Young person’s guide to lymphoma
My diagnosis

My lymphoma type and stage

Key worker contact details

My treatment
Who we are

We’re Lymphoma Action, a UK charity that provides specialist information and support to help people affected by lymphoma. We hope you feel more in control, more confident and better connected to help you cope with your diagnosis.

We follow best practice guidelines to make sure we produce reliable, high quality information.

We’ve written this book in collaboration with expert medical advisors. We are also grateful to the young people affected by lymphoma who reviewed and helped with this publication.

To find out more about us and to look for more information on any of the topics in this book, head to lymphoma-action.org.uk
How to use this book

Who’s it for?
If you are a young person with lymphoma, this book is for you. Use it however it best helps you: write in it; take it to appointments; share it with friends and family.

What’s inside?
This book tells you what lymphoma is and what to expect during and after treatment. It answers some of the common questions young people have and offers tips on looking after yourself.

You don’t have to read it all at once or in any particular order. Some sections might not be relevant for the type of lymphoma you have; others might become relevant only after you’ve been through 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 tab to make it easy to flip between them.

Yellow boxes are for you to make notes.

Quotes from young people who have had lymphoma are given in speech marks.
Top tips give ideas about how to cope with aspects of your lymphoma and treatment.

Circles signpost to other pages in this book where you'll find more information.

Useful websites are given next to an @ symbol.

Important points are shown alongside an exclamation mark.

Words in bold are explained in the glossary on pages 145 to 148.

The information in this book can be made available in large print.
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Lymphoma is a type of cancer. Being diagnosed with lymphoma can be very scary. Many people haven’t heard the word ‘lymphoma’ before they are diagnosed.

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

Although you probably don’t know anyone else your age who has had cancer, you are not alone – there are others your age.
Treatments for lymphoma in young people are generally very successful. With the right treatment, most young people who have lymphoma go into complete remission (no evidence of lymphoma) and stay in remission.

**Lymphoma** is a type of cancer. Cancer develops 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 breakdown in control means abnormal cells build up. These cells can form a cancer.

In cancer, the abnormal cells are ‘malignant’, which means they can spread to other parts of the body and start growing there too.

There are lots of different types of cells in your body. That’s 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’, which make antibodies to fight infections
- T lymphocytes, also called ‘T cells’, which 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 are called ‘T-cell lymphomas’. Very rarely, lymphomas aren’t typical of B cells or T cells. These are called ‘null’ types.

What’s the lymphatic system?

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

- your thymus – a gland where undeveloped (‘baby’) T cells grow into fully working (‘adult’) T cells
- your spleen – an organ that helps fight infection by filtering your blood as it passes through the spleen, destroying old and damaged blood cells
- your bone marrow – a spongy material in the middle of your bones (the ‘factory’) that makes all your blood cells.
Healthy lymphocytes travel around your lymphatic system in a fluid called **lymph**. They collect in your lymph nodes, 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.

![Diagram of the lymphatic system with labeled parts: Thymus, Armpit (axillary) lymph nodes, Neck (cervical) lymph nodes, Lymph vessels, Groin (inguinal) lymph nodes, Diaphragm (muscle that separates the chest from the tummy), Spleen. The diagram is labeled as "The lymphatic system".]
Lymphoma can sometimes be difficult for doctors to diagnose. Many of the symptoms (signs of illness) of lymphoma are also seen in other, less serious conditions, like viral infections. Even people who have the same type of lymphoma can have different symptoms.

In the past, you might have noticed that you had swollen glands in your neck when you had a sore throat or earache. These were lymph nodes that swelled up (enlarged) because lymphocytes were reacting to the infection and fighting it. 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.

Swollen lymph nodes are often found in the neck, armpit or groin. Not all lymphomas have obvious lumps. Sometimes lumps are deep inside you where you can’t feel them.

If the lymphoma starts in a lymph node deep inside you, you might get other symptoms. Lymphoma can grow outside your lymph nodes as well — it is then 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 big, swollen tummy, which can be uncomfortable or painful.
Other common symptoms:

**Fatigue**
Fatigue is not the normal feeling of being tired. You might feel exhausted for no obvious reason or feel washed out after doing very little.

**Unexplained weight loss**
Unexplained weight loss means losing a lot of weight quite quickly without trying to.

**Sweats**
Lymphoma can cause night sweats that make your nightclothes and bed sheets soaking wet. The night sweats are often described as ‘drenching’. They can happen with any type of lymphoma and can also happen during the day.

**Itching**
Itching (pruritus) with or without a rash can be very troublesome, particularly in hot weather.
Some symptoms often occur together:

- night sweats
- unexplained weight loss
- fevers (temperature above 38°C).

Doctors call these three symptoms 'B symptoms'. Having B symptoms can affect how you need to be treated.

You might have different symptoms from these.

"About 4 years before I was diagnosed, I had noticed a lump in my armpit and had been to my GP. At the time, he reassured me it was fatty tissue. Although the lump didn’t go, I ignored it. That was until July 2018, when I noticed the lump suddenly get a lot larger. I also noticed lumps in my neck and chest."

Adam, diagnosed at 27
Why did I develop lymphoma?

Did I catch lymphoma from someone?
No, you can’t catch lymphoma. You can’t give it to anyone either.

Did I do something that gave me lymphoma?
Nothing you have done or that other people have done has caused your lymphoma. There is also no evidence that stress or exercise (or lack of it) causes lymphoma.

Do I have lymphoma because of something I’ve eaten or drunk?
There is no evidence linking what you eat or drink with developing lymphoma.

Did I get lymphoma from my parents?
No. Lymphoma is not inherited from your parents.

Will my brothers and sisters get it?
It is very unlikely that your brothers and sisters will get it, but there is a slightly increased risk with some lymphomas.

In most cases, the cause of lymphoma is unknown.

Why me?
Some people with conditions that affect their immune system, or who have had certain viruses such as Epstein–Barr virus, might have a higher risk of developing lymphoma. However, most people with these conditions or viruses do not develop lymphoma. In most cases, no one can say why you have developed lymphoma.
Questions

Make a note here so that you remember the questions you want to ask when you see your doctor.
In this section, we outline tests that you might have. You might want to skip the sections that don’t apply to you.

Tests before treatment

- Tests before treatment help your doctors find out as much as possible about your lymphoma – for example, what type it is and where it is in your body. This is known as staging (whether the lymphoma is ‘advanced’ or not).
- Your doctors might also run tests to check how well your organs are functioning before deciding on the best treatment for you.

Tests during treatment

- During treatment, your doctors test how well your body is coping with treatment and whether the treatment is getting rid of your lymphoma.

Tests after treatment

The tests you have after finishing treatment allow your doctors to check:

- how well you are recovering
- for side effects that can develop months or years after treatment
- that there are no signs of the lymphoma coming back.

Find out more on page 33.

Some of the tests are only done for certain types of lymphoma.
I had never had an anaesthetic before so I was a bit nervous, but the nurses and doctors were really kind and cheerful when they told me what was going to happen. When they put in the anaesthetic I had no time to really worry about anything because I was fast to sleep in an instant.

Georgia, diagnosed at 11

Biopsy

A biopsy is when you have some tissue (usually a lymph node) removed and looked at under a microscope.

Why might I have one?

A biopsy is the main way of confirming if you have lymphoma or not. Doctors do laboratory tests on the biopsy sample to find out what type of lymphoma you have.

Getting the results back can take a while. Waiting isn’t easy, but your doctors need to know exactly what type of lymphoma you have so that you can get the right treatment.

What happens?

You usually have a whole lymph node removed. You are likely to have a general anaesthetic for this, so that you are asleep while it is done.

If you only need to have a small piece of lymph node removed, you might have that done under a local anaesthetic.
Scans

A scan is a way to take a picture of what's inside you. There are different types that build up pictures in different ways.

Some scans are better than others at seeing different parts of your body. Don’t worry if you have a different type of scan to someone else – your doctor decides which type of scan is best for you in your circumstances.

Why might I have one?

There are lots of lymph nodes deep inside your body and there are parts of your body that can’t be seen from the outside. Scans are used to show which parts of your body have lymphoma.

What happens?

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

Scans don’t hurt, but you have to lie very still. You might feel uncomfortable about being in an enclosed space or about being on your own. The hospital staff will do all they can to help you stay relaxed. You might be able to listen to music during your scan, and can also talk to the staff, even if they are in another room.
Let the staff know in advance if you are worried about having a scan.

Carefully follow any instructions about preparing for your scan.

Ask what you should wear and if you need to remove any jewellery.

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) before your scan to make your organs easier to see. You have it as a drink or as an injection into a vein.

You lie on a bench that moves slowly into a doughnut-shaped machine. The machine is open at both ends. It takes lots of pictures from different angles to build a 3D image of the inside of your body.

