Young person’s guide to lymphoma

Natalia, diagnosed at 20
Rebekah, diagnosed at 18
Sam, diagnosed at 23
Jon, diagnosed at 17
My diagnosis

What’s my type?

What’s my stage?

Ellie, diagnosed at 15

Greg, diagnosed at 23
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: scribble 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 most 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 may not be relevant for the type of lymphoma you have; others might become relevant only after you’ve been through treatment. Read the sections that are relevant to you at any given time.

What do the symbols and colours mean?

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

Yellow boxes give room for you to make notes.

Text in speech marks are quotes from young people who have had lymphoma.

About this book
TOP TIPS give ideas about how to cope with aspects of your lymphoma and treatment.

Signposting to other pages in this book tell you where you’ll find more information.

Useful websites are given after an @ symbol.

Text shown alongside an exclamation mark is very important.

Words in this colour are explained in the glossary on page 150.

The information in this booklet can be made available in large print.
Who we are

We’re the Lymphoma Association, a UK charity that provides specialist information and support to help people affected by lymphoma. We want to help you feel less vulnerable, more in control and more confident so you can cope well with your diagnosis.

This book was written in collaboration with expert medical advisors and reviewed by young people affected by lymphoma.

The Lymphoma Association is certified as a producer of reliable health and social care information by The Information Standard, a rigorous quality mark scheme supported by the Department of Health.

To find out more about us and to look for more information on any of the topics in this book, head to www.lymphomas.org.uk
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What’s lymphoma?

More than 450 young people develop lymphoma every year in the UK.

Being diagnosed with lymphoma can be very scary. Many people had never heard of it before they were diagnosed.

There are lots of different types of lymphoma, which need different treatment: Hodgkin lymphomas and non-Hodgkin lymphomas.

You probably don’t know anyone else your age who has had cancer, but you are not alone.

Find out where to get support on page 145.
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 happens when cells in your body become out of control. They divide when they don’t need to or don’t die when they should. This breakdown in control lets abnormal cells build up and then they 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.

The doctor who told me seemed quite concerned, but I didn’t even know what lymphoma was. It’s only when I went home and looked online that my worst fears were confirmed. I realised I had cancer. I immediately freaked out. I was 17 and I thought cancer happened to older people.

Jon, diagnosed at 17
There are lots of different types of cells and therefore lots of different types of cancer.

In lymphoma, the abnormal cells are a type of white blood cell called a lymphocyte.

There are different types of lymphocytes, but the most common are:

- T lymphocytes or T cells, which protect us from viruses and cancers by attacking them directly
- B lymphocytes or B cells, which produce antibodies to fight infection.

Normal, healthy lymphocytes travel around your body in your lymphatic system, which is part of your immune system.

Most lymphomas develop from B cells and are called ‘B-cell lymphomas’. Some non-Hodgkin lymphomas develop from T cells so they are called ‘T-cell lymphomas’.

What’s the lymphatic system?

The lymphatic system is a complicated network of narrow tubes (lymphatic vessels) and glands (lymph nodes) that run throughout your body. You also have organs that are part of your lymphatic system:

- the thymus, which is a gland in your chest where T cells are made
- the spleen, which fights infection, filters your blood and destroys old blood cells.
Lymphocytes travel around your body in a fluid called lymph. They collect in your lymph nodes, ready to fight infection and stop it from spreading around your body.

**The lymphatic system**

- Lymph nodes in the neck
- Lymph vessels
- Lymph nodes in the armpit
- Lymph nodes in the groin
- Thymus
- Diaphragm (muscle that separates the chest from the abdomen)
- Spleen
- Liver

**What happens in lymphoma and what symptoms might I have?**

Lymphoma can be difficult for doctors to diagnose. Many of the symptoms (signs of illness you might experience) of lymphoma are also seen in other, less serious conditions. 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 enlarged lymph nodes where 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, abnormal lymphocytes (lymphoma cells) can grow within your lymph nodes and make them swell. These lumps are not usually painful and they don’t shrink back down.

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.

If the lymphoma is growing in your lungs, you might feel breathless; if it is growing in some parts of your abdomen (tummy), you might get abdominal pain.
Other common symptoms:

Fatigue is not a 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 dieting.

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.
Night sweats and unexplained weight loss often occur together with fevers.

You might have different symptoms.

I had not felt myself for months. I could hardly walk around without stopping and everything just seemed too much effort. I began having really bad night sweats and itches. I’d itch so much I’d even use the nearest things to me like a remote control to hack away on my skin and try to ease it in some way.

Doctors call these 3 symptoms ‘B symptoms’. Having B symptoms can affect how you need to be treated.

I had Hodgkin lymphoma in my chest and neck. I had the usual symptoms but I also suffered bad upper back and neck pain (which was so bad I went to see a chiropractor and physiotherapist because I thought I had back problems) and shortness of breath (which my GP thought might be asthma), and pain when drinking alcohol.
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 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.

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 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.

Why me?
Some people with conditions that affect their immune system, like HIV, have a higher risk of developing lymphoma. For most people, no one can say why you have developed lymphoma.

In most cases, the cause of lymphoma is not known
Questions

Make a note here so that you remember them when you see your doctor
What tests do I need?

You have at least some of the tests described in this section while you are being diagnosed. You continue to have tests throughout your treatment and follow-up:

- Tests before treatment help your doctors find out as much as possible about your lymphoma, eg what type it is. They are also needed for staging: finding out where the lymphoma is in your body (read more about staging on page 33). This information is used to plan the best treatment for you.

- Tests during treatment are to see how well your body copes with treatment and to see whether the treatment is getting rid of your lymphoma.

- Tests after treatment check on your recovery, make sure there are no signs of lymphoma coming back and check for side effects that can develop months or years after treatment.

Some of the following tests are only done for certain types of lymphoma.

You can skip the sections about tests that don’t apply to you.
Biopsy

A biopsy is when some of the abnormal tissue (eg a lymph node) is removed and looked at under a microscope.

Why is it done?

A biopsy is the main way of confirming a suspected lymphoma. Tests are done on the biopsy 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 what type of lymphoma you have so that you can get the right treatment.

What happens?

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

If only a small piece of the lymph node is being removed, you might have a local anaesthetic.

“The biopsy is taken during a small operation.”

I had never had anaesthesia 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 anaesthesia I had no time to really worry about anything because I was fast asleep in an instant.

Georgia, diagnosed at 11
Scans

A scan is a way to build an image of what’s inside you. There are different types that build up images 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 are they done?

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 may feel uncomfortable about being in an enclosed space or about being on your own. You can’t use a phone during your scan, but you often can listen to music. You can usually 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) that makes your organs easier to see. You could have it as a drink or as an injection into your vein.

You lie on a bench that moves through a camera that is shaped like a ring doughnut. It’s open at both ends. The camera takes lots of pictures from different angles to build a 3D image of the inside of your body.

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

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

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 radioactive tracer – a liquid containing sugar and a very small amount of radioactive compound. You then wait for about an hour before you have the scan. Lymphoma cells absorb much more of the sugary liquid than normal cells and show as ‘hot spots’ on the scan image.

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.

