your medical team if you have a sore mouth that's making eating or drinking difficult for you. They can give you medicines to protect the lining of your mouth, mouthwashes to keep it clean and pain relief medication.

You could also try:

- sucking on ice cubes or ice lollies
- eating soft food, like mash, scrambled eggs or soup
- letting food cool before eating it.

Avoid things that can cause irritation to your mouth, including alcohol, tobacco, spicy and citrus fruits.



Side effects of
treatment

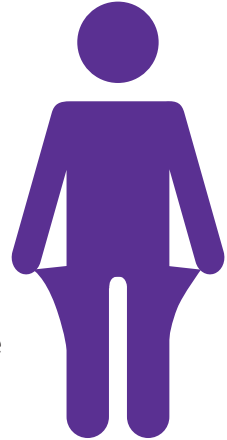
If food doesn't taste of much...

If food seems not to have much flavour, you could try adding:

- herbs, sauces and chutneys to savoury food
- fruit sauces, jam or berries to puddings.

If you're losing weight

Try to eat when you can. You might find it easier to snack or 'graze', eating little and often rather than having big meals. If you're struggling to eat because you feel sick, you might find quite plain-tasting foods easier to eat. Eating with other people might help take your focus away from food.

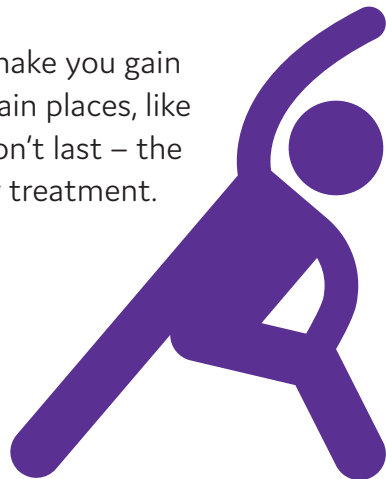


Ask your key worker for a referral to a dietitian for advice on keeping your weight up. This might include recommendations on energy-rich (high calorie) foods, nutritious drinks or supplements to keep your weight up.

If you're putting on weight...

Some treatments, like **steroids**, can make you gain weight. You might gain weight in certain places, like your face, cheeks and tummy. This won't last – the changes will gradually disappear after treatment.

Instead of trying to lose weight, focus on eating healthily to give your body the energy it needs to recover, being active and getting some rest.



Changes to your skin

Teens and young adults are more likely to get skin problems than older people because of changes in hormones. Sometimes, treatments for lymphoma can temporarily worsen them.

Your skin might be itchy or sore, and you might have a rash. This can happen with **chemotherapy**, radiotherapy, some targeted treatments and donor (allogeneic) **stem cell** transplants. If your skin is itchy, try not to scratch as this can worsen the itch and lead to infection.

If you have radiotherapy, your skin might be pink, dry and itchy in the treated area, a bit like sunburn. Some drugs make your skin more sensitive to the sun. Wear a hat and cover your skin with clothes to protect your skin from the sun. Use high factor (SPF 50) sun cream on any uncovered areas of your body.

Your medical team can give advice to help you look after your skin. Ask them which skincare products to use and any to avoid.

You might be interested in our 'skincare and make-up questions answered webinar with Look Good Feel Better. Search 'skincare webinar' on our website.



Side effects of treatment

Top tips for skin care

- Use lukewarm water. Avoid very hot and very cold temperatures – this includes indoor temperatures and water for things like bathing, showering and washing up.
- Don't spend a long time in water, as this can dry out your skin and worsen skin problems.
- Moisturise frequently – it can help to do so while your skin is still damp after bathing or showering. Ask your medical team to recommend a cream.
- To help protect the skin on your scalp, let your hair dry naturally rather than using a hairdryer. Avoid using heat styling tools like straighteners or curling wands.
- Be gentle with your skin – pat your skin dry instead of rubbing it, use an electric shaver instead of a razor.
- If you want to add colour to your skin, avoid using a sunbed – fake tan might be a suitable option but check with a member of your medical team first, and find out which products are safe to use.
- Avoid swimming pools as chlorine can irritate sensitive skin.

You can find more tips on our website – search 'managing sore skin' at lymphoma-action.org.uk



Fertility – your ability to make a baby

While you're having treatment, your ability to make a baby can be affected.

For women, periods might stop or become irregular. If your periods do continue during treatment, you might be given the 'mini-pill' (progesterone) to stop them. This can help to reduce the risk of heavy bleeding if you have low platelets.

As a side effect of chemo, men's sperm count might be lowered. Even before you have treatment, lymphoma can lower your sperm count. Having treatment with chemo before reaching puberty can affect boys' fertility later on in life – see page 117 for information about fertility preservation options.

Chemo can temporarily lower

sperm count.

With radiotherapy, effects on fertility depends on where the radiation goes to.

Side effects of
treatment

If you have radiotherapy to the testes (testicles) or surrounding areas of your body, it can affect your fertility. If it is given to the pelvic area (just below your belly button), there is a possibility of temporary or permanent infertility in men and women.

Some antibody therapies might also affect your fertility. However, as these treatments are newer, scientists are still finding out about their effects on fertility.

If you have sex during treatment, it's very important that you use reliable contraception, so that you prevent pregnancy. Some people are able to make a baby during treatment, but the baby might not develop as it should if your sperm or eggs are damaged by **chemo**. Your medical team can advise you what contraceptives are suitable.

Doctors usually recommend using a condom during treatment and for a while afterwards. As well as to prevent pregnancy, this is because the chemotherapy drugs can pass onto your partner through your semen for around a week after treatment. It is advisable to take such precautions during vaginal, anal and oral sex.



Tell your medical team straightaway if there's any chance you or your partner have become pregnant during your treatment.

Could my treatment stop me having a baby later in life?

Many young people who have had treatment for lymphoma have children later in life without any problems. However, some chemo drugs can reduce your fertility permanently. Reduced fertility is more likely if you have high-dose chemo (often given before a stem cell transplant) or radiotherapy to your testicles or ovaries.

It can take at least a year for your reproductive system to re-adjust after chemotherapy. However, you're likely to be fertile well before that, so take care to use reliable contraception. If you are concerned about your fertility, your doctor can arrange a sperm count test (for men) or hormone tests (for women).

Can I preserve my fertility?

If your treatment is likely to affect your fertility, you might be referred to a fertility specialist to talk about your options for preserving it. Fertility treatments are not always available on the NHS. However, your GP or a fertility specialist can advise on possible funding options available to you.

Talk to your medical team about fertility before treatment starts. Although treatment is planned to minimise the risk to your fertility as far as possible, no one can say for certain how your treatment will affect you.

Young men who have gone through puberty can have sperm collected and frozen before they start treatment. This is called 'sperm banking'.

Boys who haven't yet gone through puberty might be able to have tissue from their testicles frozen but this is experimental and is not widely available.

See page 181 for more about having a baby after treatment for lymphoma

If there's time before you need to start treatment, there is a possibility for women to have ovarian stimulation and eggs frozen (cryopreservation). Some women have the option of having ovarian tissue removed and stored. This might also be a possibility for girls who have not yet been through puberty. Your medical team can advise you on your options.

cancerfertilityandme.org.uk is an online resource designed to help women affected by cancer make decisions about preserving their fertility.



I was referred to a fertility clinic as a potential side effect of my chemo was the loss of fertility. Having talked through the options, I began preparations for egg freezing which involved injecting myself twice a day for two weeks. After a successful egg collection procedure, I was given regular injections to put my ovaries to sleep, from which I experienced menopause-mimicking symptoms such as hot flushes and sweating. To manage this, I always wore layers so I could adjust to my body's temperature changes.



Mila, diagnosed at 19

Wellbeing check-in



Treatment and its side effects can affect your overall wellbeing.

- Find out from your medical team what side effects you're likely to get from your treatment – remember that they're there to support you and offer advice about how to manage any you experience.
- Keep in mind that any side effects are likely to start to go away once you finish treatment – speak to your medical team for an idea of how long you might expect them to go on for.
- Try planning things in your calendar to look forward to, or even just to break up the weeks of treatment in your mind.
- Listen to our webinar on managing symptoms and side effects of lymphoma – search 'side effects webinar' on our website.
- Find information to help you live well on our website – search 'living with and beyond lymphoma'.
- Consider keeping a 'bullet journal' (BuJo) as a way of organising and reflecting. Search 'bullet journal' on the Teenage Cancer Trust website at teenagecancertrust.org for ideas and templates to get your started.