A CT/CAT scan takes about 15 to 45 minutes.
PET scan

PET stands for ‘positron-emission tomography’. This type of scan helps doctors tell the difference between scar tissue and growing lymphoma.

A lot of people feel a bit nervous before the scan. The hospital staff will help you stay warm and as relaxed as possible. You might be able to listen to music or read to help you feel calm.

You can’t eat or exercise for a few hours before a PET scan.

When you go for the scan, you have an injection of a harmless radioactive sugar. You then wait for about an hour for your cells to take up the sugar. You have to stay quite still. Lymphoma cells absorb much more of the sugary liquid than normal cells and show as ‘hot spots’ on the scan image. Your brain also uses a lot of sugar and will show up as ‘hot’.

Most people have a CT scan at the same time to get a clearer picture of where the lymphoma is – this is called a PET/CT scan. You lie on a bench and the scanner moves over you. It is open at both ends.

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.

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

MRI stands for 'magnetic resonance imaging'.

You lie on a bench that moves into a cylinder that is open at one end. The machine contains strong magnets, so you must take off anything that contains metal, including a bra and jewellery. Make sure you don’t have any bank cards in your pockets either as the machine can damage them.

An MRI machine makes a 3D picture of the inside of your body by measuring changes in magnetic waves as they pass through you.

An MRI scan usually takes up to an hour. The machine can be very noisy. You could ask the medical staff if you can wear earplugs or listen to music.

Ultrasound scan

Ultrasound scans use sound waves to create an image. They are often used for scanning the tummy (abdomen).

You lie down on a couch. A technician puts gel onto your skin and moves a small device called a ‘probe’ over the gel to produce a picture. The gel might feel cold and can be sticky but it wipes off easily.

An ultrasound usually takes about 15 minutes.
What’s lymphoma?
Bone marrow biopsy

Lymphoma can sometimes grow in your bone marrow. In a bone marrow biopsy, a doctor takes a sample of bone marrow, usually from your hip, and looks at it under a microscope. Occasionally, some people with lymphoma might have a bone marrow biopsy.

Why might I have one?

With some types of non-Hodgkin lymphoma, doctors need to know whether there is any lymphoma in your bone marrow before they can decide on the best treatment for you.

What happens?

You have either a general anaesthetic, or a local anaesthetic with a sedative (a drug that relaxes you). If you’re feeling nervous and you aren’t offered a sedative, ask your medical team if you can have one.

You lie on your side while a doctor inserts a needle through your skin into the back of your hip (pelvic) bone to take a small sample of bone marrow. You feel some pressure as the needle enters the bone. You might feel sore afterwards. Painkillers (like paracetamol) can be helpful, but talk to your medical team if you need something stronger.

Tell your medical team if the place where the needle went in becomes red or swollen or if it bleeds. It might be a sign of infection.
Lumbar puncture

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

Some people have lymphoma in their brain or spinal cord (your central nervous system or CNS). 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.

Why might I have one?

Doctors need to know whether you have lymphoma in your CNS before they can decide on 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 if you can have a sedative.

You lie on your side with your knees bent. 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 being collected.

A lumbar puncture takes about 5 to 10 minutes. You need to lie flat for a while afterwards, usually for about an hour. If you’re having chemotherapy drugs given into your CSF at the same time, it can take a couple of minutes longer. Some people get a headache after a lumbar puncture. It might feel better if you lie down.

Drink plenty of water and take painkillers if you need them. Your medical team can advise you which type is best for you.
Blood tests

You might feel like you are always having blood tests.

Blood tests help find out how lymphoma is affecting your body and how well your body is coping with treatment. You have blood tests as part of diagnosis and staging. You also have them before each cycle (round) of chemotherapy to make sure it is safe for you to have treatment.

Why might I have them?

Treatment for lymphoma affects healthy cells (especially blood cells) as well as lymphoma cells.

You have blood tests to check if you have enough of each type of blood cell and to see how well your liver and kidneys are working.

What happens?

You might have blood samples taken 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.

What if I’m scared of needles?

Talk to your medical team. They're used to helping people who are scared of needles.

We have more information about tests and scans at lymphoma-action.org.uk/Tests

Read more about low blood counts on page 79.
What can I do while I am waiting for test results?

It can be hard waiting for test results. While it can be tempting to look online, your medical team are best-placed to answer your questions. They look at all the information from your tests to find out as much as possible about your lymphoma and plan the best treatment for you. If you do look online, make sure that you are looking at sites that are reputable and have good quality information.

You might feel relieved when treatment begins and you have a plan of appointments to focus on. There are a few things you can do to help you understand what happens next:

- Talk things through with your doctors and nurses and ask all the questions you have, including how other areas of your life (such as school or work and social life) might be affected by your treatment.
- Read the information you have been given about your treatment and what side effects you might have.
- Find out how things are arranged at the hospital where you’ll be treated and what facilities there are. You might want to find out if there’s WiFi available and if there’s a kitchen for you to make drinks and snacks. Some hospitals also have a common room or lounge with a TV.

How will I feel after a diagnosis of lymphoma?

Going for medical appointments and waiting for test results can be difficult. You might be scared and anxious. You might feel angry or frustrated that you have to take time out of school, college or work. Although it might be a relief to be having the tests and scans you need, the whole process is likely to be challenging.
There is no ‘normal’ way to feel when you find out you have lymphoma.

You might have lots of reactions, even within the space of a day. People often experience a mixture of feelings when they are first diagnosed, including shock, fear, anxiety, helplessness, anger, sadness and loss, guilt and isolation.

“Like many people in their 20s, I thought I was invincible. I never thought anything could be seriously wrong. So I was totally shocked when I was told I had nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

Adam, diagnosed at 27

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 support you.

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

- what type of lymphoma you have
- what stage it is (where it is in your body)
- what happens next.

What types of lymphoma are there?

There are two main groups of lymphomas:

- Hodgkin lymphoma
- non-Hodgkin lymphoma (NHL).

In teenagers and young adults (15 to 24 years old), Hodgkin lymphoma is more than twice as common as NHL.
What’s the difference between Hodgkin lymphoma and non-Hodgkin lymphoma?

In Hodgkin lymphoma, doctors can see particular types of abnormal B cell called Reed–Sternberg cells or Hodgkin cells when they look at a biopsy sample under a microscope.

NHL is any type of lymphoma that doesn’t contain these cells.

What types of Hodgkin lymphoma are there?

There are two main types of Hodgkin lymphoma.

- The most common type is classical Hodgkin lymphoma, which makes up about 90 to 95% 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). They are all treated in the same way and have similar outcomes.

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

What types of non-Hodgkin lymphoma are there?

There are many different types of NHL. Depending on the type of lymphocyte they develop from, they can be a ‘T-cell lymphoma’ or a ‘B-cell lymphoma’. Occasionally some types of lymphoma aren’t typical of either B cells or T cells – these are known as ‘null’ types.
NHL can also be divided into fast-growing (high-grade) or slow-growing (low-grade) lymphomas. Most young people have a high-grade lymphoma. This might sound worrying, but high-grade lymphomas are more responsive to treatment and more likely to go into long-term remission (no evidence of lymphoma) than low-grade lymphomas. Low-grade lymphomas can be harder to treat and tend to come back (relapse), needing more treatment.

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

- Diffuse large B-cell lymphoma (DLBCL) is a B-cell lymphoma that can develop in lymph nodes or in extranodal sites, such as the chest and tummy.
- Burkitt lymphoma is a B-cell lymphoma that often involves lymph nodes in the tummy or bowel, head and neck.
- Lymphoblastic lymphoma is a T-cell lymphoma that most often causes swelling of lymph nodes around the heart. B-cell lymphoblastic lymphoma can also occur.
- 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.

We have more information about these and other types of lymphoma at lymphoma-action.org.uk/Types
Check that any sources of information that you use are reliable and up-to-date. Look at where the information is coming from – for example, is it a well-known and trusted organisation? Has it been written or reviewed by a lymphoma expert?

Find out when the information was updated and whether it is backed up by scientific evidence.

Be wary of information from sites that are selling something.

A lot of statistics are very general – cure rates in young people are much higher than in older people and are improving all the time.

Your medical team are the best people to talk to about your lymphoma as they know your individual circumstances.
‘Staging’ is the process of working out which parts of your body are affected by lymphoma. Doctors use your stage to help decide what treatment you need.

There is one staging system for people with Hodgkin lymphoma. Different staging systems are used for NHL in people who are under 18 and over 18. All the systems have four stages.

**What are the four stages?**

Stages of lymphoma range from 1 to 4, with 1 being the earliest and 4 being the most advanced stage. You might also see the stage written in Roman numerals: I, II, III or IV.

If you have early-stage lymphoma (stage 1 or 2), it means your lymphoma is localised to one place or a few places that are on the same side of your diaphragm (the sheet of muscle across the bottom of your ribcage that separates your chest and heart from your tummy).