A PET or PET/CT scan itself takes 30–60 minutes, but you have to be at hospital for several hours to have the radioactive tracer.
MRI scan

MRI stands for magnetic resonance imaging.

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

A 3D picture of the inside of your body is made by measuring changes in magnetic waves as they pass through you.

An MRI scan usually takes 30–60 minutes. The machine can be very noisy.

Ultrasound scan

Ultrasound uses high-energy sound waves to create an image. It is often used for scanning the abdomen (tummy).

You lie down on a couch and a gel is put onto your skin over the part of your body being scanned. The technician 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 is sometimes found in the bone marrow – the spongy filling in the middle of your bones where blood cells are made.

In a bone marrow biopsy, a sample of bone marrow, usually from your hip, is removed and looked at under a microscope. Some people with non-Hodgkin lymphoma have a bone marrow biopsy. This is rarely needed for people with Hodgkin lymphoma.

Why are they done?

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 sedative with a local anaesthetic. You lie on your side, and a needle is inserted through your skin into the back of your pelvic (hip) bone. You feel some pressure as the needle enters the bone and a small sample of bone marrow is taken. 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. You might have an infection.
Lumbar puncture

A lumbar puncture might be done as part of staging if you have non-Hodgkin lymphoma.

Some people have lymphoma in their central nervous system (CNS) – the brain and spinal cord. In a lumbar puncture, a few drops of the cerebrospinal fluid (CSF; a fluid that surrounds your brain and spinal cord) are removed and looked at under a microscope.

Why is it done?

Doctors need to know whether lymphoma is in your CNS before they can decide on the best treatment for you.

What happens?

You have a local or general anaesthetic. You lie on your side with your knees bent. The doctor puts a needle into a gap between 2 bones in your lower back. You need to lie very still while the CSF is being collected.

A lumbar puncture takes about 5–10 minutes. If you’re having chemotherapy drugs given into the CSF at the same time, it can take a couple of minutes longer.

Some people get a headache after a lumbar puncture. You are likely to be asked to lie flat after the procedure to help prevent this. Some types of needle can reduce the risk of headaches – ask your medical team for advice.

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

You might feel like you are always having blood tests.

Blood samples help to find problems and check how well your body is coping with treatment. Blood tests are done as part of diagnosis and staging. They are also done before each cycle (round) of chemotherapy to make sure it is safe to give you treatment.

Treatment for lymphoma affects normal blood cells as well as lymphoma cells.

It is important to know if you have enough of each type of blood cell – the doctors and nurses looking after you monitor your blood counts (levels of different types of blood cell) very carefully throughout your treatment.

What happens?

Blood might be 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 are used to helping people who are scared of needles.

We have more information about all of the tests included in this section at bit.do/tests-scans
What can I do while I am waiting for test results?

It can be very difficult to wait for test results that confirm your diagnosis. Remember that your medical team need to find out as much as possible about your lymphoma before they can plan the best treatment for you.

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 (e.g., 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 are going to be treated and what facilities are available, e.g., if there is a TV or sitting room, and whether there is a kitchen where you can make a snack.

How will a diagnosis of lymphoma make me feel?

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 may be a relief that doctors are investigating, the whole process is likely to be challenging.
There is no ‘usual’ way to feel when you are told 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.

“For a good hour it was like I wasn’t even there, like being in a bubble. I couldn’t feel any feelings.”

Jon, diagnosed at 17

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
You are given a diagnosis when all your test results are back. Your doctor tells 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 2 main groups of lymphomas:

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

In teenagers and young adults (15–24 years old), Hodgkin lymphoma occurs more than twice as often as NHL.

There are many subtypes of lymphoma within each of these groups. Each type of lymphoma may need specific and slightly different treatment.
What’s the difference between Hodgkin lymphoma and non-Hodgkin lymphoma?

In Hodgkin lymphoma, there are specific types of cell called Reed–Sternberg cells or Hodgkin cells. A Reed–Sternberg cell is a type of abnormal B cell that is named after the people who first identified the microscopic changes found in Hodgkin lymphoma.

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

What types of Hodgkin lymphoma are there?

There are 2 main types of Hodgkin lymphoma:

- Classical Hodgkin lymphoma, which makes up about 90–95% of cases.
- Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL), which is a rare and slower-growing type.

There are 4 subtypes of classical Hodgkin lymphoma: nodular sclerosing, mixed cellularity, lymphocyte-rich and lymphocyte-depleted. They are all treated in the same way and their cure rates are the same.

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. Lymphocytes are either T cells or B cells, so NHL can be either ‘T-cell’ or ‘B-cell’ lymphomas. They can also be divided into high-grade (fast growing) or low-grade (slow growing) lymphomas. Most young people have high-grade lymphomas. This may 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, which tend to come back (relapse).
The most common types of NHL in young people are all fast-growing and are all treated differently:

- **Anaplastic large cell lymphoma (ALCL):** a T-cell lymphoma that can develop anywhere in the body, either in the **lymph nodes** or in **extranodal** sites.

- **Burkitt lymphoma:** a B-cell lymphoma that often involves lymph nodes in the abdomen (tummy) or bowel.

- **Diffuse large B-cell lymphoma (DLBCL):** a B-cell lymphoma that can develop in internal lymph nodes or in extranodal sites, such as the chest, abdomen and bones.

- **Lymphoblastic lymphoma:** a T-cell lymphoma that most often causes swelling of lymph nodes inside the chest around the heart, in an area known as the mediastinum. B-cell lymphoblastic lymphoma can also occur.

You can jot down information about your type and stage in the space provided at the beginning of this book.
Check that any sources of information that you use are reliable and up-to-date. An easy way to check is to look for the Information Standard quality mark.

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 describes how much lymphoma you have in your body and where it is. Stage is used to help decide the amount of treatment you need.

Different staging systems are used for people under 18 and over 18 with NHL. The same staging system is used for people of all ages with Hodgkin lymphoma.

What are the 4 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 referred to 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 1 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 abdomen).

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.

As the lymphatic system is all over the body, 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, you might have a letter added to your diagnosis.

<table>
<thead>
<tr>
<th>Stage letter</th>
<th>What it means</th>
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<tbody>
<tr>
<td>A</td>
<td>You haven’t had any B symptoms (you might hear the word ‘asymptomatic’ which means ‘no symptoms’)</td>
</tr>
<tr>
<td>B</td>
<td>You’ve had one or more of the B symptoms: unexplained weight loss (without dieting), drenching night sweats or high fevers</td>
</tr>
<tr>
<td>E</td>
<td>Your lymphoma has grown in extranodal sites (ie outside the lymph nodes)</td>
</tr>
<tr>
<td>S</td>
<td>There is lymphoma in your spleen</td>
</tr>
<tr>
<td>X or bulky</td>
<td>You have big clumps of lymphoma</td>
</tr>
</tbody>
</table>

Ask your doctor to explain if you are unsure what they mean by 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 bit.do/staging-lymphoma
Will I be cured?

No-one can know for certain whether you will be cured, but treatments for lymphoma in young people are generally very very successful.