Teenage Cancer Trust has information about treatment, including personal experiences of young people who have been through treatment for cancer.



Living well with and beyond lymphoma

Ask your medical team or your GP for healthy lifestyle advice.

A healthy lifestyle has lots of benefits for physical and emotional wellbeing.

It can also help you to prepare for treatment, and reduce any side effects. Another benefit to healthy living is lowering the likelihood of developing other illnesses in the future.

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Young Lives vs Cancer helps children and young people with cancer (aged 0-25) and their families find the strength to face everything cancer throws at them. We're here to support you every step of the way, whether that's with money worries and accommodation near hospital, or emotional support and problems at work or school.

Find out more at
younglivesvscancer.org.uk

Cassie, Head of Services Access and Support,
Young Lives vs Cancer.

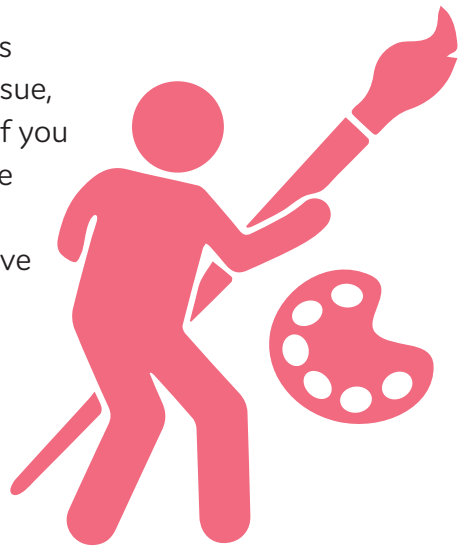


Feelings

Living with and beyond **lymphoma** can bring a range of emotions. It's important to allow yourself to feel however you feel. Ignoring your feelings can make them harder to cope with in the longer-term. Over time, this can have an impact on your overall wellbeing, as well as on relationships with family and friends.

Although challenges won't go away, you can do things to help address them.

Some of these will be practical, such as 'doing something' about a particular issue, like arranging a catch-up with friends if you feel isolated. Other strategies might be more directly focussed on managing emotions – for example, finding creative outlets to express feelings, like drawing or painting.



Search 'health and wellbeing' on our website to find resources to help with your physical and emotional wellbeing.



Top tips

for coping with your feelings

- **Think about what you *can* influence.** Having lymphoma might sometimes make you feel as though you are not in control of your life. Keep control of the things you can. Set daily or weekly routines and consider how much or little you want to tell people about your lymphoma.
- **Find out about lymphoma and its treatments.** This can help you feel more in control and be more involved with decisions about your health and care.
- **Follow a healthy lifestyle.** This includes a healthy diet, physical activity, managing stress and getting enough sleep.
- **Manage anxiety.** Try self-help strategies, like mindfulness meditation (search the NHS website for information) or counselling (see page 126).
- **Express your feelings.** Talk to the people close to you about how you feel. If this is difficult, ask your medical team to refer you to a counsellor. Find ways of letting your feelings out, for example through writing, artwork or music.
- **Make time to relax and have fun.** Spend time with the people you enjoy being around. Recognise that there'll be times when your energy level is low and give yourself permission to take things easy for a while.

See page 126 for more about counselling

It's important to remember you have other things in your life so that it doesn't feel as though lymphoma has 'taken over'.

Think about what makes you who you are beyond being someone who has had treatment for lymphoma – for example, you might be a son, a brother, a student, a guitarist. Go a bit deeper, too and think about your likes and dislikes, your values, beliefs, and future plans.

Search 'tips and resources' at teenagecancertrust.org for ideas to help you live well.



Worries that just won't go away

There can be a lot to think about when you're affected by lymphoma.

If worries keep going round and round in your head, you could try writing them down. Some people keep a pen and paper by their bed in case worries come in the night and stop them from getting a good night's sleep. Set some time aside during the day to note down what you can and can't do about the things that are troubling. You can then make plans to deal with the ones that you can do something about.

Distraction can be a good way to prevent you from feeling continuous anxiety. Keep active and do things you enjoy. Make time to relax, too. You could try meditation, yoga or mindfulness.

Living well with and beyond lymphoma

Worry	What can I do?	Who or what can help?
My lymphoma might come back after treatment.	Speak to my medical team about how likely this is, symptoms to look out for, and what to do if I notice any changes.	My CNS or keyworker can answer my questions and give me information.
I feel like I haven't kept up-to-date with what's going on with my friends.	Make contact – maybe send them a text or a message on social media.	Friends could help to arrange a meet-up with the people I haven't seen in a while.
I feel so anxious a lot of the time.	Tell my CNS or keyworker how I'm feeling and ask about support.	Try breathing techniques (see page 125) Contact our Helpline Team (page 187). Go to an online or in-person support meeting. If you're aged 18+, join our closed Facebook support group.

Search 'mindfulness' at mind.org.uk for mindfulness exercises you can try, as well as tips about how to get the most from mindfulness.

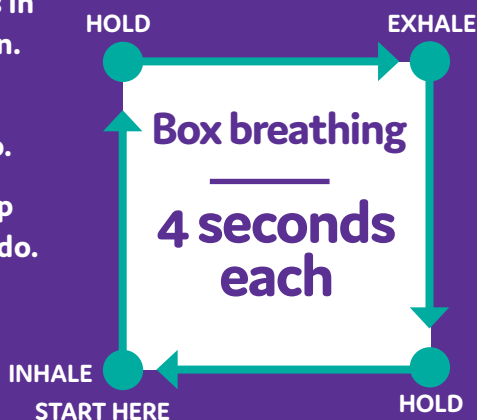


Top tips to feel calmer

Breathing techniques might help you to feel calmer. Practising these while you are calm can help you use them more easily when you feel anxious. One exercise that many people find helpful is called 'box breathing'.

Find a comfortable position, sitting, lying or standing. Breathe out slowly, and then you're ready to begin.

- **Breathe in for 4 counts.** As you do so, try to release any tension in your face. Relax your eyes, cheeks and mouth.
- **Hold your breath for 4 counts.** As you do, tense the muscles in your body as much as you can.
- **Breathe out for 4 counts.** Relax your muscles as you do.
- **Hold for 4 counts.** Try to keep your muscles relaxed as you do.
- **Repeat the above four steps a few times.**



Find relaxation techniques on the No Panic website at nopanic.org.uk/relaxation-technique



Low mood

Everyone feels sad and anxious from time to time and it's particularly common if you have cancer. However, some people feel very low a lot of the time. If this is the case, you might be affected by depression. If you've had depression in the past, your likelihood of experiencing it again after a diagnosis of lymphoma could be higher.



Let a member of your medical team know so that they can offer support.

Visit [mind.org.uk/Depression](https://www.mind.org.uk/Depression) for more information about depression.



Getting help with your feelings

If you'd like support with how you're feeling, you might consider counselling. For some people, counselling gives a chance to express the things they feel unable to talk about with the people they know, like family and friends.

There are many different types of counselling. There are also therapists who can work with you in ways that don't necessarily use words to explore feelings. For example, you could work with a creative therapist, using a form of non-verbal communication as a main way of expressing yourself, such as art, dance, music or photography.

All therapy types share an aim to offer you a safe and non-judgemental space for you to consider your feelings.

Getting support from a trained professional in this way can give you an opportunity to feel that another person is really trying to understand how things feel from your perspective. You might find this helpful at various points, such as soon after diagnosis, during or after treatment.

Counselling and creative therapies can help you to consider:

- your thoughts and feelings
- how lymphoma affects your life, for example, your work, studies or relationships
- what's important in your life
- how you usually respond to people and situations, relating this to your life at the moment
- what the people and things in your life mean to you
- your resilience and sense of ability to cope
- ideas and strategies to address challenges.



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Speaking to a psychologist at the hospital helped me to think about what I was feeling and process it in a useful way. I am very pleased that I did this as it was such a relief to get all of the muddled and heavy feelings out of my head.



Mila, diagnosed at 19

Your doctor or nurse can give you more information about professional emotional support, such as counselling. They might be able to refer you to a counsellor on the NHS, through your hospital or a local cancer support centre. Another option might be accessing a youth counselling service near to you – some offer sessions for free or at a discounted cost.

British Association of Counsellors and Psychotherapists (bacp.co.uk) has more information about different types of therapy. They also have an online search tool to help you find a private therapist if you are in a position to be able to pay for sessions.



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Talk to someone you trust about your worries and struggles.