If you have advanced-stage lymphoma (stage 3 or 4), it means your lymphoma is affecting more of your body. It 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**.

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 good treatments for all stages.
What do the letters mean?

As well as a number, your doctor might use a letter after your stage.

<table>
<thead>
<tr>
<th>Stage letter</th>
<th>What it means</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong></td>
<td>You haven’t had any B symptoms (you might hear the word ‘asymptomatic’ which means ‘no symptoms’)</td>
</tr>
<tr>
<td><strong>B</strong></td>
<td>You’ve had one or more B symptoms: unexplained weight loss, drenching night sweats or high fevers</td>
</tr>
<tr>
<td><strong>E</strong></td>
<td>Your lymphoma has grown in extranodal sites (outside the lymph nodes)</td>
</tr>
<tr>
<td><strong>S</strong></td>
<td>There is lymphoma in your spleen</td>
</tr>
<tr>
<td><strong>X</strong> or bulky</td>
<td>You have large lumps of lymphoma</td>
</tr>
</tbody>
</table>

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 for you to help you remember them.

We have more information about staging at lymphoma-action.org.uk/Staging
Will I be cured?

Treatments for lymphoma in young people are 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 get 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.
You and your medical team should decide together the best place for you to have your treatment.

Where am I treated?

Children and young people with cancer are treated in Principal Treatment Centres (PTCs) or Teenage and Young Adult (TYA) designated hospitals.

A PTC is a hospital with specialist facilities for diagnosing and treating children and young people with lymphoma.

A TYA-designated hospital is a hospital that is approved to treat teenagers and young adults with lymphoma as part of its adult cancer services.

PTCs in the UK are usually located at large teaching hospitals. They might be a long way from your home. TYA-designated hospitals are usually more local.

“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
You might have different parts of your treatment at different places. This is called a ‘joint’ or ‘shared’ care arrangement. You might see experts at different hospitals.

Some hospitals have cancer units designed specifically for teenagers and young adults. These units allow you to be with, and gain support from, people of a similar age.

Ellie 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."
Young adults aged 19 to 24

If you're between 19 and 24, you can choose whether you would like to be treated:

- in a specialised teenage and young adult unit or adult ward at a PTC
- in a teenage and young adult-friendly part of an adult ward at your local TYA-designated hospital
- in a 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
Do I have to stay in hospital?

You’ll need to spend time at the hospital during your treatment. Generally, you won’t need to stay in hospital overnight, although this depends on the type of treatment you have.

You are likely to have most of your treatment as an outpatient. This means you go to the hospital for your treatment but you don’t need to stay overnight. Ask how long you’ll be at the hospital for each time. You can usually take someone with you to keep you company.

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, like infections. If you are under 19 and you’re being treated in a teenage and young adult unit at a PTC, someone can stay with you overnight in most units, 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 are admitted to hospital.

You might have the option of having chemo at home. This is called 'ambulatory chemotherapy'. You go to the hospital every day for check-ups and to have your treatment set up in a special pump. You wear the pump in a backpack or bumbag. This means you can have the treatment away from the hospital. You can contact the hospital at any time if you have any problems.
Questions you might like to ask about hospital:

Where am I being treated?

Is there WiFi? Can I use my mobile phone or tablet?

Is there a TV? Can I bring a TV? Do I have to pay for 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?

If I am staying in, when can my friends and family visit?

Is there anywhere for my friends and family to stay?

What should I take with me to hospital?
Top tips when staying in hospital

Ask to visit the unit so you know how it is set up before you stay.

Keep in touch with what’s going on at school, college or work.

Bring things from home to make your space friendly and comforting, like photos and bedding.

Wear your own night and day clothes, and get dressed whenever you can.

Find out when visiting hours are so that friends and family can spend time with you.

Bring something to do, such as books, music, magazines, your phone or tablet.

Preload your phone or tablet with apps, music and films to keep you occupied.
Who looks after me?

You see lots of different health professionals during your treatment. They all have different roles in your care. This is sometimes called a ‘multidisciplinary team’ (MDT). You have one main contact (known as your ‘key worker’) who you can talk to about your questions or concerns. Your key worker is often a clinical nurse specialist (CNS), or sometimes a teenage and young adult (TYA) nurse specialist.

Who is ‘my doctor’?

You have a consultant or specialist who is in charge of planning your treatment, checking your progress and seeing you after treatment ends. This is often a haematologist (a specialist in blood conditions) or an oncologist (a specialist in cancer). You see other doctors, too, but your consultant oversees your care. The hospital should also tell your GP what’s happening with your treatment.

Who else is involved?

You might also meet a:

- radiographer or medical technician, who carries out X-rays and scans
- research nurse, who looks after you if you take part in a clinical trial
- dietitian, who gives advice about food and nutrition during your treatment
- physiotherapist or occupational therapist, who keeps you fit and active
- social worker or young people’s community worker, who can help you and your family with the day-to-day impact of your illness, for example, by helping you to get advice about money
- psychologist or counsellor, who can help you work through your feelings about your diagnosis and treatment.
There might be other people involved in your care too. There can be a lot of names and job titles to remember. You can use the space below to help you keep track of who’s who. You could include any important phone numbers or other contact details too.

<table>
<thead>
<tr>
<th>What do they do?</th>
<th>Name and contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key worker (clinical nurse specialist)</td>
<td></td>
</tr>
<tr>
<td>Consultant</td>
<td></td>
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<tr>
<td>Other doctors</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td></td>
</tr>
<tr>
<td>Physiotherapist/occupational therapist</td>
<td></td>
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<tr>
<td>Psychologist/counsellor</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
</tr>
</tbody>
</table>
Who makes decisions about my treatment?

Your medical team should talk to you about your illness and treatment in a way that you understand. You should be involved in decisions about your care. You should also be told about possible side effects and what to do if you have a problem.

It's up to you how much you want to know about your care. You might just want to know the basics or you might want to know every detail.

If you take someone with you to appointments, such as a parent, carer or partner, decide beforehand how you would like them to act. You might want them to lead the discussions or you might prefer to talk to the medical team yourself. You might want your medical team to involve you and your family equally.

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.
TOP tips for asking questions

If you have a question, ask.

If you think a question is 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 have several questions, write a list.

If you don’t understand the answer, say so.

Write down answers or ask someone to take notes for you.

If you forget the answer, don’t be embarrassed to ask your question again.
Questions

Make a note here so that you remember the questions you want to ask when you see your doctor.
Do I have a choice about what treatment I have?

There are UK guidelines setting out the best treatment for each type of lymphoma.

It is your doctor’s duty to offer you the best treatment that is recommended for your type of lymphoma. If there are treatment choices, your medical team should explain them to you. Most treatment for young people with lymphoma is done as part of a clinical trial.

Who agrees to my treatment?

You can only have treatment if you, or an adult responsible for you, agrees to it by signing a consent form.

If you are 16 or over, you are considered capable of deciding on your own medical treatment unless there is significant evidence to suggest otherwise. You can sign your own consent form. You can’t have any treatment without your agreement.

If you are under 16, you might be able to sign your own consent (assent) form if your doctors think it is appropriate, but 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 on your behalf.
Clinical trials are an important way of improving treatments for lymphoma in young people.

A clinical trial tests a new treatment against the best existing treatment (sometimes called the ‘gold standard’ of treatment), or compares existing treatments against each other. Trials can test new drugs or tried-and-tested drugs used in different ways or amounts.

Even though treatment is usually successful, clinical trials are still 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
- find ways to work out who might need more intensive or different treatments
- test whether newer treatments could be safer and more effective than the current best treatments.

See page 138 for information on late effects.
Clinical trials are designed to be safe, fair and ethical.

You will always be given active treatment in a clinical trial if you would be having active treatment outside of a clinical trial. Everyone taking part is monitored very carefully at every stage of treatment and during follow-up.

Will I be offered a clinical trial?

Your doctor is likely to recommend that you are treated either following nationally agreed treatment guidelines or as part of a clinical trial. You should always be offered treatment on a clinical trial if there is one available for your type of lymphoma. If your doctor suggests a trial, they should give you information about it. You should have time to think it over and then to ask any questions you might have.

To help you decide whether to take part, you might want to talk it through with friends, family members or your GP.

“
I was offered to go on a clinical trial and my initial reaction was that I did not want to be experimented on. I later realised it was in my best interest and I would be monitored closely.

Ruchi, diagnosed at 24
What happens if I say ‘no’?

You don’t have to take part in a clinical trial. It is your decision and 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, which is often very similar to the trial treatment.

How do doctors decide which trial treatment I get?

Clinical trials usually compare two or more treatments. Which treatment you get is often ‘randomised’, which means it is allocated by a computer. You can’t decide which treatment you have and neither can your doctor. You usually know what treatment you are having and you get 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 have information about all the different treatments you might be on.

What if there’s not a trial for me?