With the right treatment, most young people who have lymphoma go into complete remission and stay in remission. Your lymphoma doctor is the best person to talk to about cure rates as they know your individual circumstances.
You and your medical team should decide together the best place for you to have your treatment.

Where am I treated?

UK guidelines recommend that children and young people with cancer are treated in a Principal Treatment Centre (PTC).

A PTC is a hospital where specialists treat children and young people with lymphoma. These hospitals have all the facilities they need to help with diagnosis and treatment.

Travelling to a PTC can be difficult for some people because PTCs in the UK tend to be located at large teaching hospitals. If travel is a problem, some of your treatment or check-ups might take place in a local hospital with facilities for teenagers and young people.
These are called ‘teenage and young adult (TYA) designated hospitals’. When parts of your treatment are handled by different places, it is called a ‘shared care’ arrangement with the PTC. You might see experts at different hospitals.

There are cancer units designed specifically for teenagers and young adults in some hospitals across the country. These units allow you to mix 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 the Lymphoma Association."
Young adults aged 19–24

If you are a young adult, you could be treated in a specialised teenage and young adult unit or adult ward at the PTC. You could choose to be treated in a teenage and young adult friendly part of an adult ward at your local TYA designated hospital. You have the choice about where you are treated. You can discuss all the options with your hospital team. You might want to think about how much time the medical team expects you will spend in hospital and how close each available option is to your home.

Natalia, diagnosed at 20, was treated on an adult ward. She says:

“I was given the option of moving to a Principal Treatment Centre for teens and young adults. I decided to stay at the hospital I was diagnosed in as I felt confident in my doctor and it was easier to get to. I was the youngest on the ward but really appreciated the banter and support from everyone.”

Rebekah, diagnosed at 18, was mainly treated in a teenage and young adult ward but stayed in several different wards. She says:

“They have all been different experiences but the care given from all the nurses and doctors has been exceptional. They have all been so kind; and for me that is what makes the whole experience not so scary.”
Do I have to stay in hospital?

You have to spend a lot of time at the hospital during your treatment.

Ask how long you’ll be at the hospital for each time. You can usually take someone with you to keep you company.

Think about what you might like to bring to entertain you – ask if you can use your mobile phone or tablet.

You are likely to have most of your treatment as an outpatient. This means you go to the hospital for your treatment but don’t need to stay overnight.

You may have to have some of your treatment as an inpatient, which means you need to stay in the 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 being treated in a teenage and young adult unit at a PTC, someone can stay with you in hospital 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, eg common rooms, games rooms or a kitchen. You should be able to have a look around before you are admitted to hospital.
Questions you might like to ask about hospital:

Where am I being treated?

Is there WiFi? Can I use my mobile phone/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?

Things to take 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, eg 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, eg books, music, magazines, your iPad/tablet.
**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 are given a contact person (key worker) who can answer your questions or concerns. Your key worker is often a clinical nurse specialist (CNS), 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, keeping an eye on your progress and seeing you after treatment ends. This is often a haematologist (a specialist in blood problems) or 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 eating 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 impact of your illness and can give advice about money and provide help with other things you might need
- 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>
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<tbody>
<tr>
<td>Key worker (clinical nurse specialist)</td>
<td></td>
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<tr>
<td>Consultant</td>
<td></td>
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<tr>
<td>Other doctors</td>
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<tr>
<td>Dietitian</td>
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<tr>
<td>Physiotherapist/Occupational therapist</td>
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<tr>
<td>Psychologist/Counsellor</td>
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<tr>
<td>Social worker</td>
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</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, like your parents/carers or partner, discuss beforehand how you would like them to act. You might want them to lead the discussions, you might want to talk to the medical team yourself or 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.”

Ellie, diagnosed at 15
If you have a question, ask.

If you think a question is silly, ask anyway – the doctors and nurses have heard it all before.

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 them 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.

Most treatment in young people is currently done as part of a clinical trial. 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, these should be explained to you.

What happens if I am under 18?

Your parents or carers might need to agree to certain treatments, if you under 16. They might have to sign a written agreement known as a ‘consent form’. You may be able to sign your own consent (assent) form if your doctors consider this to be appropriate.

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 then sign your own consent form. No treatment can be carried out without your agreement.
A clinical trial tests a new treatment against the best existing treatment, or compares existing treatments against each other. Trials can test new drugs, or the same drugs used in existing treatments but in different amounts or in different ways.

Even when 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 the effectiveness of existing treatments if it is unclear
- find ways to identify people who need more intensive or different treatments
test whether newer treatments could be safer and more effective than the current best treatments.

Questions about treatment can only be answered by clinical trials.

Clinical trials are designed to be safe and fair. Everyone taking part is monitored very carefully at every stage of treatment and during follow-up.

**Is my doctor likely to suggest that I take part in 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 a trial open for your type of lymphoma. If your doctor suggests a trial, you should be given information about it and time to ask questions.

To help you decide whether to take part, you can talk about the trial 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 interests 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. You won’t upset or offend anyone if you say ‘no’ – you will still get the best available standard treatment, which is often very similar to the trial treatment.

How do doctors decide which treatment I get?

Clinical trials are often ‘randomised’. This means that the treatment you get is allocated by a computer. You can’t decide what treatment you have and neither can your doctor. You normally know what treatment you are having and you get information about it.

Sometimes the trial is blinded, which means you don’t know what treatment you have. This is because your expectations about a treatment can influence the results of the trial, without you meaning to do so.

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 a trial that’s suitable for you.
Clinical trials have criteria that the people taking part have to meet.

These criteria are important in making sure that the trial compares groups of people with similar characteristics. They are also important in making sure the trial is as safe as possible for the people taking part. 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.

**Clinical trials only run at certain hospitals.**

PTCs run trials, but only some of the designated local hospitals for teenagers and young adults run trials. It might be possible to be treated at another hospital if a suitable trial is running there. Your doctor can give you more information in that case.

Find out more about clinical trials at www.lymphomas.org.uk/lymphoma-trialslink
Everyone is different so treatment is planned individually, but:

- most people have **chemotherapy**
- some people, eg those with Hodgkin lymphoma, may also have **radiotherapy**
- some people with 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. The drugs are designed to kill cancer cells.

**Why do I have several different drugs?**

Several drugs are usually combined in a ‘**regimen**’. Each drug kills cancer cells in a slightly different way. Regimens are often known as abbreviations of the names of drugs they include, eg OEPA, COPDAC, ABVD. Each letter stands for the name of one of the drugs.
You’ll probably have steroids as part of your chemo regimen too. Steroids help to reduce the size of your lymphoma and can help with some of the side effects of chemo. The steroids you have are corticosteroids, not the anabolic steroids taken for body building.

**How long does chemo take?**

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

The amount of time chemo takes depends on what treatment is planned and how your body responds to it. It can take anything from a few weeks to 2 years to complete.

Your medical team check how well your body is coping throughout the 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.
My treatment

What drugs am I having?

Will I have to stay in hospital?

How long will my treatment take?

What tests do I need during my treatment?
How is chemo given?

Some drugs are given orally (by mouth), usually as tablets for you to swallow.

Many chemo drugs have to be given intravenously (through a drip into a vein).