Aidan, diagnosed at 20



Diet and nutrition

Eating well can help you to cope with treatment. It can also help your recovery from treatment and how you feel in yourself.

A healthy diet is made up of foods from different groups, as shown in the Eatwell guide on the page opposite. The Vegetarian Society have a version for people who eat a vegetarian diet, and The Vegan Society give guidance on nutrition for those following a vegan diet.

Include all food groups in the Eatwell guide in your diet. If you follow a vegetarian diet, you can get protein from dairy products, egg and soya products.

Vegan sources of protein
include
pulses, nuts and soya products.

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.

Each serving (150g) contains

Energy	3.0g	1.3g	3.4g	0.9g
Total fat	1.0g	1.0g	1.0g	1.0g
Total sugars	1.0g	1.0g	1.0g	1.0g
Total salt	0.1g	0.1g	0.1g	0.1g
% of an adult's reference intake	4%	7%	8%	15%

Typical values (as sold) per 100g: 697kJ/167kcal

Choose foods lower in fat, salt and sugars

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

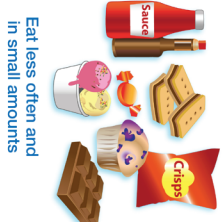


Eat more beans and pulses, fish, eggs, meat and other proteins
sourced fish per week, one of which is oily. Eat less red and processed meat

Choose wholegrain or higher fibre versions with less added fat, salt and sugar
Potatoes, bread, rice, pasta and other starchy carbohydrates

Dairy and alternatives
Choose lower fat and lower sugar options

Choose unsaturated oils and use in small amounts



Eat less often and in small amounts

6-8 a day

Water, lower fat milk, sugar-free drinks including tea and coffee all count.

Limit fruit juice and/or smoothies to a total of 150ml a day.

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

Is it OK to diet?

Generally, doctors advise that you do not try to lose weight while you're having treatment. Dieting can make it harder for your **immune system** to recover. If you are gaining weight because of your treatment, which can often be the case with **steroids**, cut down on unhealthy foods such as sweets, chips, cakes and biscuits. Focus instead on eating a healthy diet.



Speak to your doctor if you are worried about your weight.

Can any foods cure my lymphoma?

You might hear stories in the news about 'wonder foods' or 'cancer diets'. Eating well is important and has lots of health benefits, but there is no evidence that any foods or drinks can cure lymphoma or stop it from coming back.

Are there certain foods or drinks I should avoid?

Some foods might affect how well drugs work. Your medical team can give you advice specific to your treatment. In some cases, you might be advised to avoid eating (or drinking the juices of) some fruits during treatment. Check with your medical team whether it's OK for you to drink green tea.

See page 133
for information
about alcohol

We have more FAQs about food on our website.
Search 'diet and nutrition'.



Living well with and
beyond lymphoma

Top tips for eating out

- It's generally safe for people with lymphoma to eat out or get a takeaway, but check with your doctor if you are neutropenic. Make sure that the restaurant, pub or café has a high hygiene rating. Usually, these ratings are shown on stickers in the window. You can also go online to scoresonthedoors.org.uk to check food hygiene ratings.
- Check that meat is cooked all the way through. The juices should run clear when you cut through the thickest part.
- Reduce your risk of infection by avoiding unpackaged food, like kebabs, loose sweets or bakery goods, unpackaged ice cream and salad from a salad bar or buffet. Free tasting samples given out in shops or on market stalls are often unwrapped, so avoid these too.



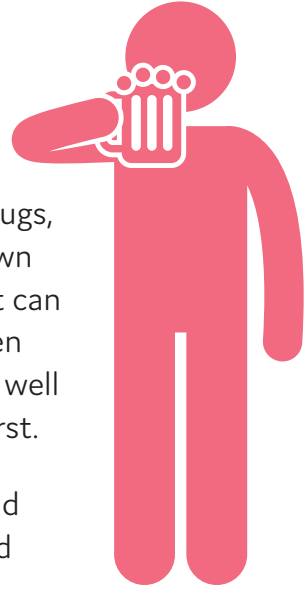
Is it safe to drink alcohol?

It is best not to drink alcohol while you are having treatment for lymphoma.

If you're having **chemotherapy** or targeted drugs, your liver is already working hard to break down the drugs, and alcohol could affect how well it can do this. The occasional alcoholic drink between cycles of chemotherapy when you are feeling well should be OK – but check with your doctor first.

If you're having **radiotherapy** to your head and neck area, alcohol could make your mouth and throat sore. Drinking alcohol if you're having radiotherapy to your pelvic area can irritate your bladder.

Be aware that you might feel the effects of alcohol more quickly than you did before treatment. Remember also that alcohol is dehydrating, so if you are drinking alcohol, drink plenty of water too.



What about taking recreational drugs?

Avoid recreational drugs. During treatment for lymphoma, your body is already working really hard to break down and process your lymphoma treatment.

Let your medical team know if you take recreational drugs – the drugs could make your treatment less effective, or they might affect your test results.



Even after treatment, it's still a good idea to lead a healthy lifestyle, free from recreational drugs. This helps to put you in the best position to maintain good health.

I'm a smoker – how does this affect my health?

Smoking increases your likelihood of developing infections, particularly in the lungs. The risk is even higher if you are having treatment for lymphoma. This is because some treatments for lymphoma can increase your risk of developing **late effects**, like other cancers, heart disease and stroke. Stopping smoking can reduce these risks.



Less is known about the effects of vaping and e-cigarettes. However, it is preferable not to use them.

Search 'stop smoking' at [nhs.uk](https://www.nhs.uk) for tips to help you quit smoking.



Exercise and physical activity

Staying fit and active is a great way to help you feel better. It might also help to reduce some of the side effects of treatment.

Exercising can be a good way to spend time with friends. Or, if you choose to exercise alone, it can help to give you some mental headspace.

Physical activity during and after your treatment can help to:

- prepare your body for the most suitable treatment
- reduce side effects of some treatments for lymphoma
- reduce risk of infections while you are on treatment
- reduce the risk of developing blood clots while you are on treatment
- reduce fatigue
- increase muscle strength and balance
- control your weight, blood pressure and blood-sugar levels
- reduce the risk of coronary heart disease
- build bone strength to help prevent brittle bones (osteoporosis), which is particularly important for women given treatment that affects their ovaries (such as pelvic radiotherapy) or that causes early menopause
- improve your general emotional wellbeing, for example by managing stress – some people find it additionally beneficial to be outside and around nature.

Your doctors might recommend certain exercises before treatment, as part of prehabilitation (page 53)



Living well with and beyond lymphoma

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Before I was diagnosed, I was very active and enjoyed running. I found it quite difficult when I realised I would have to start from the very beginning and so I did light exercise such as walking. Once I was back at school I just had to cope with being a bit slow in my PE classes. This was difficult as I have always been competitive but I improved bit by bit. I joined the hockey club and the badminton club once I was able to.

Georgia, diagnosed at 11



How much exercise should I do?

As long as you are otherwise well, the recommendations are the same as they are for people who do not have lymphoma:

- **up to 18 years old:** at least 60 minutes each day
- **18+ year olds:** at least 30 minutes a day, 5 days a week.

You should include some strengthening activities a couple of times a week within these times. Examples include dancing, walking and resistance band exercises.

See page 138 for more info about exercising at a gym

Find out more about physical activity recommendations at [nhs.uk/live-well/exercise](https://www.nhs.uk/live-well/exercise)



Realistically, the amount of exercise you do depends on things like your overall health, energy levels, and whether you're having treatment for lymphoma. Sometimes, chemotherapy and steroids can make your legs weak. This can make it difficult to do anything strenuous. Keep active by moving and staying up and about. Ask your medical team for advice about the type and intensity of exercise that is suitable for you.

Top tips

for building exercise into your daily life

- Walk or cycle to the shops.
- Get off the bus a stop early and walk the rest of the way.
- Take the stairs instead of the lift or escalator.
- Carry your school or work bag.
- Push a shopping trolley, carry a shopping basket or shopping bags.
- Get some resistance bands to do some light exercise during the day.
- Play frisbee or fly a kite in the park.
- Watch our video on exercise and keeping physically active – search 'exercise' on our website.



Search '10 minute workouts' on Teenage Cancer Trust's website at teenagecancertrust.org for suggestions of workouts you can do at home with little or no equipment.



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I am taking more care of my body now. In fact, I feel healthier than I did before my treatment. I have joined a gym and am doing exercise 5 or 6 times a week now. This isn't something I did before, but I'm really enjoying it.