You might feel disappointed if you’d like to take part in a trial but there isn’t one that’s suitable for you.
Clinical trials have criteria that the people taking part have to meet.

These criteria are important in making sure the trial is as safe as possible for the people taking part. They also make sure the trial compares treatments fairly in groups of people with similar characteristics. If you don’t meet the criteria for the trial, you can’t take part. Sometimes, there might not be a trial open for your type of lymphoma. Although you might be disappointed not to take part in a trial, you will get the best available standard treatment instead.

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. Your doctor can give you more information if this is the case for you.

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

Your treatment depends on the type and stage of your lymphoma and other factors, including your age and general health. Everyone is different so treatment is planned individually, but:

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

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

Chemotherapy

Chemotherapy means ‘treatment with drugs’. It is often called ‘chemo’ for short. Chemo drugs are designed to kill cancer cells.

Why do I have several different drugs?

You usually have several different chemo drugs combined in a regimen. Each drug kills cancer in a slightly different way. Having several together helps kill 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.
You’ll probably have steroids 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. The steroids you have are not ‘body building’ (anabolic) steroids.

**How long does chemo take?**

Chemo is given in cycles. A cycle is a block of treatment that is given over several days, followed by some time off (usually a few weeks) to let your body recover. You need time to recover because chemo kills healthy (rapidly dividing) cells as well as lymphoma cells. Each cycle is usually 2 to 3 weeks long. A series of cycles makes up a course of treatment.

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 until it is safe for you to have more.

How long your whole course of chemo lasts 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.

Go to lymphoma-action.org.uk/Chemotherapy to watch an animation about how chemo works.
My treatment

What drugs am I having?

How often do I have them?

Will I have to stay in hospital?

How long will my treatment take?

What tests do I need during my treatment?
How do I have chemo?

You have some drugs by mouth (orally), usually as tablets for you to swallow.

Many chemo drugs have to be given through a drip into a vein (intravenously). 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 (a PICC line) or your chest. It is called a ‘central’ line because the end of the tube goes into a central vein (superior vena cava) just above your heart.

You can have lots of different types of treatment through a central line. You can have blood taken through it too. Speak to a member of your medical team if you are worried about having a central line.
There are different types of lines:

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 lumens. This is easier to fit. It is usually used for short-term treatment or until you have one of the longer-lasting lines fitted, if you need one.

A Port-A-Cath® is a line that ends in a reservoir (port) just under the skin on your chest. A special needle goes through your skin into the port each time you have treatment.

There are advantages and disadvantages to each type of line. You can talk to your medical team to decide which type is best for you.
TOP tips for lines

Don’t go swimming or get your line wet unless you have a Port-a-Cath® fitted. Ask your nurse for the best way to protect your line when you shower or bath.

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 Port-a-Cath®) and every time it’s used. Ask your nurse about this if they don’t do it.

Ask what signs of infection to look for.

Make sure you know who to call if you have any problems with your line.
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 are not in hospital.

You have your central line taken out when you finish your treatment. This will also involve a small operation.

Questions

Make a note here so that you remember the questions you want to ask when you see your doctor.
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.

**What side effects from chemo might I have?**

Chemo works by killing cells that are dividing. Unfortunately, this kills healthy cells as well as lymphoma cells, particularly cells that divide rapidly like your blood cells, hair root cells or the cells that line your gut. The damage to healthy cells causes many of the side effects (unwanted effects on your body) of chemo.

Most people treated with chemo get some of the following side effects during their treatment:

- 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
- fatigue.
You might have other side effects. 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.

See page 74 for more information about side effects and tips on coping with them.

Everyone responds **differently** to treatment. Some people get more side effects than others.

“For my own mental sanity, I weirdly wanted the treatment to make me ill. I needed the confirmation that the drugs were working.”

Natalia, diagnosed at 20
Radiotherapy

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

How does radiotherapy work?

Radiotherapy uses powerful X-rays focused on the lymphoma cells to kill them. The type of radiotherapy used in lymphoma treatment doesn’t make you radioactive – you won’t harm anyone else by being close to them after your treatment.

The lowest possible dose of X-rays is used to reduce the chances of long-term side effects and late effects.

How long does radiotherapy take?

You have radiotherapy each weekday 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 to keep very still during the treatment.

I had five sessions of radiotherapy. They said I would need a metal plate for the bottom of my back. I joked, ‘like Robocop?’ But no, it was far less cool than that. It was basically me lying down, then they brought a big machine down to the hole in the plate and zapped it.

Dwayne, diagnosed at 25
What side effects from radiotherapy might I have?

Many people treated with radiotherapy have sore skin in the area being treated. Other side effects depend on the area of your body that is treated. 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.

Targeted drugs

Targeted drugs are treatments that affect certain cells without affecting others.

They work a bit like guided missiles or magic bullets, homing in on specific proteins that lymphoma cells have but most healthy cells don’t.

Lots of targeted drugs are used to treat lymphoma and many more are being developed. They’re often used to treat adults but are sometimes used for under 18s.

If you’re under 18, you might have a targeted drug as part of a clinical trial.

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 delivers 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 aged 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.

How do I have targeted drugs?

Most targeted drugs are given intravenously (into a vein). How often you have them depends on your exact treatment.

What side effects might I have?

Targeted drugs usually cause fewer side effects than chemo because they have less effect on healthy cells. Different targeted drugs cause different side effects. Your medical team should give you information on the side effects of any treatment they recommend.
Complementary therapy

Complementary therapies do not treat your lymphoma. They are used in addition to your hospital treatment. Some research suggests that complementary therapies might help to:

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

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

‘Alternative’ therapies are not ‘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.
I’m pregnant – will this affect my treatment?

Generally, you’re advised not to get pregnant if you are having, or will soon start, treatment for lymphoma.

If you’re already pregnant when you are diagnosed, your medical team will take this into account when planning your treatment.

Some treatments could carry a risk of abnormalities or serious harm to your unborn baby. Depending on the stage of your pregnancy, your medical team might advise you to delay treatment until after your baby is born.

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.

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 alter your treatment plan. They will discuss the risks and benefits of different treatment options with you.

If your treatment is urgent, 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: pregnancychoicesdirectory.com
How do I know my treatment has worked?

You have tests at the end of treatment to make sure your lymphoma is in remission (no evidence of lymphoma).

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.

A few people need more treatment at this point. You can find out more about what happens if your first treatment wasn’t successful or your lymphoma has come back (relapsed) on page 68.

Coping with treatment

Treatment and its side effects can be a lot to cope with, both physically and emotionally. You’re likely to feel lots of different emotions, sometimes even within the space of a single day. Find suggestions for coping with difficult feelings on page 96.

“ My feelings were all over the place. When I was having chemotherapy, my family were always there to keep my spirits high; we played silly games and made up stories and those things always brightened my day. I also played online video games and read books which helped distract me from the treatment.

Georgia, diagnosed at 11
Most people go into remission after their first treatment and stay in remission. 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 (no evidence of lymphoma). If your lymphoma seems to be resisting the treatment, it is called refractory lymphoma. If this is the case, 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 stronger chemotherapy.”
What is relapse?

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 62), usually through a clinical trial
- CAR T-cell therapy (page 63), usually through a clinical trial.

High-dose treatment and stem cell transplants

Your body constantly replaces your blood cells when they naturally get worn out and die. New blood cells are made from stem cells, which live in your bone marrow (spongy tissue inside your bones). A stem cell is an immature blood cell that can develop 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 kill lymphoma cells than standard treatment but it also kills your 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.
Do I need 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 tell you if they think you need a stem cell transplant.

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.

How does it work?

You have treatment to help your body make more 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. They find their way back to your bone marrow where they can start making new blood cells.
The autologous stem cell transplant process

1. Preparation
You have tests and scans to make sure you are fit enough to have a stem cell transplant, and treatment to get your body ready.

2. Stem cell collection
Your stem cells are collected from your bloodstream and frozen until they are needed.

3. Conditioning
You have high-dose anti-cancer therapy to treat your lymphoma. This destroys your remaining stem cells.

4. Stem cell infusion
Your stored stem cells are thawed and given back to you.

5. Engraftment
Your infused stem cells settle into your bone marrow and start making new blood cells.

How are stem cells collected from the blood?

You have a drug (granulocyte-colony stimulating factor, G-CSF) to encourage 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 several hours to collect the cells.
You have blood taken from a vein, usually in your arm. The blood passes through a special 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 come back to hospital for a few days in a row for more collections.

The collected stem cells are frozen and stored.

**What happens next?**

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

After high-dose 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 be kept 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.

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](http://lymphoma-action.org.uk/SCT) or visit [lymphoma-action.org.uk/Books](http://lymphoma-action.org.uk/Books) to download our book on autologous stem cell transplants.
Newer drugs and clinical trials

There are lots of new drugs in development for lymphoma. Many of these are ‘targeted therapies’. Most are only available in clinical trials at the time of writing.