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. You can have other types of treatment through a central line and you can have blood taken through it too. You can choose not to have a central line.

A central line is a thin, soft tube that stays in your vein throughout your treatment. The line is inserted either through a vein in your arm or directly into your chest. It is called a ‘central’ line because the end of the line goes into a central vein (superior vena cava) just above your heart.
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 more permanent lines fitted.

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.

“Although I now have tattoos, at that time I was petrified of needles! I had a Hickman line so that the chemo could be given through that.”

Jon, diagnosed at 17
TOP tips for lines

Don’t go swimming or get your line wet unless you have a port fitted – ask your nurse for the best way to protect your line when you shower.

Your nurse should flush the line (inject fluids through it) every week to keep it clean – tell your nurse if this isn’t done.

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 tell you how to look after the line when you are not in hospital.

Central lines are removed at the end of treatment. This also involves a small operation.

Questions

Make a note here so that you remember them when you see your doctor.
Some people also have chemo given into their **cerebrospinal fluid (CSF)** so that the chemo reaches their **central nervous system** (brain and spinal cord). This is called ‘**intrathecal chemotherapy**’. It is given during a lumbar puncture.

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

Chemo works by killing any dividing cells. Unfortunately, this kills healthy cells as well as lymphoma cells, particularly cells that divide rapidly like your blood 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:**

- nausea and vomiting (these are often well controlled with anti-sickness medicines)
- hair loss
- effects on the blood: **neutropenia, anaemia** and **thrombocytopenia**
- sore mouth and throat
- weight loss or gain
- constipation or diarrhoea
- fatigue.
I felt dreadful for about a week after. Then I’d pick up a bit. Then it would be time for the next round of chemo.

Jon, diagnosed at 17

Other side effects can happen. 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.

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

“

For my own mental sanity, I weirdly wanted to be 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?

Radiotherapy is given each day over several days or weeks, but giving each treatment dose only lasts a few minutes. You have to keep very still during the treatment.

Although the treatment time is short, appointments can take a while. The X-ray beam has to be carefully positioned so that it gets all the lymphoma cells but as few of your healthy cells as possible.

Ink marks or tiny tattoos are made on your skin to make sure the same area is treated every time.
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, eg if you have radiotherapy to your head, neck or upper chest you may have a sore mouth or throat. Your medical team should tell you what side effects to expect from your treatment.

See page 74 for more on side effects.

Antibody therapy

Normally, antibodies are produced by the body naturally to fight infection.

They stick to foreign organisms that don’t belong in your body, such as viruses. The antibodies then attract other cells of the immune system to help fight the infection. Antibody therapy uses antibodies that have been made in a laboratory to attack certain lymphoma cells.

Rituximab is an antibody therapy that sticks to B cells so it can be used with chemo to treat some types of B-cell lymphoma; for example, Burkitt lymphoma, diffuse large B-cell lymphoma (DLBCL) and rare forms of B-cell Hodgkin lymphoma.

Some antibodies are joined to a chemo drug and take the drug to the lymphoma cells, eg brentuximab vedotin. Brentuximab vedotin is sometimes used in some types of lymphoma in adults, like Hodgkin lymphoma and anaplastic large cell lymphoma. It is most likely to be used when the lymphoma has relapsed (come back) or hasn’t responded to the first treatment.
How is antibody therapy given?

Both rituximab and brentuximab vedotin are usually given intravenously (into a vein). You usually have them once per cycle of treatment (once every few weeks).

What side effects might I have?

Antibody treatments are ‘targeted’ therapies. They are designed to target certain cell types. This means they usually cause fewer side effects than chemo as they have less effect on other types of healthy cell.

The most common side effects happen soon after the treatment begins and are known as ‘infusion-related’ side effects. These include fever, chills and shivering. These side effects are most common during your first treatment. Your nurse keeps a close eye on you during treatment and you are given medicines to help prevent these side effects.
Antibody therapies can also cause other side effects, like low blood counts. 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 may 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 herbal remedies and homeopathy. Alternative therapies are used instead of mainstream hospital treatments. There is no evidence for their effectiveness in 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 may carry a risk of abnormalities or serious harm to your unborn baby. Depending on the stage of your pregnancy, you might be advised to delay treatment until after your baby is born.

If you need treatment straightaway, or you are in the first trimester of your pregnancy (when certain risks to your baby may be higher), it might be possible to alter your treatment plan but this will need careful discussion.

Less is known about the effects of antibody therapy and newer treatments on an unborn baby. Your medical team may advise you against having this type of treatment if you are pregnant.

If your treatment is urgent, your medical team might suggest that you do not continue with the 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.
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 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 relapsed (come back) 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 131.

“

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 videogames and read books which helped distract me from the treatment.

Georgia, diagnosed at 11
You might want to skip this section if it doesn’t apply to you – most people go into remission after their first treatment and stay in remission.

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. Should this be the case, you will probably need a stronger treatment.

“The PET scan results after the first 2 cycles showed that my chest was still affected by Hodgkin lymphoma. I needed to change to a more toxic chemotherapy.”

Natalia, diagnosed at 20
What is relapse?

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

Can I have more treatment?

You might have:

- a different, probably stronger, chemo regimen
- high-dose treatment and a stem cell transplant
- a newer drug, possibly as part of a clinical trial.

High-dose treatment and stem cell transplants

Your body constantly replaces your blood cells as they 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 early blood cell that can develop into all the different types of blood cell, depending on what your body needs.

What’s a stem cell transplant?

Some people need high-dose therapy to treat their lymphoma. This is usually chemo alone but occasionally radiotherapy is given as well. High-dose therapy is more likely to kill lymphoma cells than standard treatment but it also kills more of the normal cells in your bone marrow. When this happens, your body can’t make the blood cells that it needs.

A stem cell transplant gives you stem cells after your high-dose treatment so that you can start to make new blood cells again.
Most people with lymphoma have an autologous stem cell transplant, which uses their own stem cells.

Do I need an autologous stem cell transplant?

Stem cell transplants are an intensive type of treatment and are not needed to treat most lymphomas. Most people who have a stem cell transplant need this treatment because they still have lymphoma after chemo alone or their lymphoma has come back after treatment. Your medical team will tell you if they think you need a stem cell transplant.

How does it work?

Your stem cells are usually collected from your blood before high-dose treatment. 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 body through a drip. They find their way back to your bone marrow and replace the damaged cells, which helps you to recover and start making new blood cells more quickly.
The autologous stem cell transplant process

1. Stem cell mobilisation
Chemotherapy and growth factors to increase blood stem cell number and move the stem cells from your bone marrow to your bloodstream.

2. Stem cell harvest
Stem cells are collected from your bloodstream.

3. Storage
Stem cells are frozen and stored until they are needed.

4. High-dose therapy
Chemotherapy and sometimes total body irradiation (radiotherapy to the whole body).

5. Stem cell transplant
Your stem cells are given back to you.

How are stem cells collected from the blood?