Lyle, diagnosed at 19

Can I play sport?

During treatment and for a little while after, your risk of infection, bruising and bleeding might be higher. Avoid activities where injury is more likely, such as football, rugby and mountain biking.

Is it OK to work out at the gym?

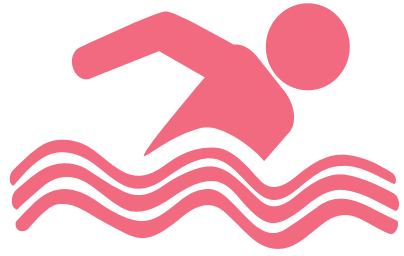
Speak to your medical team about whether it's safe to work out at the gym. If you have a physiotherapist or personal trainer, ask for guidance about the types of exercise that are most suitable for you based on advice from your medical team.

As part of your treatment, you might have had anthracyclines – a group of chemotherapy drugs that can affect the strength of your heart. If you've had them, you might be advised not to do resistance exercises, like heavy weights or lifting, because of the strain these can put on your heart.



Can I go swimming?

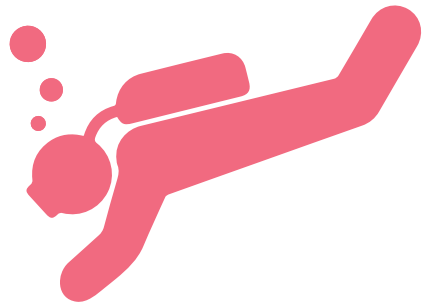
The warmth and damp of pools means that bacteria multiply easily. You might be advised not to go swimming if you:



- are neutropenic (to avoid infection from public pools and changing rooms)
- are having radiotherapy (as chlorine can irritate skin in the area treated)
- have a **central line** fitted (other than a **portacath**).

Am I allowed to go diving?

If your heart is affected by treatment for lymphoma, you might not be allowed to dive for a while after treatment. You'll need to have a medical assessment and be declared fit to dive. Find out more on the British Sub Aqua Club (BSAC)'s website at bsac.com



Trekstock is a charity that supports people in their 20s and 30s who have cancer, including with physical activity – search 'exercise' at trekstock.com



Sleep and rest

Many people have difficulties sleeping sometimes. This can include difficulty falling or staying asleep (insomnia), waking too early, sleeping a lot of the time, and having unsettling dreams or nightmares.

Having lymphoma can make you more likely to experience sleep difficulties. For example side effects of treatment including cancer-related fatigue, stress and anxiety can all lower the quality of your sleep. For this reason, addressing these side effects might help to improve your sleep.

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

Find information to help you sleep well on the Royal College of Psychiatrists website.

Search 'sleep well' at [rcpsych.ac.uk](https://www.rcpsych.ac.uk)

The Mental Health Foundation have a guide on how to sleep better. Search 'sleep better' at [mentalhealth.org.uk](https://www.mentalhealth.org.uk)



Top tips

for getting a
good night's
sleep

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



Relationships, family and friends

Having lymphoma can have a significant impact on relationships.

Often relationships become strained as people don't know quite what to say or do. Things can then start to feel awkward, and misunderstandings might arise.

Despite the challenges they can bring, research shows that people with cancer cope better when they are supported through strong relationships. You might even grow closer to some people.



My brother came to biopsies with me. Without him and his family keeping me busy it probably would've been worse, but it wasn't.

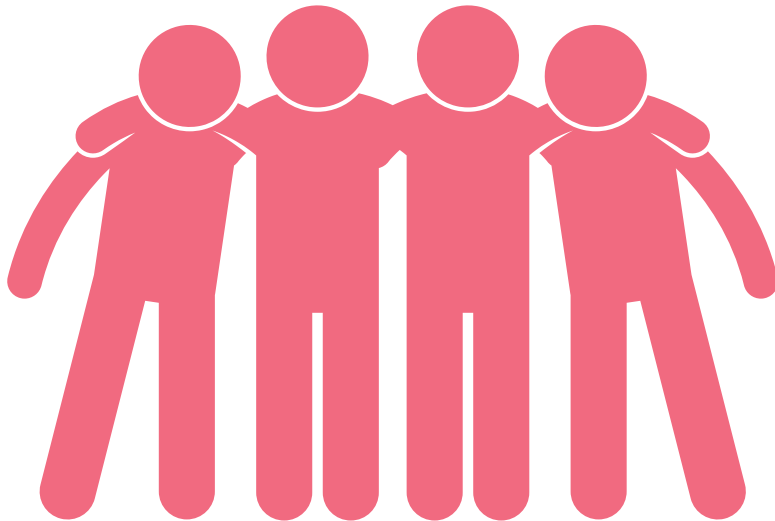
Dwayne, diagnosed at 25



Friends

Your friends might not know much about lymphoma – perhaps they haven't even heard of it. You might find they don't seem to understand that you're unwell if you look OK. Think about how much or little you want them to know about your lymphoma. If the thought of telling them about it in person is difficult, you could send a message or email as a starting point.

Let your friends know what you'd like from them – whether this is to talk about how you're feeling or you just want to chat about other things, like sport or the latest TV show. The chances are, they'll want to be there for you and will be pleased for some guidance about how best to help you.



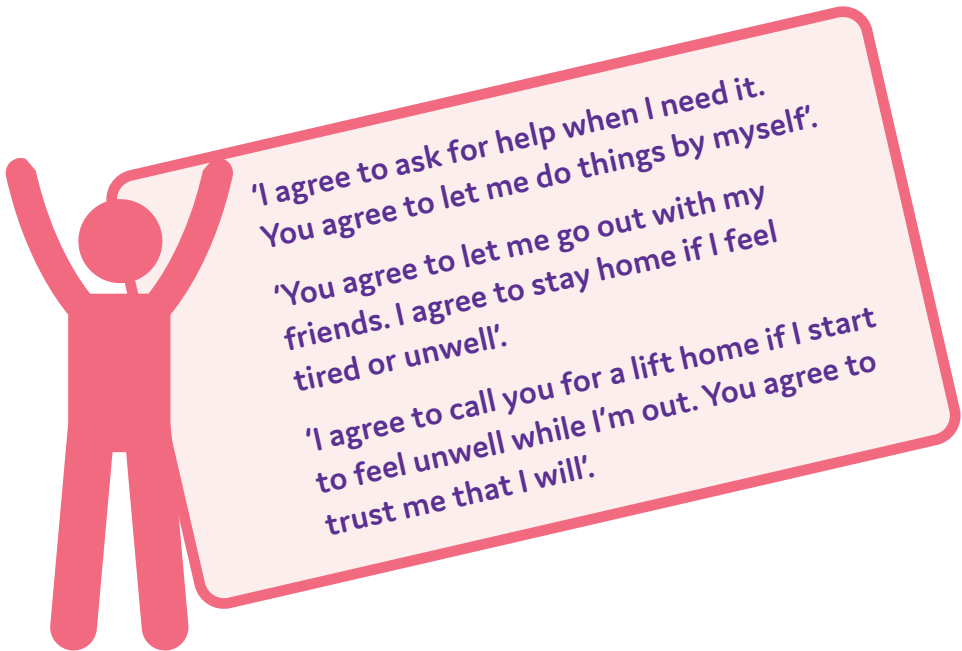
Do fun things with your friends. Just remember to avoid places like clubs, cinemas, crowded shops and public transport if you have **neutropenia**, to lower your risk of infection.

Parents and carers

Your relationship with your parents or carers might have changed since you were diagnosed with lymphoma.

It's quite common for parents to become more protective after their child has had a lymphoma diagnosis. Although this is through love and wanting to look after you, it might feel overbearing and as though they are controlling you.

Talk to your parents about how you feel. You could tell them if there are things you miss about how your relationship used to be. It's often best to have this conversation when you're both calm. Do your best to see their point of view as well as explaining yours. Build trust by making agreements or deals. Some examples are shown below.



Brothers and sisters

Having lymphoma can affect how you get on with brothers and sisters. If you're tired, feel unwell and frustrated, it's easy to snap. Your brothers or sisters might feel jealous of you for the extra attention you're getting. You might feel jealous of them because they're able to do things like play sport when you're still finding it an effort to climb stairs. Some siblings might become very protective of you, acting a bit like another parent.

Try explaining how you feel. Listen to how they feel too. You might be surprised at how supportive they are and find that you get a better understanding of one another.



Boyfriends and girlfriends

If you are in a relationship, this is likely to be a tough time for both of you. Your partner might feel helpless and not know what to say or do. Talk to them about how you feel.