New drugs are usually tested first in people who have lymphoma that has come back (relapsed) or didn’t respond to their previous treatment (refractory). Clinical trials of newer drugs can offer more treatment options for some people.

Read more about targeted therapies on page 62 and clinical trials on page 48.
Notes

About treatment
All treatments for lymphoma cause unwanted effects on your body (side effects). Each treatment has its own set of possible side effects, and different people can react differently to the same treatment. This means that even if you have the same treatment as someone else, your side effects might be different.

Your medical team can tell you what side effects to expect and give you advice to help you cope with them. They are experienced in helping people with all sorts of side effects.

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

Late effects can also develop. These are side effects that develop months or years after treatment.

See page 138 for more on late effects.
What side effects can I expect?
Hair loss

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

*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, but you might only lose some of it. It might thin or fall out in patches. Other body hair could fall out too. With radiotherapy, hair is only affected on the part of your body treated.

*When does hair start to fall out?*

Most people begin to lose some hair a couple of weeks after starting chemo. With radiotherapy, hair loss tends to happen gradually towards the end of treatment. Some people try out shorter hairstyles to get used to having less hair before it starts to fall out.

“At times I just wanted to vent about losing my hair. Comments such as ‘it will grow back’ made me feel like my friends didn’t understand how important it was to me.

Raveen, diagnosed at 23
When will it grow back?

It’ll usually start growing back when you’ve finished treatment although it might take a few months to recover. Your hair might not be the same as before – it could grow back thicker, straighter, curlier or even a slightly different colour. For some people, changes are short-term; for others, they are longer lasting.

What can I do about it?

You might want to embrace your hair loss. Remember to keep your head warm in winter and protect your scalp from the sun in summer.

There are lots of things you can try to see what looks and feels best:

- ask your hospital if the NHS or a charity can help you get a wig
- try headscarves, turbans or bandanas
- experiment with different styles of hats.

“My hair started to fall out after the first chemo. My sisters treated me to a nice wig which I wore for events or going out. But it felt like it was squashing my head, so I preferred to feel free and bald.”

Georgia M, diagnosed at 24
TOP tips for looking after your head

Don’t shave your head during chemo as small cuts could get infected. Shave it before chemo starts if you are planning to do so.

Be gentle with your hair during treatment and as it starts to grow back. Don't use heated styling tools like hairdryers or straighteners.

Use soft hairbrushes or wide-toothed combs and gentle products, like baby shampoo.

Moisturise your scalp using gentle, unperfumed products.

Cover your head to protect it from the sun, wind and cold. Wear sunscreen if you go bare-headed.

Don’t dye your hair until it has grown back all over your head.
Low blood counts are one of the most serious and early side effects of chemo. Chemo kills blood cells as well as lymphoma cells. Blood cells can also be killed by radiotherapy directed at large bones.

Different types of blood cells do different jobs in your body. The table below explains what they are and what low levels (a shortage) might mean.

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.

<table>
<thead>
<tr>
<th>Medical name</th>
<th>White cells</th>
<th>Red cells</th>
<th>Platelets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutrophils and lymphocytes</td>
<td>Erythrocytes</td>
<td>Platelets</td>
<td></td>
</tr>
<tr>
<td>What do they do?</td>
<td>Fight infection</td>
<td>Carry oxygen</td>
<td>Stop bleeding</td>
</tr>
<tr>
<td>Neutropenia and lymphopenia</td>
<td>Anaemia</td>
<td>Thrombocytoppenia</td>
<td></td>
</tr>
<tr>
<td>What's the shortage called?</td>
<td>More infections and difficulty getting rid of them</td>
<td>Pale skin, feeling tired, breathless, cold, dizzy</td>
<td>Bruising easily, bleeding longer</td>
</tr>
<tr>
<td>What happens if I have a shortage?</td>
<td>• Delay lymphoma treatment • Take antibiotics if you have an infection</td>
<td>• Delay lymphoma treatment • Red cell transfusion if needed</td>
<td>• Delay lymphoma treatment • Platelet transfusion if needed</td>
</tr>
</tbody>
</table>
Infections can be very serious when you’re having treatment for lymphoma. **Follow any advice from your medical team to help lower your risk of infection.**

**Neutropenia** puts you at a much higher risk of infection than you’d normally be.

**When am I most at risk?**

Neutrophil counts are lowest about 7 to 10 days after chemo. Your risk of infection is highest at this time. From then on, your **bone marrow** starts to recover and make blood cells again.

**Can I prevent infections?**

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 could do if your blood counts are low.**
There are lots of ways to reduce your risk of infection:

Carefully follow all advice from your medical team about what is safe to do and what you should avoid.

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 are ill, for example if they have 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.

Stay clean. Wash your hands before meals and after using the toilet. Brush your teeth at least twice a day.

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.

For more info, visit lymphoma-action.org.uk/Infection
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 sore mouth
Redness and swelling around skin sores, or injuries to intravenous lines
Diarrhoea
A burning or stinging sensation when weeing
Unusual genital discharge or itching
Unusual stiffness of the neck and discomfort around bright light.

Only take medicines your doctor tells you to.
Nausea is feeling sick. Vomiting is being sick.

**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.

If you do get nausea, it usually starts soon after your treatment and lasts a day or two.

**What can I do about it?**

Tell your medical team if you feel sick, even if you've already had treatment for it. They can give you anti-sickness drugs (antiemetics). There are lots of different types, so if one type doesn't work for you, ask to try another one.
TOP tips for coping with nausea

Drink water or fizzy water.

Suck ice cubes or sweets.

Eat foods with ginger or try ginger ale.

Try eating little, often and slowly.

Plain-tasting food like toast, rice, pasta and potatoes might be easier to stomach.

Distract yourself with music or games.

Try travel sickness wristbands.
Lots of people get diarrhoea (looser, more frequent poo) or constipation (find it hard to 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. You might be given medicines to help. Don’t take over-the-counter medicines without checking with your doctor first.

What can I do about diarrhoea?

- Drink plenty of water.
- Avoid milk and fried food.
- Try bland food ‘binders’ like potatoes, white rice, white bread, eggs and bananas.
- Cut down on raw fruit and veg for a while.
- If your bottom is sore, wash it clean instead of wiping it.
- Have a warm bath and then apply a simple barrier cream or soothing cream, such as one that’s used for haemorrhoids (‘piles’).
- Wash your hands carefully to help reduce the risk of infection.

What can I do about constipation?

- Drink plenty of water or try fruit juice.
- Build some physical activity into your everyday life.
- Don’t strain when trying to poo.
- Eat high-fibre food like fresh fruit and veg, and cereals.
- Ask your pharmacist or GP about laxatives (medication that can help to treat constipation).
Eating can be difficult during treatment. You might feel sick, food might taste different and your mouth might be sore.

My mouth’s so sore…

Tell your medical team if your sore mouth is making it difficult to eat. They can give you medicines to protect the lining of your mouth, mouthwashes to keep it clean and painkillers to help. Try:

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

It’s also a good idea to avoid alcohol, tobacco, spicy and citrus foods as these can cause irritation to your mouth.

Food doesn’t taste the same…

Flavouring your food might help. You could try adding:

- herbs, sauces and chutneys to savoury food
- fruit sauce or jam to puddings.
I’m gaining weight…

Some treatments, like steroids, can make you gain weight. You might gain weight in certain places, like your face, cheeks and tummy. This is temporary and the changes will gradually disappear after treatment. Don’t try to lose weight. Focus on eating healthily (avoid things like cakes and biscuits), being active and giving your body the energy it needs to recover.

I’m 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. Bland foods can be easier to stomach. Eating with other people might help shift your focus away from food. If you are losing weight, speak to your hospital’s dietitian for advice on high-calorie foods, nutritious drinks or supplements to keep your weight up.

Focus on healthy eating and being active.
Skin problems are common in young people. Sometimes, chemo can temporarily make these problems worse. Your skin might be itchy or sore and you might have a rash.

Radiotherapy can make your skin 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 up with clothes to protect your skin from the sun. Use high factor sun cream (SPF 50) 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 you should use.
If your skin is itchy, try not to scratch as it worsens the itch and can cause infection.

Moisturise frequently. Ask your medical team to recommend a cream.

Take lukewarm baths or showers of no more than 20 minutes.

Be gentle with your skin – use soft cloths, pat your skin dry instead of rubbing it, and use an electric shaver instead of a razor.

Let your hair dry naturally rather than using a hairdryer.

Don’t dye your hair or use sunbeds.

Avoid swimming pools as chlorine can irritate sensitive skin.
Fatigue

Fatigue is extreme tiredness. 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. The emotional impact of lymphoma can add to physical and mental exhaustion.

You are likely to have good days and bad days, which might be related to your treatment. Keep a diary to see if you can work out a pattern. Plan to do things on days when you think you are likely to have more energy.