You get a drug (granulocyte-colony stimulating factor, G-CSF) to encourage the stem cells to move out from the bone marrow and into the blood. When you have enough stem cells in your blood, you go into hospital for stem cell collection. It takes several hours to collect enough cells and you might have to have several collections.
Blood is taken from a vein, usually in your arm. The blood is passed through a special machine that separates and collects the stem cells while the rest of the blood is returned to your body. You might have other treatments to help collect enough stem cells.

**The collected stem cells are frozen and stored.**

> I travelled to a different hospital to have my stem cells collected as my local hospital did not have the special machine used to collect stem cells. It took about 3–4 hours for my stem cells to be collected. It didn’t hurt at all but it was quite boring sitting hooked up to the machine for so long, so take a magazine or two to read!

*Sam, diagnosed at 23*

**What happens next?**

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

After treatment, the stem cells are given back to you, usually through your **central line**. You can expect to stay in hospital for at least 3 weeks after getting the stem cells. Depending on your hospital’s policy, you may be kept in an isolation room. This is to protect you from an infection until the treatment is over and your bone marrow is working properly again. During this time some of your family and friends can come and see you.
Newer drugs and clinical trials

There are lots of new drugs in development for lymphoma. Many of these are ‘targeted therapies’. They aim to kill lymphoma cells with minimum damage to normal cells.

Some newer drugs are already being used for people with relapsed or refractory lymphoma, eg brentuximab vedotin (see page 62), which is a targeted therapy used for Hodgkin lymphoma and anaplastic large cell lymphoma.

I was in hospital for about 4 weeks for my stem cell transplant. I had my own room, which was nice, but I wasn’t allowed to leave it while I was immunosuppressed. My family and friends were allowed to visit me. I spent my 24th birthday in hospital. Two of my close friends came to visit and threw me a special mini birthday party in my room.

Sam, diagnosed at 23

Very rarely, an allogeneic stem cell transplant is given, where donor stem cells are used instead of your own stem cells.

If you are having a stem cell transplant, read more at bit.do/stem-cell-transplant or request a free copy of our booklet on autologous stem cell transplant at bit.do/lymphoma-information
There are many more drugs in development and 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 relapsed (come back) or is refractory (didn’t respond to their previous treatment). Clinical trials of newer drugs can offer more treatment options for some people.

Read about clinical trials on page 48.
All treatments for lymphoma cause unwanted effects on the body (side effects). Everyone reacts differently to treatment and each treatment has its own set of possible side effects.

Ask your medical team what side effects to expect and ask for advice if you are worried about any side effects you’re having. Tell your medical team how you are feeling. They are experienced in helping people with all sorts of side effects.

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. Either way, this section outlines the most common early side effects and gives you tips on how to cope with them.

Late effects can also develop. These are side effects that develop months or years after treatment and are described on page 138.
What side effects should I expect?
Hair loss

The thought of losing your hair can be very difficult. You might be worried about how you'll look and what people will think. Remember that your hair will grow back.

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.

If you have radiotherapy, hair is only affected on the part of your body treated.

When does hair start to fall out?

Most people start losing hair a couple of weeks after starting chemo. With radiotherapy, hair loss tends to happen gradually towards the end of treatment. Trying out shorter hairstyles could help lessen the impact of your hair falling out.
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.

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.

“I did not let my baldness define me.
Natalia, diagnosed at 20"
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 before it falls out and when it’s growing 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.
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 focused on large bones.

The 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>White cells</th>
<th>Red cells</th>
<th>Platelets</th>
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<tbody>
<tr>
<td>Medical name</td>
<td>Neutrophils and lymphocytes</td>
<td>Erythrocytes</td>
</tr>
<tr>
<td>What they do?</td>
<td>Fight infection</td>
<td>Carry oxygen</td>
</tr>
<tr>
<td>Name of shortage</td>
<td>Neutropenia and lymphopenia</td>
<td>Anaemia</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Infections</td>
<td>Pale skin, feeling tired, breathless, cold, dizzy</td>
</tr>
<tr>
<td>What happens if you have a shortage</td>
<td>• Delay treatment</td>
<td>• Delay treatment</td>
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<td></td>
<td>• Take antibiotics if you have an infection</td>
<td>• Red cell infusion if needed</td>
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</tbody>
</table>
Infections can be very serious when you're having treatment for lymphoma. Make sure you think about the risk of infection whatever you do and follow any advice from your medical team.

Neutropenia puts you at a much higher risk of infection than normal.

When am I most at risk?

Your neutrophil count is lowest about 7–10 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?

You can’t prevent all infections however careful you are. Infections can come from other people, food, your surroundings, even from germs that normally live in your body.

These germs have an important role in making your body function properly but can cause a problem 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, eg if they have a heavy cold, flu, diarrhoea, vomiting or chickenpox.

Ask someone else to clean up after pets. Wash your hands after touching pets.

Keep yourself clean, wash your hands before meals and after using the toilet, and brush your teeth after every meal.

Clean any cuts or grazes with soap, warm water and an antiseptic.

Be careful with anything sharp, like knives, scissors, gardening tools and razors. You can use an electric shaver.

Follow food safety advice. Ask what food to avoid.

Read our page on neutropenia for more tips on avoiding infection: bit.do/neutropenia
Contact your medical team immediately if you have any of the following symptoms:

- Fever (temperature above 38°C)
- Shivering
- Chills and sweating
- Feeling generally unwell, confused or disoriented
- Earache, cough, sore throat or mouth
- Redness and swelling around skin sores, injuries to intravenous lines
- Diarrhoea
- A burning or stinging sensation when passing urine
- Unusual vaginal discharge or itching
- Unusual stiffness of the neck and discomfort around bright light.

Don’t take any medicines unless 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 abdomen (tummy) can make you feel sick too.

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

What can I do about it?

Tell your medical team if you felt sick after your last treatment. They can give you antiemetics (anti-sickness drugs). There are lots of different types, so you can try another one if the one you were given first didn’t help.
TOP tips for coping with nausea

Drink water or fizzy water.

Suck ice cubes or sweets.

Eat foods with ginger or try ginger beer.

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 computer 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 fried food.
- Try bland food like potatoes, white rice, white bread or bananas.
- Cut down on raw fruit and veg for a while.
- Wash instead of wiping your bottom if it is sore.
- Have a warm bath and use a soothing cream.
- Make sure you wash your hands carefully in case of infection.

What can I do about constipation?

- Drink plenty of water or try fruit juice.
- Try being more active.
- Don’t strain when trying to poo.
- Eat high-fibre food like fresh fruit and veg and cereal.
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 a 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 so that you can eat. Try:

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

**Food doesn’t taste the same...**

Flavouring your food might help. You could try adding:

- herbs, spices, sauces and chutneys to savoury food
- fruit coulis to puddings.
I’m losing weight…

Try to eat when you can. Eating little and often might be more manageable than having big meals. Bland foods can be easier to stomach. Eating with other people might help take your mind off 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.

I’m gaining weight…

Some treatments, like steroids, can make you gain weight.

You might gain weight in certain places, like your cheeks. Remember that this is only 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.
Many young people have problems with their skin anyway and sometimes chemo can make skin problems temporarily 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. Protect your skin from the sun by wearing hats and long sleeves. Use sun cream on any areas exposed to the sun.