See page 147 for tips on talking to the people close to you

Sex and intimacy

Take care if your **platelet** count is low as you are likely to bruise easily. It's important to use a condom to avoid passing chemo on to your partner, to protect against infection and to prevent pregnancy. You could use a water-based lubricant if vaginal dryness is a problem.

Talk to your doctor about **suitable contraception.**

Living well with and beyond lymphoma

Loss of interest in sex

Don't worry if you're less interested in sex than usual. There are lots of possible reasons for this. You might feel fatigued and have low energy levels. You might feel less confident about your body, especially if your weight has changed or you've lost some hair.

Stress and anxiety can also lower your sex drive.



It's easier said than done, but try not to worry – it's very common for your sex drive to drop during treatment and it usually returns once you have recovered from treatment. Talk to your partner about how you feel so that they know your lowered interest in sex isn't because of anything they've said or done and it isn't because you no longer find them attractive. Think about other ways of being intimate and showing affection until you are interested in sex again.

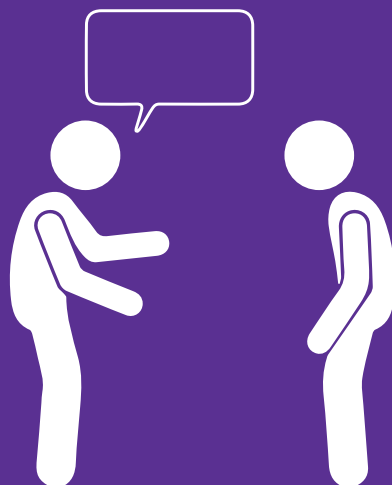
Search 'sex and relationships' at
younglivesvscancer.org.uk



Top tips

for talking to
the people close
to you

- **Agree to be honest with each other. Set aside time when you're free from interruptions and can really listen to one another.**
- **Explain what you'd like from them, for example, their company, time to talk about how you feel, or doing something fun together.**
- **Use 'I' statements to help take the blame out of what you say – see page 148.**
- **Consider using social media to update a lot of people quickly. Think carefully about what you post though as once you have done so, lots of people will see it and it'll stay out there in the years to come. You might like to create a closed group or have a group chat to post updates for the people you're closer to.**



'I' statements

Statement: 'It really annoyed me yesterday when you kept telling me to sit down and rest', **rephrased using I statements:**

Say	Example
How you feel/felt	I felt frustrated yesterday.
When	When you insisted that I rest.
Why	I know you only said it because you care but I felt disappointed.
What you'd like	I want to do things when I have the energy, as I did yesterday. It helps me to feel more like myself. I'd really like you to trust me to tell you when I feel tired and need to rest.

People you see around

You might be worried about what to say to people you don't know well – maybe someone who lives on your road that you usually just say 'hi' to. People might ask lots of questions if they know you have been unwell, or they might say very little for fear of offending you. Although this can feel hurtful, remember that they're not deliberately trying to upset you – they probably just don't want to say the wrong thing. You might need to be the one to start the conversation.

Think about
how much
or little you want
**people
to know.**

It can help if you prepare a few things to say about your lymphoma. 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 chemo, which is why I'm bald!'

“

It dawned on me that I had to find a way to tell people about my cancer. I simply wrote, 'I've got cancer.' Since that first message, I continue to receive the most overwhelming support from everyone.

Natalia, diagnosed at 20



Things you might say to people about your lymphoma.

Wellbeing check-in



A healthy lifestyle can help you to cope with some of the physical and emotional challenges that can come with living with lymphoma.

Think about how you can take good care of your overall health and wellbeing, including socially and emotionally. You can also talk this through with your key worker.

Remember that relationships with family and friends can be an important part of emotional wellbeing. Think about how they can support you.

Search 'living with and beyond lymphoma' for more information about everyday life and healthy living.



Practical aspects of life

You might need to make some changes in your day-to-day life during, and for a little while after treatment.



“

Before my diagnosis, I worked as an apprentice in financial services. Being a 'numbers person' I really enjoyed the role, working four days in the office, and studying for the other day. The study element of the apprenticeship needed to be completed within a two-year limit but the organisation was incredibly supportive, giving me six months off during my treatment and ensuring the timescales were expanded so that I could complete my studies.



Lyle, diagnosed at 19

Education and training

During treatment, you'll probably need to take some time out of school, college or university. Your medical team should speak to you about how treatment could affect your studies.



My college tutors have been very supportive in making adjustments to allow me to continue with my education. For example, my energy levels tend to be low in the mornings so I miss the first two lessons of the day and can instead work from home. The tutors send me work so that I can stay up-to-date.



Maddie, diagnosed at 16

What should I tell my school, college or university?

Be open and honest about your **lymphoma** so that your teachers or lecturers can support you as best as they can. Your doctor should also write a letter to your school, college or university about your lymphoma. This can help them to understand a bit about your condition, treatment and the effects of your treatment.

Be
**open and
honest**
about your
lymphoma.

Practical aspects
of life

“

I was just three months away from my GCSEs when I started treatment. My school teachers sent me revision resources and offered me video calls, and I was able to use the hospital's school too. I took two of my GCSEs at home at my kitchen table.

Tamsin, diagnosed at 16

What support is available?

If you are under 16, you might be able to get support from your local education authority (LEA), through your local council. The help they provide can include teaching in hospital or home tutoring.

Whether or not you are eligible for such help, most units have a hospital school with teachers who are used to helping people with their studies during treatment. You'll be supported to go into school or college when you feel well enough.

“

My school was very accommodating. I was determined not to fall behind with my GCSEs. A nurse came into school to take blood and do tests each week so I wouldn't need to go to hospital specifically for that. When I needed to stay in hospital, I always asked school to send work to me, which was helpful, giving me something productive to do! Happily, I did well in my exams and was able to move straight onto A-Levels.

Ellie, diagnosed at 15

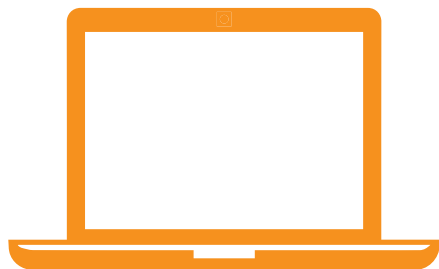
Teenage Cancer Trust has information about school, college and university. Search 'education after cancer' at teenagecancertrust.org



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.

Under the Equality Act 2010, a diagnosis of cancer meets the government's definition of disability and there's a wide range of financial support you may qualify for from the government. Find out more about your rights at gov.uk/browse/disabilities.



“

My employer has been supportive with working around my follow-up appointments and offering flexible working. Even two years after treatment, I have to watch my energy levels. I try to take time out when I need it and be careful not to say yes to everything all the time. Five years after treatment, I have now moved jobs, where my new employer is equally supportive.

Callum, diagnosed at 21



A cancer diagnosis should not create a barrier for Teenage and Young adults (TYA) with regards to Education and Employment. You have protected rights under the Equality Act 2010, this means that reasonable adjustments must be made by education providers and employers. Please speak to a member of your TYA team, they will signpost you to a professional who can then offer the correct advice.

Stephen Harcourt, Youth Support Coordinator and
Education & Employment Mentor

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.



Top tips

for speaking to your employer

- Arrange a time to meet with your line manager and/or HR department. Talk honestly about your situation. If you don't know how soon you'll return, say so.
- Ask about the possibility of making some changes to your working arrangements, like working from home or going in a bit later to avoid the rush hour commute.
- Think about whether you could delegate some responsibilities for a while, avoiding some of the more tiring parts of your role.
- Be aware of your rights. Your employer must, by law, make any 'reasonable adjustments' that allow you to continue working while you are having treatment and afterwards. To find out more, search 'employment' at macmillan.org.uk



You'll find a list of organisations that provide specialist information and advice about finances at lymphoma-action.org.uk/Finances



Driving and getting around

It's usually considered safe to drive if you have lymphoma. However, check with your medical team if any of your medication means that it is illegal or unsafe for you to drive – some treatments or medicines can make you feel drowsy or unwell, which can affect your concentration.

If you have peripheral neuropathy (nerve damage, often noticeable as tingling in your hands and feet), you must tell the DVLA.

Remember that you might feel tired on days that you have treatment. It can be helpful to arrange for someone to drive you to and from appointments.



Tell your car insurance company if you have lymphoma – you could be fined if you don't, and any claims you make could be rejected.