YAWN!

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

Pace yourself – be active when you can and use your energy for the things that are most important to you.

Take frequent rests.

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.

Get into a sleep routine.

Eat well.

See page 104 for more info about living well.
Fertility

Fertility is your ability to make a baby.

Does my treatment affect fertility?

Many people lose their ability to have a baby during their treatment. For young women, periods might stop or become irregular. If you are still having periods, you might be given the ‘mini-pill’ (progesterone) to stop them. It can help prevent heavy bleeding if you have low platelets.

If you have sex during treatment, it is very important that you use reliable contraception, in order to 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.

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

Small amounts of chemo stay in your body for a few days after treatment. It's important not to pass the drugs to your partner. Men should use a condom during the whole treatment period. Avoid unprotected oral sex for 5 days after having chemo.
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.

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

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?

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

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.

See page 140 for more about having a baby after treatment for lymphoma.

Visit fertilitynetworkuk.org/fertility-preservation for more info about preserving your fertility.

cancerfertilityandme.org.uk is an online resource designed to help women affected by cancer make decisions about preserving their fertility.
Life during & after treatment for lymphoma

Adjusting to a life with lymphoma is a lot to deal with. You’re likely to experience a whole range of feelings, some of which can be difficult to cope with.
Adjusting to life with lymphoma

Uncertainty is a big part of living with lymphoma. You might feel uneasy and anxious while you are waiting for appointments, test results, further information and treatment. Let your medical team know how you feel and ask all the questions you have.

There can be a lot of information to take in, so tell your medical team if there are things you want them to go over. Remember, they are used to answering questions and should be happy to explain the same thing as many times as you’d like. You could also ask a family member or friend to come to your appointment with you. That way, they can take notes while you listen and ask questions.

Many people are relieved to start treatment and have an optimistic outlook. Even so, there might still be times when you struggle to cope. Treatment and its side effects can have ripple effects on other areas of your life, too, such as your friendships, appearance and studies or work. All of this can affect your self-confidence and how you feel overall.

“I look in the mirror and I am not Natalia with cancer, I am not Natalia before cancer, I am something in the middle.”

Natalia, diagnosed at 20
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.

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.

What cancer has made me realise is that there is a dramatic difference between existence and living.

Natalia, diagnosed at 20
Depression

We all feel 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.

Counselling

We all struggle with our feelings from time to time, and having lymphoma can be overwhelming. If you’d like some extra support with your emotions, you might consider counselling.

For some people, counselling provides an opportunity to talk about the things they feel unable to talk about with others. There are many different types of counselling. What they all have in common is the counsellor’s aim to provide a safe and non-judgemental space for you to feel heard and to explore your feelings. Counselling could help at various points, such as soon after diagnosis, during or after treatment.

For more about depression, visit mind.org.uk/Depression
Your doctor or nurse can give you more information about counselling. They might be able to refer you to a counsellor on the NHS, through your hospital or a local cancer support centre. Otherwise, you could ask if they know of a youth counselling service near to you – some offer sessions for free or at a discounted cost. If you’re in a position to be able to pay for counselling, you can search for a private therapist using the British Association of Counsellors and Psychotherapists online tool at itsgoodtotalk.org.uk/therapists

One of the best decisions I have ever made was to see a counsellor to help with my anxiety. She helped me come to terms with the changes I had been through.

Georgia, diagnosed at 11
Finishing treatment and leaving hospital

Leaving hospital can bring mixed feelings: excitement and relief, nervousness and sadness.

It’s not unusual to feel low and unsettled once treatment finishes. This can be particularly difficult if the people around you seem to expect you to be ‘back to normal’ straightaway. You might miss staff who cared for you and the friends you’ve made. Perhaps you’re scared that your treatment is finishing and anxious that your lymphoma could return. Remember that you’ll have regular health checks and that you can contact your key worker at any time if you have concerns.

It takes time to re-adjust to life outside of hospital. Be kind and patient with yourself. Trust yourself and listen to your needs, whether this is to rest, be alone, or have fun with friends.

Speak to someone about how you feel, perhaps a family member or close friend. You could also share your experiences on forums or social media.

If you’re 16 or over, you could get in touch with other young people who have had cancer on the Young Lives vs Cancer CLIC Sargent forums at clicsargent.org.uk

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

Natalia, diagnosed at 20"
Prevent worries from going round and round in your head by writing them down. You could keep a pen and paper by your bed in case your worries come to you in the night. Set some time aside during the day to note down what you can and can’t do about them. You can then make plans to deal with the concerns that you’re able to 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. The pharmaceutical company AbbVie has information and podcasts about mindfulness for people with blood cancer. Search ‘mindfulness’ at abbvie.co.uk

### Examples are shown below.

<table>
<thead>
<tr>
<th>Worry</th>
<th>What can I do?</th>
<th>Who or what can help?</th>
</tr>
</thead>
<tbody>
<tr>
<td>My lymphoma might come back after treatment.</td>
<td>Speak to my medical team about how likely this is, symptoms to look out for and what to do if I notice any changes.</td>
<td>My CNS or keyworker can answer my questions and give me information.</td>
</tr>
<tr>
<td>I’ve lost touch with some of my friends.</td>
<td>Make contact – maybe send them a text or a message on social media.</td>
<td>Friends could help arrange to meet up with the people I haven’t seen in a while.</td>
</tr>
<tr>
<td>I feel so anxious a lot of the time.</td>
<td>Tell my CNS or keyworker how I’m feeling and ask about support.</td>
<td>Try breathing techniques (see page 102). Contact Lymphoma Action’s Helpline Services over the phone, by email or via Live Chat on our website. Attend a support group.</td>
</tr>
</tbody>
</table>
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 ‘7/11 breathing’.

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

Don’t worry if you’re unable to breathe in for the count of 7 and out for the count of 11 at first. The main thing is to breathe out for longer than you breathe in. You could start by breathing in for 3 counts and out for 5.
It’s important to focus on things other than lymphoma, too. Think about what makes you who you are beyond being someone who has had treatment for lymphoma – for example, you might be a daughter, a brother, a student, a guitarist. Go a bit deeper, too, by thinking about your likes and dislikes, your values, beliefs, and future plans. Remind yourself of all the aspects of you.

**Should I celebrate the end of treatment?**

It’s an achievement to have got through all that you have. If and how you want to celebrate it is entirely up to. You could have a party or organise a day out. You might prefer not to do anything big but treat yourself to a present 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 especially hard, though, 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.

“Being a survivor isn’t a clean conclusion to the cancer experience. Worries can linger, world-views can shift. Ellie, diagnosed at 15

My nurse gave me a call and told me I was in complete remission. It was finally all over. I had told my mum that if I was told the good news I would be so happy that I’d do a celebratory dance. I didn’t feel like that at all. I was so relieved but also just overwhelmed. My initial reaction was to cry.

Ruchi, diagnosed at 24
Living well during and after treatment is important to your wellbeing. There are lots of ways you can help yourself feel well.

**Diet and nutrition**

Eating well can help you to cope well 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, protein can come from dairy products, egg and soya products. Vegan sources of protein include pulses, nuts and soya products.
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.

- **Choose wholegrain or higher fibre versions** with less added fat, salt and sugar.
- **Potatoes, bread, rice, pasta and other starchy carbohydrate foods**
- **Limit fruit juice and/or smoothies to a total of 150ml a day.**
- **Water, lower fat milk, sugar-free drinks including tea and coffee all count.**

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

**Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less...**

**Eat less often and in small amounts.**

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

Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

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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 is often 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 ‘miracle 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 prevent it from coming back.

We have more FAQs about food on our website. Search ‘diet and nutrition’.
TOP tips for eating out

It’s generally safe for people with lymphoma to eat out 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 check food hygiene ratings online at scoresonthedoors.org.uk

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, ice cream from a parlour and salad from a salad bar. Free tasting samples given out in shops or on market stalls are often unwrapped, so avoid these too.

Find tips about food safety on our website at lymphoma-action.org.uk/Infection
Is it safe to drink alcohol?

It is best not to drink alcohol while you are having chemotherapy. Your liver is already working hard to handle the chemo drugs, and alcohol could affect how your liver breaks them down.

The occasional alcoholic drink between cycles of chemotherapy when you are feeling well should be OK – but check with your doctor first. Be aware that you might feel the effects of alcohol more quickly than you did before treatment. Remember also that alcohol is dehydrating, so alternate alcoholic drinks with non-alcoholic drinks.

What about recreational drugs?

It’s best not to take recreational drugs. During treatment for lymphoma, your body is already working really hard to break down and process your lymphoma treatment.

Even after treatment, it is 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.

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.
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. 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.

Visit nhs.uk/smokefree for support to help you quit smoking.

Find out more about late effects on page 138.
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 you might prefer to exercise alone for some time out and headspace.