Your medical team can give advice on how to look after your skin. Ask them what skincare products you should use.
TOP tips for skin care

Don’t scratch – this worsens the itch.

Moisturise frequently with creams recommended by your medical team.

Be gentle – use soft cloths, pat your skin dry instead of rubbing it and don’t use razors (electric shavers are gentler).

Take short, lukewarm baths or showers.

Don’t use hairdryers, dye your hair or use sunbeds.

Avoid swimming pools.
Fatigue is extreme tiredness. You might feel drained and unable to carry on with day-to-day tasks. Most people with lymphoma feel fatigue at some point. It can be because of the lymphoma, or the treatment, or both.

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.

Talk to your doctor, too. Side effects like anaemia can cause fatigue; there might be treatments that can help.

Keep a diary to see if you can work out a pattern.
TOP tips for fighting fatigue

Pace yourself – be active when you can but use your energy for the most important things.

Plan regular rests.

Take regular, light exercise – just going for a short walk can make you feel better.

Relax when you can – listen to music, take a bath or try mindfulness techniques like meditation.

Keep a regular sleep routine.

Eat well.
Fertility

Fertility is your ability to make a baby.

Does my treatment affect fertility?

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

Some people might still be able to make a baby during treatment, but the baby might not develop normally if your sperm or eggs are damaged by chemo.

It is very important that you use reliable contraception if you have sex during treatment to prevent pregnancy. 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. Use a condom during your 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 (eg 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 know for certain how your treatment will affect you.

**Can I preserve my fertility?**

You might be referred to a fertility specialist to talk about your options for preserving fertility. Fertility treatments are not always available on the NHS. The specialist can advise what funding options you may have.

**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 gone through puberty yet may have tissue from their testicles frozen but this is experimental.

It may be possible for eggs to be frozen too if there is time to do so before you need to start treatment.
Sam had her eggs harvested after her Hodgkin lymphoma relapsed. I was able to delay starting my treatment to have fertility treatment. I had a couple of weeks of hormone injections and then my eggs were harvested. It was a scary thing to do at the age of 23, but now I’m 31 and I have lost my fertility I am so grateful to my consultant for giving me the chance to preserve my fertility and hopefully have children one day.

Rebekah, 18, had to change to a stronger chemotherapy and was advised to have ovarian tissue preservation.

My new chemotherapy had a higher risk of infertility. My doctor referred me to a different hospital that was more specialised in fertility. They got my appointment for the ovarian tissue procedure very quickly and recovery time was quick, so the new course of chemotherapy was only delayed by about 3 weeks.
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 might be difficult to cope with.
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 is anything you want them to go over. Remember, they are used to answering questions and should be happy to explain things as many times as you’d like. You could also ask a family member or friend to come to your appointments with you. That way, they can take notes while you listen and ask questions.

Many people are relieved to start treatment and feel optimistic about their outlook. Even so, there may 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
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 to 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 or drawing.

Make time to relax and have fun. Spend time with the people you enjoy being around. Recognise that there may be times when your energy levels are 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 an illness like lymphoma.

However, some people feel very low a lot of the time. If this is the case, you might be affected by depression. If you have had depression in the past, you may be more likely to experience it after a diagnosis of lymphoma.

Counselling

Having an illness like lymphoma can be overwhelming at times. If you’re finding it hard to cope with your feelings, you may want to get some extra support. This may include counselling.

For some people, counselling provides an opportunity to talk about the things they feel unable to talk about to 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 may help at various points, such as after diagnosis, during or after treatment.
If you are interested in counselling, speak to your doctor or nurse. They may be able to refer you to a counsellor on the NHS, through your hospital or a local cancer support centre. You can also search for a private therapist in your local area using the British Association of Counsellors and Psychotherapists online tool at www.itstsgoodtotalk.org.uk/therapists. There is a fee for private counselling sessions.

"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 and helped me feel a lot better.

Georgia, diagnosed at 11

Counselling can help you to consider:

your thoughts and feelings
the impact of lymphoma on your life (eg work, studies or caring for others)
what’s important in your life
how you tend to respond to people and things, relating this to your current situation
what the people and things in your life mean to you
your resilience and inner coping resources
strategies to address problems.
Finishing treatment and leaving hospital

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

It’s not unusual to feel low once treatment finishes. You might miss staff who cared for you and the friends you’ve made. You may feel scared that your treatment is finishing and anxious that your lymphoma could return. Remember that you’ll have regular checks on your health and you can contact your key worker at any time if you have any concerns.

It takes time to re-adjust to life outside of hospital. Be kind and patient with yourself. Trust yourself to know what you need – whether this is rest, time alone or 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 may want to get in touch with other young people who have had cancer on the CLIC Sargent forums.

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. Also note down what you can and can’t do about them. You can then make plans for how to deal with the concerns you can address.

An example is 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. I could also lower my anxiety levels using breathing techniques (see page 102).</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>
</tbody>
</table>

Distraction can be a good way to prevent you from feeling continuous anxiety. Keep active and do the things you enjoy. Make time to relax, too. You could try meditation, yoga or mindfulness.
Breathing techniques may help you to feel calmer. Practising these while you are calm can help you to use them more easily when you are feeling anxious. One exercise that many people find helpful is ‘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 son, a brother, a student, a guitarist. Go a bit deeper, too – think 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.

“

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 on the page opposite. Include all food groups in your diet to get the nutrients you need to grow, recover and function well.
Eatwell Guide

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

Check the label on packaged foods:
Each serving (115g) contains:
- Energy: 1564kJ/379kcal (13% of an adult’s reference intake)
- Fat: 3.0g (4%)
- Salt: 0.9g (7%)
- Sugars: 13.5g (15%)

Choose foods lower in fat, salt and sugars:
- Eat at least 5 portions of a variety of fruit and vegetables every day.
- Choose wholegrain or higher fibre versions with less added fat, salt and sugar.
- Limit fruit juice and/or smoothies to a total of 150ml a day.

Eat less often and in small amounts:
- Choose unsaturated oils and use in small amounts.
- Eat more beans and pulses, 2 portions of sustainably farmed and processed meat.

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

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

Is it OK to diet?

Generally, doctors advise that you do not try to lose weight while you’re having treatment.

Dieting can make it harder for your immune system to recover. If you are gaining weight because of your treatment, especially steroids, cut out 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’. 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.

Read answers to more FAQs about food and lymphoma at bit.do/diet_nutrition
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.

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 loose sweets or bakery goods, ice cream from a parlour or salad from a salad bar.

Read more top tips about food safety at bit.do/food_safety
Is it safe to drink alcohol?

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

The occasional alcoholic drink between cycles of chemo when you are feeling well should not be a problem – but check with your doctor first. Be aware that you may 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 the treatment drugs.

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.
Exercise

Staying fit and active is a great way to help you feel better. It may 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:

- control your weight
- lower fatigue (tiredness)
- increase muscle and bone strength
- lower your risk of infections
- increase your overall physical health
- 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:

- 5–18 year olds: at least 1 hour a day
- 18+ year olds: at least 30 minutes a day, 5 days a week.
In reality, the amount of exercise you need depends on things like your overall health, energy levels, and whether you are having treatment for lymphoma. Sometimes, chemotherapy and steroids can make your legs weak. This can make it difficult to do anything strenuous.