Search 'driving health conditions' on the UK Government website at GOV.UK to check how lymphoma might affect your driving and whether you need to report it to the DVLA.



Help with transport costs and arrangements

The costs of travelling to and from medical appointments can add up. You might also be interested in finding out about:

- Any free or reduced-cost parking that might be available at your hospital. Macmillan Cancer Support has more information about transport and parking costs.
- The Healthcare Travel Costs Scheme, which might qualify you to claim a refund on travel costs if you are referred for NHS tests or treatment. Your CNS should be able to give you the relevant form.

Support from the government

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

- Search 'support with the cost of transport' for help if your 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 more information about the help with travel and other costs. Search 'welfare rights advisors' at macmillan.org.uk



If you're aged 18 to 24, you might be eligible for a grant from Young Lives vs Cancer, to help with costs. Search 'cancer grant' at younglivesvscancer.org.uk

You'll find more organisations who can offer or signpost you to sources of financial support. Search 'useful orgs' on our website.



Wellbeing check-in



Living with lymphoma can affect lots of aspects of your day-to-day life. If you need to make changes to your schedule and activities, try to be patient with yourself. Remember, these are likely to be short-term. Ask your medical team when you're likely to be able to get back to doing all of the things you want to do.

Remember that you'll have regular health checks and that you can contact your key worker at any time if you have any concerns.

You should be offered a holistic needs assessment (HNA) as part of your personalised care plan. The HNA is a questionnaire to help you and your medical team work together to identify and address any practical, financial, physical, emotional and social needs you might have. 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.

Ask your key worker for assistance with any areas of your life that you'd like help with.

“

I tried to take the pressure off myself, knowing that I could return to my studies the next academic year. I tried to look at it as an opportunity to just take some time out and prioritise the things that would bring me joy, like spending time with friends.

Maddie, diagnosed at 16

Finishing treatment and leaving hospital

You might experience lots of different emotions, whether this is straightaway, weeks, months or even years later. We cover some of these in this section.

Feelings

There isn't a 'normal' way to feel. Try to allow yourself to experience whatever emotions you feel.

“

Unexpectedly and out of nowhere, all the emotions that had been stuffed away and hidden, erupted.

Natalia, diagnosed at 20



Isolation

You might feel more alone now that you no longer see hospital staff so often. Perhaps it seems that the people around you don't really understand what you've been through.

Shock and anger

When your treatment finishes, the shock and reality of what has happened might hit you. You might feel angry about what you and the people you care about have been through, or about the disruption lymphoma has caused in your life.



Irritability and blame

You might feel irritated with people who don't seem to understand what you've been through. Some people describe a changed view of life or a new sense of perspective.

You might also 'snap at' or get upset about things that wouldn't normally bother you. It is not unusual to look for someone to blame, whether this is yourself or others.

Loss of confidence

You might not feel confident about getting 'back to normal' and doing all the things you used to do. Physical changes such as hair loss or a change in your weight can also make you feel self-conscious.

Physical changes
like hair loss or a change in
weight can affect your

self-esteem.

Finishing treatment
and leaving hospital

Anxiety and uncertainty

Even though many people with **lymphoma** only need one course of treatment, it's natural to worry about the lymphoma coming back (relapsing) or that a new health problem could arise. Feeling uncertain and not fully in control can be very hard to live with. Waiting for follow-up appointments can be especially difficult.

Low mood

It's not unusual to feel low once treatment finishes – some people find it a very unsettling time. It can be particularly difficult if the people around you seem to expect you to be 'back to normal' straightaway. You might miss the health professionals who cared for you, and you might have made friends through the process. Perhaps you're scared that your treatment is finishing and feel anxious that your lymphoma could return.

For some people, low mood continues and has a significant impact on day-to-day life. If this happens, you might be experiencing depression.

Search 'depression' at www.nhs.uk for information about depression and how to cope if you are affected by it.



How can I cope with difficult feelings?

People find different ways of coping with difficult feelings.

Some things people find helpful are to:

- **Recognise your feelings** – be honest with yourself and the people around you about how you are feeling. This isn't always easy but hiding how you feel can make it harder to cope with your emotions in the long run.
- **Talk through your feelings and fears** – talking can help you to work through and understand your feelings. You could do this with family, friends or your partner. Sometimes it's hard to talk about feelings with the people we are closest to. If this is the case for you, ask your GP if they could refer you to a therapist such as a counsellor (see page 126). You can also speak to a member of our Helpline Team about how you feel.
- **Write about how you feel** – writing down your thoughts and feelings in a diary or journal can be really helpful. Even if no one else reads it, the process can be very therapeutic. Some people keep a blog or vlog, which they share with others. This can help when you don't want to explain how you are feeling over and over again to different people. Getting your thoughts and emotions out can help you to make sense of them and to feel calmer and more in control.
- **Express yourself creatively** – you might want to paint, draw or play music to help you process how you're feeling.

- **Find others you can relate to** – you might like to speak to others who have been affected by lymphoma. Even though their experience is not the same as yours, you might like to be in touch with someone else who understands what it's like to have lymphoma.

Find out more
about how we can
support you on
page 187



Once I finished treatment I found my mental health declined a lot as all the mixed emotions kicked in at once. I found the support from the Lymphoma Action Facebook group really beneficial during this time and everyone was always lovely when I reached out.



Tiff, diagnosed at 24

Search 'leaving hospital' at [younglivesvs cancer.org.uk](https://www.younglivesvs cancer.org.uk) for tips on getting back to 'normal' after treatment ends. If you're 16 or over, you could get in touch with other young people who have had cancer on their Facebook support group: [facebook.com/groups/teamyounglives](https://www.facebook.com/groups/teamyounglives)



Positive life changes

After a diagnosis of lymphoma, many people go on to experience positive life changes such as having:

- a healthier lifestyle
- closer relationships with family and friends
- better connections with yourself and the world
- new priorities and greater appreciation for life
- a sense that life has more meaning
- a better ability to live in the moment
- more 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'm making the most of everything that comes my way. Although the thought of cancer still lingers in my head, being in an environment where people have supported me has helped to boost my confidence.

Tamsin, diagnosed at 16

Finishing treatment
and leaving hospital

“

Being a survivor isn't a clean conclusion to the cancer experience. Worries can linger, world-views can shift.

Ellie, diagnosed at 15

Should I celebrate the end of treatment?

What you have been through is a big part of your life experience. If and how you want to celebrate it is entirely up to you. You could have a party or a day out. You might prefer not to do anything big but treat yourself to something you'd really like instead.

Feeling anxious about stopping treatment is a common experience, but it usually fades as you grow in confidence about your health.

It can be hard if people around you expect you to be happy and to celebrate but you don't feel like it. Let them know how you feel. They might not realise that this is still a challenging time for you.

“

I felt massive relief to be in remission but unhappy with my body and the changes it had gone through during treatment. Luckily the majority of these changes were reversed very quickly and the experience inspired me to really look after my body and I'm now physically fitter than I was before.

Alfie, diagnosed at 13



Connecting with other people who have been affected by cancer

Although everyone's experience is unique, some people find it helps to connect with someone else who's been treated for cancer.

- If you're aged 16 or over, you might be interested in our Live your Life programme. It's designed for people who have finished treatment, and can help you to meet others and find your 'new normal'. Search 'Live your life' on our website to find out more.
- Shine Cancer Support offer a range of support for people in their 20s to 40s. Their online 'Break Out' programme gives you the chance to be part of a small group of young adults with cancer, connecting with each other while also getting useful information and support.
- Teenage Cancer Trust offer 'Find your sense of tumour' events. These give 15 to 27 year olds a chance to spend a weekend with other young people who have had cancer, and to join activities and listen to talks, as well as connect with one another.

“

Some people think that because your scans are clear, that's it – there's nothing to worry about. It can be difficult for friends to understand but I still worry about going for scans and what might be found. I try to compartmentalise and focus on living my life.

Maddie, diagnosed at 16

Finishing treatment and leaving hospital

Medical matters after treatment



It's important that medical professionals treating you know that you've had **lymphoma** and what treatment you've had. This is to help with taking any safety precautions needed.

Check with your doctors what medical issues you should be aware of, and any health and safety precautions to take.

What's a treatment summary and why do I need one?

A treatment summary outlines:

- treatment you've had
- possible side effects and **late effects** of your treatment
- possible signs that your lymphoma might be coming back (**relapsing**).

The point of a treatment summary is to help you stay well. 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.

A treatment summary is for you and your doctors. Your hospital should send it to your GP and provide you with a copy. It should be added to your medical records, 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. Keep copies in case you lose the original.