Physical activity during and after your treatment can help:

- improve your overall physical health
- reduce some of the side effects of treatment
- control your weight
- lower fatigue (extreme tiredness)
- increase muscle and bone strength
- lower your risk of infections
- improve your mental wellbeing by relieving stress and anxiety and making you feel better about yourself.

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:

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

You should also do some strengthening activities a couple of times a week. Examples include dancing, walking and resistance band exercises.
In reality, 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 – move and stay up and about. Ask your medical team for advice about the type and intensity of exercise that is suitable for you.

When I was younger, 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
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 schoolbag or shopping bags.

Get some resistance bands to do some light exercise during the day.

Play Frisbee or fly a kite in the park.
As part of your treatment, you might have had anthracyclines – a group of powerful 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.

Georgia, diagnosed at 11

The main thing for me was to do sports and exercises that I found fun. Then I could be as bad as I wanted but I would still have a good time. It takes time and you need patience. Now I play for my school hockey team, go to badminton every week and run my school’s annual 10k.

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.
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 Port-a-Cath®).

Am I allowed to go diving?

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

If you’re in your 20s or 30s, Trekstock can help you get moving physically, socially and psychologically. Find out more at trekstock.com
You will probably need to take some time out of school, college or university during your treatment. Your medical team should speak to you about how treatment could affect your studies.

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 is to help them understand a bit about your condition, treatment and the effects of your treatment.

“I was just 3 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 tuition 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. I then went on to study English Literature and Journalism at Cardiff uni, which I really enjoyed.

Search ‘back to school’ on the Teenage Cancer Trust website for more information about school, college and university at teenagecancertrust.org
Work

It’s a good idea to tell your boss or your human resources (HR) department about your lymphoma, especially as you’re likely to need some time off during your treatment.

“Ten days after finishing treatment, I started work. I had meetings with my managers to discuss reducing my hours to start with but I felt well enough to keep to my normal number of hours each week.

Adam, diagnosed at 27

“Most employers are flexible and supportive.

My employer has been supportive with working around my follow-up appointments and offering flexible working. Even 2 years after treatment, I have to watch my energy levels. I try to take time out when I need it and be careful to not say ‘yes’ to everything all the time.

Callum, diagnosed at 21

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 on the UK Government website at gov.uk/browse/disabilities
TOP tips for speaking to your employer

Arrange a time to meet with your boss 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 alternative working arrangements, like working from home or going in a bit later to avoid the rush hour commute.

Discuss whether you could change some of your duties to avoid the most tiring ones. Think about whether you could delegate some responsibilities.

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. Search 'working' at macmillan.org.uk to find out more.

We have more info on working and finances at lymphoma-action.org.uk/Day-to-day
Having lymphoma can put pressure on relationships.

Often they become strained as people don’t know quite what to say or do. Things can then start to feel awkward and misunderstandings can arise. Despite these challenges, research shows that people with cancer cope better when they are supported through strong relationships. You might even grow closer to some people.

Friends

Your friends might not know much about lymphoma – perhaps they haven’t even heard of it. You might find they seem not to understand that you are 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 text or email as a starting point.

Let your friends know what you need from them – whether this is to talk about how you’re feeling or just 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.

“

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
I lost contact with a lot of people I considered to be really close friends, but I’ve also become a lot closer friends with people I didn’t expect to. Some people knew to treat me exactly the same as before, but also to remember to ask how I was feeling after having chemo.

Ruchi, diagnosed at 24

Do fun things with your friends.

like watching a show or playing a game.
Just remember to avoid places like clubs, cinemas, crowded shops and public transport if you are neutropenic, to lower your risk of infection.

Blood Cancer UK (Bloodwise) has tips for young adults to help with friends and relationships at bloodcanceruncovered.org.uk
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 experienced lymphoma. They love you and want to help you get better as quickly as possible. For you, it can 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 with them, for example:

‘I agree to ask for help when I need it. You agree to let me do things by myself.’

‘You agree to let me go out with my friends. I agree to stay home if I feel tired or unwell.’

‘I agree to call you for a lift home if I start to feel unwell while I’m out. You agree to trust me that I will.’

Blood Cancer UK (Bloodwise) has tips for young adults to help with friends and relationships at bloodcanceruncovered.org.uk
Agreements

Write down any agreements you’d like to make with your parents or carers.
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 may become very protective of you, acting a bit like another parent.

Try explaining to them 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 may feel helpless and not know what to say or do. Talk to them about how you feel.
Be honest about how you feel and ask them to be honest with you. Set aside time where you are free from interruptions and can really listen to one another.

Explain what you need 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.

Social media can be a great way to update a lot of people quickly. Think carefully about what you post though – 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.
Statement: ‘It really annoyed me yesterday when you kept telling me to sit down and rest’, rephrased using I statements:

<table>
<thead>
<tr>
<th>Say</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>How you feel/felt</td>
<td>I felt frustrated yesterday</td>
</tr>
<tr>
<td>When</td>
<td>when you insisted that I rest.</td>
</tr>
<tr>
<td>Why</td>
<td>I know you only said it because you care but I felt…</td>
</tr>
<tr>
<td>What you’d like</td>
<td>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.</td>
</tr>
</tbody>
</table>

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.
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

‘I’ve been unwell but I’m having treatment and I’m doing OK’.

‘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.
Notes

Things you might want to say to people about your lymphoma.
Sex and intimacy

There’s no reason not to have sex but take care if your platelet count is low as you are likely to bruise easily.

Talk to your doctor about suitable contraception. It’s important to use a condom to avoid passing chemo on to your partner, to protect against infection and to prevent pregnancy. If vaginal dryness is a problem, try using a water-based lubricant.

Why have I gone off 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 clicsargent.org.uk
Many people go through a wide range of emotions after treatment – whether this is straightaway, weeks, months or even years later. There isn’t a ‘normal’ way to feel, but some of the emotions you might experience are described below.

**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 seem not 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 (self-blame) 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.

Anxiety and uncertainty

Even though treatment is very effective for many young people with lymphoma, it is only 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.

Sadness and depression

It is natural to feel low from time-to-time and to be upset about what has happened to you and those close to you. If these feelings continue over time, you could be affected by depression.

Looking back, I can barely believe what has happened to me in the past year. My perspective on life has changed so much. I get frustrated with reality TV and all the moaning about silly things.

Adam, diagnosed at 27

I am in remission but still find I get really anxious before a scan. I get so paranoid and assume the worst. Even though my anxiety increases so much around the time of my scan, I know I would be in a continuous state of anxiety without them.

Ruchi, diagnosed at 24
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 counsellor. You can contact our Helpline Services to talk to someone 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.

- **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 149.
Lymphoma is part of your medical history. Anyone treating you needs to know that you had lymphoma and what treatment you had.

Some of your treatment might mean you have to take certain precautions in the future or that you are at higher risk of developing certain problems.

Ask your doctor what medical issues you need to be aware of after your treatment for lymphoma.
Follow-up

Once treatment has finished and you’re in remission, you’ll have regular check-ups at the hospital for the next few years.

This is called *follow-up* and it’s really important to go to all your follow-up appointments.

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.

Your check-ups also give 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.

What happens during a check-up?

You have tests and, sometimes, scans during your check-ups. 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*).
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 passes and the risk of relapse reduces. After several years, you have visits once a year to check for late effects of your treatment.

What can I do if I’m worried between appointments?

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

Contact your medical team if you have any concerns. They can reassure you or arrange for you to see them sooner than planned.
Anyone treating you in the future (including your dentist) needs to know that you’ve had lymphoma and what treatment you’ve had.

For example, if you have an operation and need a general anaesthetic, the anaesthetist needs to know what treatment you’ve had. Certain drugs can cause problems if the health professional treating you isn’t aware you’ve had them. For example:

- bleomycin can affect your breathing
- anthracyclines, such as doxorubicin, can affect the strength of your heart.

You and your GP should be given a letter with all the important information on. This is your treatment summary. Ask for it if you haven’t been given one.
Some treatments mean you need to be treated differently in certain situations – for example, if you have an accident or need a blood transfusion. Your medical team should talk to you about any precautions you need to take.

Precautions if you 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 (this is called ‘splenectomy’) or treated with radiotherapy, 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 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 vaccine booster every 5 years.
- If you travel to another country, you might need extra vaccinations and, depending on where you’re going, to take extra care to avoid malaria.
- Be prepared in case of emergency. Keep an emergency supply of antibiotics. Always carry a card with your treatment details.
Precautions if you need a blood transfusion

Some people treated for lymphoma need irradiated blood if they have a blood transfusion in the future. Irradiated blood is blood treated with X-rays to kill any donor white blood cells that might attack your own cells. Your doctor will tell you if you need irradiated blood and you will be given a card that says so. Keep your card with you at all times. 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. 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.

Precautions if you’ve had steroids

If you had steroids as part of your treatment, your body might not make enough natural steroids if you are ill, have an accident or need surgery in the future. 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.
What are late effects?