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
TOP tips
for building exercise into your daily life

Walk or cycle to the shops.

Get off the bus a stop early and walk the rest of the way.

Take the stairs instead of the lift or escalator.

Carry your 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 drugs can put on your heart.

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.

Georgia, diagnosed at 11

Can I play sport?

During treatment and for a little while after, your risk of infection, bruising and bleeding may 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, you could 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 breed easily, so you may 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 may not be allowed to dive. Find out more on the British Sub Aqua Club (BSAC) website at www.bsac.com.

CLIC Sargent and Trekstock have teamed up to create **RENEW**, a 12-week physical activity programme for young people (aged 16+) who have had cancer. Find out more at www.trekstock.com/renew
Education and training

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 illness, treatment and the effects of your treatment.

“My teacher was really involved and considerate and sometimes came around to my house to give me worksheets and help me catch up with my school work.”

Georgia, diagnosed at 11

“College was very supportive and understood why I couldn’t always be there.”

Brittany, diagnosed at 19
What support is available?

If you are under 16, you may be able to get support from your local education authority (LEA). You can find your LEA at bit.do/local-ed-authority. 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 at times 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. And when I did need to stay in hospital, I always asked school to send work to me, which was helpful, giving me something productive to do! Happily, I managed to do well in my exams and was able to move straight onto A-Levels. I’m now 19 and in my second year studying English Literature and Journalism at Cardiff, and I’m loving the course and my life there.

Ellie, diagnosed at 15
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.

Most employers are flexible and supportive.

My part-time job kept the position open for me and actually raised money for me.

Brittany, diagnosed at 19
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, eg 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. Find out more at bit.do/Macmillan_work_rights.

You'll find a list of organisations that provide specialist information and advice about finances at bit.do/financial-support.
Having lymphoma can put pressure on relationships.

Often they become strained; misunderstandings arise or things are left unsaid. Despite the challenges they can bring, research shows that people with cancer cope better when they are supported through strong relationships.

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 you just want to chat about other things, like sport or the latest TV show. The chances are, they’ll want to be there for you and will be pleased for some guidance about how best to help you.
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. Just remember to avoid places like clubs, cinemas, crowded shops and public transport if you are neutropenic, to lower your risk of infection.
Parents

You may find that your relationship with your parents has changed since you were diagnosed with lymphoma.

It’s quite common for parents to become more protective after their child has been through an illness like lymphoma. They love you and want to help you get better as quickly as possible but 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’.
Agreements

you'd like to make with parents
**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 may 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, eg company, time to talk about how you feel, or to do something fun together.

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 remain out there for years to come.

Use ‘I’ statements to help take the blame out of what you say.
‘I’ statements

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…</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 might feel hurtful, remember that they’re not deliberately upsetting you – they just don’t want to say the wrong thing. You might need to be the one to open 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

Or you might want to give a bit more detail, for example:

‘I’ve had a really tough few months going through treatment for lymphoma. I’ve been feeling stressed and low. I lost some of my hair because of the chemo, which is why I’m bald’

‘I’ve been unwell but I’m having treatment and I’m doing OK’
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 feel interested in sex again.

CLIC Sargent has information about relationships and sex where they answer young people’s FAQs: bit.do/CLIC-relationships
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. 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 many people with lymphoma are cured by their first course of treatment, it is only natural to worry about the lymphoma relapsing (coming back) or that a new health problem may arise. Feeling uncertain and not fully in control can be very hard to live with.

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 though, I know I would be in a continuous state of anxiety without them.

Ruchi, diagnosed at 24

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.

See page 98 for more on depression.
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 is not 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 also speak to a member of our helpline team about how you feel.

- **Write about how you feel** – writing down your thoughts and feelings in a diary or journal can be really helpful. Even if no one else reads it, the process can be very therapeutic. Some people keep an online blog, 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 who can relate to you** – you might like to speak to others who have been affected by lymphoma. Even though their experience is not the same as yours, you may like to be in touch with someone else who understands what having lymphoma means.
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.
Once treatment has finished and you are in remission you’ll have regular check-ups at the hospital for the next few years.

This is called ‘follow-up’.

It is really important that you go to your follow-up appointments even if you worry there might be a problem. Remember that if your test results are good, you’ll be relieved to know that you are still in remission. If there is a problem, finding it sooner often means it is easier to deal with.

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, see page 138).
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 if I’m worried before my appointment?

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

Contact your medical team if you’re worried. They can reassure you or arrange for you to see them earlier 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, eg:

- bleomycin can affect your breathing
- anthracyclines (eg doxorubicin) can affect the strength of your heart.

You may be given a card or a letter with all the important information on. Ask for it if you haven’t been given one.

Always carry it with you. Make some copies in case you lose the original.
Some treatments mean you need to be treated differently, or take extra medications in certain situations, eg if you have an accident or need a blood transfusion.

Precautions if you had a splenectomy or radiotherapy to the spleen

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

- You’ll need to take low-dose protective antibiotics every day for the rest of your life. If you don’t take them every day, make sure you have an emergency supply of antibiotics ready to take if you get an infection. Discuss this with your doctor.

- You might need regular vaccinations, eg the flu jab. If you travel to another country, you may need extra vaccinations or 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 states it. Keep your card with you at all times. If you ever need a blood transfusion, the hospital that treated you will know that you need irradiated blood but other hospitals won’t know this. You will need irradiated blood products in the future if:

- you’ve had Hodgkin lymphoma
- you were treated with certain drugs, like purine analogues (eg fludarabine) or purine antagonists (eg 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, this could prevent you making enough natural steroids if you become ill or unconscious after an accident in the future. Your doctor should tell you if you are not making enough natural steroids at the end of treatment. This is quite rare. You can be given steroid replacements as needed.
What are late effects?

Your treatment damages healthy cells as well as lymphoma cells. Problems caused by damage to healthy cells can take time to develop. Late effects are side effects that develop months or years after treatment, such as heart disease or a second cancer.

These problems don’t mean your lymphoma is coming back, but can still be worrying. Your doctor can give you information about the possible late effects of your treatment but remember that not everyone gets them. Catching problems early often makes them easier to treat, so it is important you know what to look out for.

Many hospitals have a ‘late effects’ clinic. You can see the late effects team when your follow-up with your lymphoma doctor ends. This is usually 5 years after your treatment has finished.
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.

Find more information about late effects at bit.do/late-effects-treatment
Many couples go on to conceive a baby without difficulties after having 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 chemo 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 chemo.

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.

For more information about fertility, see page 92.
Pregnancy and giving birth

Many women go on to have children 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 relapse 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 chemo 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 any risks related to having a baby after lymphoma treatment?

There is strong evidence that there is no increased risk of birth defects if you conceive 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?

Not all fertility treatments are funded on the NHS and there are variations across the UK.
Most vaccinations are safe for people who have had lymphoma. You should not, however, have vaccinations too soon after finishing treatment. You may be advised to wait 6 – 12 months after treatment. Ask your doctor for guidance specific to your situation.