Follow-up appointments

Once you've finished treatment and you're in **remission**, you'll have regular check-ups (follow-up) at the hospital for the next few years.

Follow-up gives you a chance to talk to your doctor about any worries you have. Your medical team can see if there's anything else they could do to support your recovery.

The check-up appointments you have are called **'follow-up'** appointments. It's really important that you go to them.

Medical matters
after treatment

“


I've worked hard to regain my fitness and I work out weekly with my personal trainer. I'm disciplined with my diet and I've developed a love of cooking. I had follow-up check-ups (scans and consultations) every 3 months for the first 2 years. I reached the 2-year remission mark in December 2022, so for the next 3 years I will have 6 monthly check-ups. Then at 5 years, I'll be discharged from follow-up.

Alfie, diagnosed at 13

It's natural to worry that there could be something wrong, but finding problems sooner often means they're easier to deal with. Often, people come out of follow-up appointments feeling reassured by test results that show they're still in remission.

What happens during a check-up?

During your check-ups, you have tests. Sometimes, you also have scans. These are to make sure your lymphoma is in remission and that you are recovering well. Later on, you might have different tests to check for problems that can develop months or years after treatment has finished (late effects).



See page 177 for more about late effects

How often do I need a check-up?

You'll need a check-up every couple of months at first. As long as you are well, your visits become less frequent as time goes on and the risk of **relapse** reduces.



After a number of years,
you have visits once a
year to check for late
effects of your treatment.



Supported self-management

Once you start to recover from treatment, you might be offered a programme of 'supported self-management'.

Your medical team offer a range of support to help you develop the skills, knowledge and confidence to take a supported self-management approach to your follow-up.

The aim of this is to help you take control of your health and wellbeing, so that you can live well, physically and emotionally, with and beyond lymphoma. It involves keeping track of any symptoms you might be experiencing as well as taking care of your overall health.

Search 'self-management' on our website to find out more about this approach.



If you have new symptoms or you're worried in between check-ups, don't wait until your next appointment.

Contact your medical team. They can reassure you or arrange for you to see them sooner than planned.

What precautions should I take after treatment?

Some treatments mean you need to be treated differently in certain situations, for example, if you have an accident and need a blood transfusion. Your medical team should talk to you about any precautions you need to take.

If you've had steroids

If you had **steroids** as part of your treatment, your body might not make enough natural steroids 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. You can be given steroid replacements if you need them.

You will also need to carry a warning card to show to anyone who treats you.

If you've had a splenectomy or radiotherapy to your spleen

Your **spleen** is part of your **immune system**. It helps to fight infection and filters your blood, removing anything that shouldn't be there and destroying old blood **cells**. If your spleen has been removed (splenectomy) or you've had treatment with **radiotherapy** to your spleen, you won't be able to fight infection as well as you used to.

- **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.
- **You might need to top-up your vaccinations.** You should also have the flu jab every year and a pneumococcal (pneumonia) vaccine booster every 5 years.

- **If you travel to another country, you might need particular vaccinations.** For some parts of the world, you'll need to take precautions to avoid malaria (a tropical disease that's spread by mosquitoes).

See page 183
for more
information about
travel safety

- **In case of emergency keep an emergency supply of antibiotics.** Always carry a card with your treatment details.

Read more about splenectomy at
lymphoma-action.org.uk/Splenectomy



If you need a blood 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.

Keep your
card with you
at all times.

Your doctor will tell you if you need irradiated blood and you will be given a card that says so.

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.

Late effects

Late effects are health problems that develop months or years after treatment. Late effects of lymphoma treatment can include lung problems, heart disease or a second cancer. Not everyone gets late effects, but it's a good idea to find out from your medical team if there's any that you should be aware of.

Knowing what to look out for means you're more likely to catch any problems early. This can make them easier to treat.

Many hospitals have a late effects clinic. You might see the late effects team after your follow-up with your lymphoma doctor ends, or you might be referred back to your GP. Your medical team should give you a treatment summary (see page 170). This explains what late effects you're at risk of and how you'll be monitored for them. If you don't think you have this information, ask a member of your medical team for it.

“

I've moved to Dubai and am enjoying the beaches and sunshine. I still have regular check-ups with my London doctors to see how I am getting on and if there is anything I am concerned about. I have now been in remission for 3 years.

Georgia, diagnosed at 24



Medical matters
after treatment

Top tips for managing late effects

- Find out what problems you are at risk of and any signs or symptoms to look out for.
- Contact your medical team if you have any symptoms.
- Go to your follow-up appointments so your doctor can check for signs of late effects.
- Have any screening tests or health checks you're called for.
- Lead a healthy lifestyle. This includes eating a balanced diet, taking regular physical activity and making time to relax.
- If you smoke, try to give up – this reduces your risk of getting late effects.



Find more information about late effects at lymphoma-action.org.uk/LateEffects



Vaccinations

Most vaccinations are safe for people who have had lymphoma. However, you shouldn't have vaccinations too soon after finishing treatment. This is often the case with 'live' vaccines, made using bacteria or viruses that are weakened but still alive.

After treatment for lymphoma, your doctor is likely to advise that you have the winter flu vaccine. The children's nasal flu vaccine (available up until the age of 17) contains live viruses so speak to your doctor about what to do if you are under this age. From the age of 18, you'll probably be offered the adult flu jab.

Once you finish treatment, you might be advised to get re-vaccinated with all boosters of childhood vaccinations. If you have no spleen or you have had a stem cell transplant, you will need additional vaccines.

Ask your medical
about the the
COVID-19
vaccination.

“

After my treatment, I had to get all my childhood vaccinations done again, as the chemotherapy had wiped my immunity. This was really quick and easy though.

Georgia M, diagnosed at 24

[Check with your GP which vaccines
are safe and necessary for you.]

If you are going to another country, you might need specific vaccinations. You can get advice about these before you travel from your GP or a travel clinic. These clinics are separate from the NHS but advice consultations are often free of charge.

You can search online for your nearest travel clinic. One website that has an online search tool is Masta.



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.



Having a baby after treatment for lymphoma

Many couples go on to conceive a baby without difficulties once they've recovered from treatment for lymphoma.

For more information about fertility, see page 115

Becoming a father

Men often go on to father a child naturally after recovering from treatment for lymphoma. After a standard-dose chemotherapy **regimen**, your sperm count usually recovers and your fertility returns to the level it was at before you had treatment. It can take a year or more after finishing treatment for this to happen, though.

As a general guide, to give your body time to recover, it is not recommended to conceive within 3 months of completing chemotherapy. Some people wait for around 2 years afterwards, when the risk of lymphoma coming back (relapsing) is usually lower. Ask your doctor for advice specific to your individual circumstances.

If your fertility is reduced and you stored sperm before you had treatment, you can use these to begin a pregnancy when you are ready. Even if your sperm count is very low after treatment, modern assisted conception can help you have a family. If you didn't store sperm, then using sperm from a donor might be appropriate for you.

Pregnancy and giving birth

Most women go on to have children naturally after treatment for lymphoma. **Your medical team should advise you how long to wait after finishing treatment for lymphoma before you try for a baby. Most women are advised to wait for up to 2 years.** This gives your body time to recover. There is also a higher risk of your lymphoma coming back (relapsing) in this time, which could mean that you need more treatment.

If your fertility is reduced and you froze your eggs before you had treatment, you can use these to begin a pregnancy when you are ready. Some women might need to use eggs from a donor to have a baby.

Some chemotherapy drugs can damage your heart or lungs in the long term. Pregnancy could place an additional strain on your body. Your hospital specialist can advise you on whether to have your heart and lung function tested before you decide if and when to try to conceive.

Are there risks to the baby if a parent has had lymphoma treatment?

There is strong evidence that there is no increased risk of health problems in babies conceived after treatment for lymphoma. There is also a lot of evidence that babies born to people who have had cancer are not at an increased risk of developing lymphoma themselves.

If I need fertility treatment, will I have to pay for it?

There are variations across the UK. Not all fertility treatments are funded on the NHS.

Search 'infertility treatment' at [nhs.uk](https://www.nhs.uk)



Travelling to another country

Speak to your consultant, nurse specialist or GP about whether your travel plans are safe. They might also be able to tell you a bit about medical services in the part of the world where you're hoping to go.

It's important to have medical cover as part of your travel insurance. This could save you from paying for treatment if you are unwell while you are away. It can also cover extra expenses such as flights if you need to come home early.