Lymphoma treatment damages healthy cells as well as lymphoma cells. Problems caused by damage to healthy cells can take a long time to develop. Late effects are side effects that might develop months or years after treatment. Late effects of lymphoma treatment can include lung problems, heart disease or a second cancer.

Remember that not everyone gets late effects.

The risk of late effects might seem worrying, but knowing what to look out for means you can catch problems early. This often makes them easier to treat.

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 treatment summary letter should explain what late effects you’re at risk of and how you’ll be monitored for them. Ask for a summary if your medical team don’t give one to you.

Many hospitals have a late effects clinic.
TOP tips for late effects

Find out what problems you are at risk of and what 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
Many couples go on to conceive a baby without difficulties once they’ve recovered from treatment for lymphoma.

Fathering a child

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. Even if your recovery is quicker, doctors advise against conceiving a baby within 3 months of completing chemotherapy.

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. 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 system. Your hospital specialist can advise you on whether to have your heart and lung function tested before you decide to try to conceive.

Are there risks to a baby born to someone who’s 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
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 you to 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.

**Check with your GP which vaccines are safe for you.**

If you are going abroad, you might need specific vaccinations. You can get advice about these from your GP or travel clinic. Travel clinics give health advice before you travel. Although these clinics are separate from the NHS, their advice consultations are generally free of charge.

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.
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 (a tropical disease that’s spread by mosquitoes). Your GP or travel clinic can advise you whether you need anti-malaria tablets and which ones are best for you. 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
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, and use an insect repellent that contains DEET.

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.

Find more tips about travelling abroad at lymphoma-action.org.uk/TravellInsurance
Glossary: what does that mean?

**Allogeneic** from another person (a donor), not yourself

**Anaemia** shortage of red blood cells in your blood

**Anaesthetic** drugs given to make a part of the body numb (local anaesthetic) or put the whole body to sleep (general anaesthetic)

**Antibody** a protein produced by your immune system to fight infection

**Autologous** from your own body

**B symptoms** unexplained weight loss, drenching night sweats and high fevers (temperature above 38°C)

**Biopsy** a small operation 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, platelets) you have in your blood

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

**Bulky disease** very large, swollen lymph nodes

**Cell** the microscopic building blocks of our bodies

**Central line** a thin plastic tube inserted into a vein deep inside you to give chemo 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 treatment with drugs that are poisonous to cells – can be called ‘chemo’ for short

Diaphragm the sheet of muscle across the bottom of your ribcage that separates your chest and heart from your tummy

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

Erythrocyte the scientific name for a red blood cell

Extranodal outside the lymph nodes

Groshong® line a type of central line inserted into a vein to give chemo and take blood

Haematologist a doctor who specialises in diseases of the blood

Hickman® line a type of central line inserted into a vein to give chemo and take blood

Immune cells cells of the immune system that help to protect your body from infection

Immune system the system in your body that fights infections

Intrathecal injections given directly into the spinal fluid (CSF)

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

Lymph clear fluid that carries lymphocytes around the lymphatic system
**Lymph node** a 'gland' that acts as a sieve in the lymphatic system and where lymphocytes gather to fight infection

**Lymphatic system** a network of vessels, nodes and organs that filters out waste products from the body and protects you from infection

**Lymphatic vessels** tubes that carry lymph around the body

**Lymphocyte** a type of white blood cell that fights infection

**Lymphoma** cancer that develops from white blood cells called lymphocytes in the lymphatic system

**Lymphopenia** a shortage of lymphocytes in your blood

**Neutropenia** a shortage of neutrophils in your blood

**Neutropenic** being short of neutrophils in your blood

**Neutrophil** the main type of white blood cell that fights infection, particularly bacterial and fungal infections

**Oncologist** a doctor who specialises in treating cancer

**PICC line** ‘peripherally inserted central catheter’ – a flexible tube inserted into one of the large veins in your arm, above your elbow, that is used to take blood or give chemo

**Platelets** the tiny fragments of cells in your blood that help your blood clot

**Port-a-Cath®** a central line that has a reservoir (port) just under the skin, used to take blood or give chemo

**Radiotherapy** treatment with X-rays
**Refractory** lymphoma that does not respond to treatment

**Regimen** a plan of treatment that specifies what drugs you have, how much of each you have, 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

**Remission** when lymphoma no longer shows up on any tests

**Sedative** a drug to help you relax

**Spleen** an organ in your immune system that helps to fight infections and clear bacteria and old or damaged blood cells from your body

**Stage** a number used to describe how much lymphoma is in your body and where it is – sometimes there’s a letter as well

**Staging** tests to find out how much lymphoma you have in your body

**Stem cell (blood)** an undeveloped cell that can divide and mature into all the different types of blood cell your body needs

**Stem cell transplant** a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells

**Steroid** the backbone of treatment for many lymphomas and also an anti-inflammatory medicine that affects the body’s metabolism and immune response

**Thrombocytopenia** shortage of platelets in your blood

**Thymus** a gland in your chest where T cells mature

**Transfusion** giving of blood or blood products (such as red blood cells) into a vein
You might find it helpful to speak to someone else who has personal experience of lymphoma. Although their experience won’t 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 are any groups in your area for young people with lymphoma. Lymphoma Action Support Groups 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, for example through Young Lives vs Cancer CLIC Sargent’s website.

How we can help

For more information about any of the topics in this book, and details of our support services, visit lymphoma-action.org.uk

If you’d like to talk to someone about anything to do with lymphoma, including how you feel, get in touch:

Call our Helpline freephone 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

If you are 18 or over, come to one of our Support Groups. Find one near you at lymphoma-action.org.uk/SupportGroups
If you are 18 or over, you can use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details.

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

Watch short films of people sharing their personal experiences of lymphoma and medical explainer videos and animations on our **YouTube channel**. These include videos of young people talking about various aspects of living with lymphoma.

For our latest news and updates, follow us on social media:

[@LymphomaAction](https://twitter.com/LymphomaAction)  [lymphoma_action](https://www.instagram.com/lymphoma_action)

Our information is evidence-based, approved by experts and reviewed by users. By keeping up-to-date with latest developments, we ensure that our information reflects current practice and stays relevant. Learn more at lymphoma-action.org.uk/HealthInfo.

**We produce many other publications that give information about lymphoma. Visit our website at lymphoma-action.org.uk or call 0808 808 5555 for more information.**
Other organisations & support

**Blood Cancer UK (Bloodwise)** funds research into blood cancers. They have a resource for young adults, ‘Uncovered’, that has tips on living with blood cancer.

**Children’s Cancer and Leukaemia Group (CCLG)** provide information for those living with cancer and their families, including about treatment and after treatment.

**Ellie’s Friends** is an online resource that enables people (aged 16+) living with cancer to access free and discounted services or products in their area.

**Health and Social Care (HSC) Online Northern Ireland** has information about cancer services in Northern Ireland and signposts to other organisations that offer help and support.

**Jimmyteens.tv** features young people who are having, or have had, treatment for cancer. They share their experiences through video diaries, short films, music and animation.

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

**Look good feel better** provides practical support (including make-up workshops and skincare sessions) for people who are struggling with the side effects of cancer treatment.

**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 Service Network (MSN) for children and young people with cancer, NHS Scotland has information about cancer and related issues for young people.

MOVE provides support to help children and young people affected by cancer to get active and exercise.

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

The NHS Website has information about cancer.

Shine Cancer Support supports adults in their 20s, 30s and 40s diagnosed with any type of cancer. They have videos, podcasts and personal experiences on their website. They also organise support events around the UK and have an online forum on Facebook.

Siblinks offers a network of support for young people aged 13 to 25 who are siblings or children of people affected by cancer.

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. They run an annual conference called ‘Find your sense of tumour’, which 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 living 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 on issues relating to returning to work, remaining in work or finding employment at any stage during or after cancer treatment.

Young Lives vs Cancer (CLIC Sargent) offers clinical, emotional and practical support to children and young people with cancer, and to their families.

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

Youth Minds aims to improve the emotional wellbeing of children and young people. They offer online information and self-help tips.
We continually try to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Helpline on 0808 808 5555.

References
The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community.

Whether it's raising awareness in your local community, supporting someone living with lymphoma or being part of our cheer squads, we'll help you find a role that suits your time and interests. You'll also develop skills and experience that will stand out on your CV and support your future career aspirations.

If you’d like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

“I volunteer at Lymphoma Action, alongside studying at university, to support my community. Volunteering has helped me gain and develop my skills, which will greatly benefit my future.

Ravi, Lymphoma Action volunteer
Lymphoma Action is a charity and relies on the generosity of its supporters.

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Helpline (freephone) **0808 808 5555** (Mon to Fri, 10am to 3pm)
Email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)
Visit [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)
**Live Chat** via our website (Mon to Fri, 10am to 3pm)

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