After treatment for lymphoma, it is advisable to have the winter flu vaccine – your doctor should talk to you about this. 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 to check whether your travel plans are safe. They may also be able to tell you a bit about medical services in the part of the world you’re hoping to go.

It’s important to have medical cover as part of your travel insurance. This could save you from having to pay for treatment you might need if you are unwell while you are away. It can also cover extra expenses such as flights if you need to come home early. Your consultant or key worker might be able to give you the 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.

Avoid ice in your drinks, unless you know it’s made from sterilised water.
You might find it helpful to speak to someone else who has personal experience of lymphoma. Although their experience isn’t 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 Association support groups are for people of all ages. 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, such as those on our website, or through other organisations, like CLIC Sargent.

How we can help

For more information about any of the topics in this booklet, visit www.lymphomas.org.uk/about-lymphoma.

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

Call our Information and Support Team on Freephone 0808 808 5555, Monday to Friday, 9am to 5pm. You can also contact us by WhatsApp or text on 07786 202030 or use Live Chat on our website.

Come to one of our support groups. Find your nearest one at bit.do/support-groups.
If you’re 16 or over, join our online forum to chat with others who are affected by lymphoma.

Join us on Facebook.

Follow us on Twitter @LymphomaAssoc.

Watch short films of people sharing their personal experiences of lymphoma on our YouTube channel at bit.do/Lymphoma-YPG-videos. These include videos of young people talking about various aspects of living with lymphoma.

Other organisations & support

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

0116 252 5858 | www.cclg.org.uk | info@cclg.org.uk

@CCLG_UK

**CLIC Sargent** (Cancer and Leukaemia In Childhood) offer clinical, emotional and practical support to children and young people with cancer, and to their families.

0300 330 0803 | www.clicsargent.org.uk | online enquiry form

@CLIC_Sargent

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

www.elliesfriends.org | info@eleanorrose.org

@ElliesFriends
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.

online.hscni.net

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

www.jtvcancersupport.com | info@jtvcancersupport.com

Look Good Feel Better provides practical support (including make-up workshops and skincare sessions) for women who are struggling with the side effects of cancer treatment.

01372 747 500 | www.lookgoodfeelbetter.co.uk | info@lgfb.co.uk

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

0808 808 0000 | www.macmillan.org.uk | online enquiry form

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

www.youngcancer.scot.nhs.uk | online enquiry form
**Mummy’s Star** offers emotional and financial support for women who have cancer in pregnancy and for a year afterwards.

www.mummysstar.org | online enquiry form

[@MummysStar](https://twitter.com/MummysStar)

**NHS Choices** has information about cancer. There is a separate area of their website for people aged 19–24.

www.nhs.uk/young-cancer-care/pages

[@NHSChoices](https://twitter.com/NHSChoices)

**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. They have a large online forum on Facebook.

www.shinecancersupport.org | hi@shinecancersupport.org

[@ShineCancerSupp](https://twitter.com/ShineCancerSupp)

**Siblinks** offers a network of support for young people aged 13–25 who are siblings or children of people affected by cancer. They have an online forum and information.

www.siblinks.org

**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.

0207 612 0370 | www.teenagecancertrust.org | hello@teenagecancertrust.org

[@TeenageCancer](https://twitter.com/TeenageCancer)
**Trekstock** is a charity that provides support to young adults in their 20s and 30s living with cancer and its affects.

0207 439 8607 | www.trekstock.com | hello@trekstock.com

[@trekstock](https://twitter.com/trekstock)

**Willow Foundation** is a charity that offers days out for young adults (aged 16–40) who are seriously ill.

01707 259 777 | www.willowfoundation.org.uk | info@willowfoundation.org.uk

[@Willow_Fdn](https://twitter.com/Willow_Fdn)

**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.

07919 147 784 | www.workingwithcancer.co.uk | online enquiry form

[@WorkWithCancer](https://twitter.com/WorkWithCancer)

**Young Minds** is a charity committed to improving the emotional wellbeing and mental health of children and young people. They offer online information.

0207 089 5050 | www.youngminds.org.uk | ymenquiries@youngminds.org.uk

[@YoungMindsUK](https://twitter.com/YoungMindsUK)

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

01202 763 591 | www.youthcancertrust.org | admin@yct.org.uk

[@YouthCancerYCT](https://twitter.com/YouthCancerYCT)
Glossary: what does that mean?

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

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

**Anaesthetic** A drug that stops feeling, especially of pain: in a general anaesthetic the drugs will also make you unconscious; in a local anaesthetic the drug just numbs part of the body

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

**Autologous** from your own body

**B symptoms** unexplained weight loss, drenching night sweats, high fevers

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

**Blood count** finds out how many blood cells of each type (red blood cells, white blood cells, platelets) are in your blood

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

**Bulky disease** very enlarged lymph nodes

**Cell** all our organs are made up of cells and although they have the same basic structure, they are specially adapted to form each part of the body
**Central line** a hollow 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 central nervous system

**Chemotherapy** treatment with drugs that are poisonous to cells – can be called ‘chemo’ for short

**Diaphragm** a sheet of muscle across the bottom of the ribcage

**Drip** the slow, drop-by-drop infusion of a liquid

**Erythrocyte** a red blood cell containing haemoglobin and transporting oxygen

**Extranodal** outside the lymph nodes

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

**Haematologist** a doctor who specialises in diseases of the blood and blood cells

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

**Immune system** the system in the body that fights infections and causes allergic reactions. It consists of white blood cells, the spleen and the lymph nodes

**Intrathecal** injections given directly into the spinal fluid (CSF)
Late effects health problems that first appear 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 vessels tubes that carry lymph around the body, connected by lymph nodes

Lymphocyte a type of white blood cell that fights infection

Lymphoma cancer of 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 stands for ‘peripherally inserted central line’ – a flexible tube inserted into one of the large veins in your arm, above your elbow, and is used to take blood or give chemo

Platelets the tiny fragments of cells in your blood which help to stop bleeding

Port-a-cath® a central line that is put into a vein in your chest and has a reservoir (port) just under the skin. It allows medicines to be given into the main veins and blood to be taken from the vein
Radiotherapy: treatment by X-rays

Refractory: lymphoma that is not cleared by or responding to treatment

Regimen: a programme of treatment including drugs, 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 in any test

Spleen: a part of your immune system – it helps to fight infections and clear bacteria and old red blood cells from the body

Stage: a number used to show how much lymphoma you have and where it is – sometimes there’s a letter as well

Staging: examination and tests that are done to find out the stage of your lymphoma

Stem cell (blood): an early blood cell that the body hasn’t yet turned into a red cell, white cell or platelet

Steroid: a type of drug used to treat swelling and inflammation. They might be called ‘corticosteroids’

Thrombocytopenia: shortage of platelets in your blood

Thymus: a gland in your chest where T cells are made
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Are you a young person with lymphoma?

This booklet is for you. Find out more about lymphoma – what it is, how it is treated and how to look after yourself during your treatment and beyond.

If you need information or support, the Lymphoma Association is here for you. Freephone helpline 0808 808 5555
information@lymphomas.org.uk
www.lymphomas.org.uk

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