Ask your consultant or key worker if they're able to tell you names of companies that have provided travel insurance with medical cover for other people with lymphoma.

Be cautious about travelling to areas where there is a high risk of malaria. Your GP or travel clinic can advise you whether you need anti-malaria tablets and which ones are best for you. Make sure you have any travel vaccinations you need too.

“

I was going travelling for 6 months after being told I was in remission. To ensure I was ready, I began to do more exercise, which helped improve my physical and mental health and gave me more energy. If you are going on holiday, don't let your cancer diagnosis stop you. Listen to the advice given to you by medical professionals and most importantly, enjoy yourself!

Greg, diagnosed at 23



Medical matters after treatment

Top tips when travelling to another country

- If you're taking medication, carry some in your check-in suitcase and some in your hand luggage. Take extra supplies in case your baggage gets lost. Ask your GP to write a letter explaining your situation in case you are stopped at security.
- Avoid mosquito bites by using air conditioning in your accommodation, if you can. Sleep under a mosquito net, 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-toluidide) are generally considered to be most effective.
- Choose clean accommodation and be extra careful with your own personal hygiene.
- 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.

Search 'travel' on our website for more tips on travelling outside of the UK.



Wellbeing check-in



We're here to support you as you adjust to life beyond diagnosis and treatment for lymphoma.



Looking after your own physical and emotional wellbeing is an important part of living well with and managing your lymphoma. There are many services to support you and the people who are important to you. Whether you are new to lymphoma or you have been living with it a while, our services are here for you every step of the way.

Rona, Education and Support Services Manager

- Search 'useful orgs' on our website for a list of organisations you might find helpful, ranging from practical, emotional and various sources of specialist support.
- Find more information about living with and beyond lymphoma on our website.
- Visit lymphoma-action.org.uk/Support to find out how we can support you.

Help, support and more info

You might find it helpful to speak to someone else who has personal experience of lymphoma. Although their experience isn't likely to be exactly the same as yours, it can be reassuring to speak to someone who has been through something similar.

Ask your key worker if there is any support for young people with lymphoma in your area.

Lymphoma Action Online Support Meetings are for people aged 18 and over. Although many people who go are older, you might still want to come along to meet others affected by lymphoma. You are welcome to bring someone with you. If you are 16 or over, you could join an online forum through another organisation.

**[Call our freephone Helpline on
0808 808 5555
Mon to Fri, 10am to 3pm.]**

How we can help

For more information about any of the topics in this book, visit lymphoma-action.org.uk/AboutLymphoma

You might also be interested in our Easy Read books, which include large font and images.

If you'd like to talk to someone about anything to do with lymphoma – including how you feel:



Call our freephone Helpline on **0808 808 5555**, Monday to Friday, 10am to 3pm. You can also use Live Chat on our website or email [**information@lymphoma-action.org.uk**](mailto:information@lymphoma-action.org.uk)



Find an Online Support Meeting for you at [**lymphoma-action.org.uk/OSM**](https://lymphoma-action.org.uk/OSM)



Watch short videos about lymphoma on our YouTube channel. These videos include other young people sharing their story, medical explainers and animations.



[**@lymphomaaction**](https://www.facebook.com/lymphomaaction)



[**lymphoma_action**](https://www.instagram.com/lymphoma_action)

Help, support and
more info

Support from other organisations

Blood Cancer UK funds research into blood cancers. They have information for young people about living with a blood cancer.

Children's Cancer and Leukaemia Group (CCLG) have information about treatment and afterwards for people affected by cancer.

Ellie's Friends is an online resource that lets people aged 16+ living with cancer access free and discounted services in their area.

Jimmyteens.tv features video diaries, short films, music and animations from young people who are having, or have had, treatment for cancer.

Kooth.com offers free, safe and anonymous support for young people, including online counselling.

Look Good Feel Better provides practical support, workshops and tutorials (including on skincare, nail care, make-up and grooming) for people experiencing side effects of cancer treatment.

Lymphoma Out Loud raises awareness of lymphoma in young people. They also have personal stories of people affected by lymphoma on their website.

Macmillan Cancer Support gives practical, medical, emotional and financial support to people affected by cancer. They have separate information for young people.

Maggie's Cancer Centres give free practical, emotional and social support to people with cancer, their families and friends.

Managed Services Network (MSN) for children and young people is part of NHS Scotland and has information about cancer and related issues for young people.

Mummy's Star offers emotional and financial support for women who have cancer in pregnancy and for a year afterwards.

Shine Cancer Support supports adults in their 20s, 30s and 40s diagnosed with cancer. They offer videos, podcasts, personal experiences, an online forum and support events around the UK.

Something to look forward to offers gifts donated by individuals and companies to people affected by cancer.

Teenage Cancer Trust offers information and support for young people living with cancer and for their families. Their annual 'Find your sense of tumour' event brings together young people who have had cancer for a weekend of talks, workshops and socialising.

Trekstock supports young adults in their 20s and 30s with cancer.

Willow Foundation offers days out for young adults (aged 16 to 40) who are seriously ill.

Working With Cancer advises people affected by cancer about returning to work, remaining in work or finding employment at any stage during or after cancer treatment.

Young Lives vs Cancer offers practical, emotional and social support to children and young people with cancer, and to their families.

Young Minds offer online information and self-help tips to improve wellbeing of children and young people.

Youth Cancer Trust provides free activity-based holidays for young people aged 14 to 30 who have cancer.

Help, support and
more info

Glossary

Anaemia shortage of red blood cells in your blood

Anaesthetic a drug that stops feeling, especially of pain: in a general anaesthetic the drugs put you into a sleep-like state; in a local anaesthetic the drug numbs just part of the body

Antibody a protein made by your immune system to fight infection

B symptoms unexplained weight loss, drenching night sweats, high temperature (fever)

Biopsy a test that takes cells from your body to be looked at under a microscope

Blood count how many blood cells of each type (red blood cells, white blood cells and platelets) you have in your blood

Bone marrow the spongy tissue inside your bones where blood cells are made

Cell the tiny building blocks of our bodies; they make up different parts of your body, like blood, muscle and bone

Central line a thin plastic tube inserted into a vein deep inside you to give treatments (like chemotherapy) and take blood samples

Central nervous system (CNS) your brain and spinal cord

Cerebrospinal fluid (CSF) the fluid that surrounds your brain and spinal cord

Chemotherapy (chemo) treatment with drugs to kill cancer cells

Drip slow, drop-by-drop infusion of a liquid into a vein

Extranodal outside the lymph nodes

Immune system the system in your body that fights infections

Late effects health problems that might develop months or years after treatment has finished

Lymph node a gland that acts as a filter in the lymphatic system and is where lymphocytes gather to fight infection

Lymphocyte a type of white blood cell that fights infection; lymphoma develops when lymphocytes grow out of control

Lymphoma a type of blood cancer that develops when white blood cells (lymphocytes) grow out of control

Neutropenia a shortage of neutrophils, the main type of white blood cells that fights infection

PICC line 'peripherally inserted central line' – a flexible tube inserted into one of the large veins in your arm, above your elbow; it can be used to take blood or give treatment

Platelets tiny fragments of cells in your blood that help your blood clot when you cut yourself

Portacath a central line that has a reservoir (port) just under the skin, which can be used to take blood or give treatment

Protein found in all living things; they have many important roles and help to control how our cells work

Help, support and
more info

Radiotherapy treatment that uses high-energy waves (X-rays)

Refractory Doctors might say that your lymphoma is refractory if it comes back within 6 months of treatment

Regimen a treatment plan listing types, how much you have of each (dose), and when you have them; often named after the first letter of each drug in the regimen

Relapse lymphoma that comes back after successful treatment and a remission lasting at least 6 months

Remission no evidence of lymphoma in tests and scans after treatment

Sedative a drug to help you relax

Spleen a part of your immune system that helps fight infections; it also clears bacteria and old or damaged blood cells from your body

Staging the process of working out which parts of your body are affected by lymphoma; doctors then give your lymphoma a 'stage' (a letter and sometimes also a number)

Stem cell undeveloped cells that can divide and mature into all the different types of cell your body needs

Steroid anti-inflammatory medicine that also regulates your metabolism and immune response

Thrombocytopenia shortage of platelets in your blood

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References

We have used books, online information and journal articles to develop this information. If you would like our reference list, please contact us on 01296 619400 or email publications@lymphoma-action.org.uk

Help, support and
more info

Notes

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This book offers information about what lymphoma is and how it's treated in young people. It gives tips to help you live well 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.



Helpline (freephone) **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)

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