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

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

To make a donation towards our work please visit lymphoma-action.org.uk/Donate
Your Hodgkin lymphoma type and stage

Your treatment

Key contact

Name: ________________________________

Role: ________________________________

Contact details: ________________________________

<table>
<thead>
<tr>
<th>Job title/role</th>
<th>Name and contact details</th>
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<tr>
<td>GP</td>
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<td>Consultant haematologist/ oncologist</td>
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<td>Clinical nurse specialist or key worker</td>
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Hodgkin lymphoma is a type of blood cancer that develops from white blood cells called lymphocytes.

This book explains what Hodgkin lymphoma is and how it is diagnosed and treated. It includes tips on coping with treatment and dealing with day-to-day life.

The book is split into chapters. You can dip in and out of it and read the sections that are relevant to you at any given time.

Important and summary points are written in the chapter colour.

- Lists practical tips and chapter summaries.
- Space for questions and notes.
- Lists other resources you might find useful.

This book uses some scientific words. Words that are in bold are explained in the glossary on pages 143 to 147.

The information in this book can be made available in large print.
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I had several tests during the course of a week and the doctors monitored me closely to see if my condition got worse. The results were inconclusive. They did tell me, though, that they suspected this was Hodgkin lymphoma. I had never even heard of this disease before.

Adam P, diagnosed with Hodgkin lymphoma in 2013
Introduction to lymphoma

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What is lymphoma?

Lymphoma is a type of blood cancer that develops when white blood cells called lymphocytes grow out of control. These lymphocytes divide in an abnormal way or do not die when they should.

Lymphocytes travel around your body in your lymphatic system, helping you fight infections. If you have lymphoma, abnormal lymphocytes build up in your lymphatic system, usually in lymph nodes in your armpits, neck or groin. However, they can collect in almost any part of your body.

Lymphoma is the fifth most common type of cancer in the UK. Each year, over 19,500 people are diagnosed with lymphoma in the UK.

Lymphoma is almost always treatable.

What is the lymphatic system?

Your lymphatic system is part of your immune system, which helps protect you from infection. It runs throughout your body carrying a fluid called lymph.
Your lymphatic system is a network of tubes called lymph vessels, and lymph nodes (sometimes known as lymph glands). It also includes organs, such as your **spleen** and **thymus**.
The lymphatic system protects your body by filtering out germs and poisons (toxins) and helping to destroy cells that are old, damaged or abnormal. It also drains waste fluids from your tissues.

You have lymph nodes and lymph vessels throughout your body. Some groups of lymph nodes are easy to feel, particularly in the neck, under the arms and in your groin. Others are deeper inside the body where they’re harder to feel.

**How does lymphoma develop?**

Most of the cells in your body are dividing all the time to make new cells. These replace old cells that die off naturally. Usually, cell division and cell loss are kept carefully in balance so you only make the number of new cells your body needs.

Lymphoma occurs when this carefully controlled system breaks down. Instead of dying as they should, ‘rogue’ lymphocytes divide in an uncontrolled way. These abnormal lymphocytes build up and can form a lump. The lymphocytes usually collect in a lymph node but they can collect in other parts of the body, such as the spleen, liver or **bone marrow**.
What types of lymphoma are there?

There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphoma and non-Hodgkin lymphoma depending on what they look like under a microscope. Different types of lymphoma behave differently and need different treatment.

Hodgkin lymphoma is named after Dr Thomas Hodgkin, who was the first person to describe it in 1832. When you look at Hodgkin lymphoma under a microscope, you can see large, abnormal cells called Reed–Sternberg cells.

There are two types of Hodgkin lymphoma (see page 16):

- classical Hodgkin lymphoma
- nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).
Non-Hodgkin lymphoma is any lymphoma that does not have Reed–Sternberg cells. There are many different types of non-Hodgkin lymphoma. They are often grouped further depending on whether they are slow-growing (low-grade) or fast-growing (high-grade).

For more information on the different types of lymphoma, visit lymphoma-action.org.uk/Types

Summary

• Lymphoma is a type of blood cancer.
• Lymphoma develops when white blood cells called lymphocytes grow out of control.
• There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma.
I had night sweats and a persistent cough. I also noticed that my body temperature didn’t seem to be regulating itself as it always had – I would feel really cold and then suddenly very hot.

Andy, diagnosed with Hodgkin lymphoma in 2009
Hodgkin lymphoma

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Who gets Hodgkin lymphoma? 18
What causes Hodgkin lymphoma? 19
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What is the outlook for people with Hodgkin lymphoma? 24
Types of Hodgkin lymphoma

There are two main types of Hodgkin lymphoma: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL). Scientists tell them apart based on laboratory tests that check:

- what the cells look like under a microscope
- what proteins the lymphoma cells make
- changes in the DNA of the lymphoma cells.

Classical Hodgkin lymphoma

Most people with Hodgkin lymphoma have classical Hodgkin lymphoma.

Classical Hodgkin lymphoma contains particular cells called Reed–Sternberg cells. These are large, abnormal lymphocytes that look a bit like owl eyes under a microscope. It also contains Hodgkin cells, which have similar proteins and DNA to Reed–Sternberg cells but don’t look like owl eyes.

Figure: Reed–Sternberg cells under a microscope
There are four subtypes of classical Hodgkin lymphoma:

- nodular sclerosis classical Hodgkin lymphoma
- mixed cellularity classical Hodgkin lymphoma
- lymphocyte-rich classical Hodgkin lymphoma
- lymphocyte-depleted classical Hodgkin lymphoma.

All four subtypes are treated in the same way (see page 51).

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)
Around 1 in 10 people with Hodgkin lymphoma have NLPHL.

NLPHL contains variants of Reed–Sternberg cells called lymphocyte-predominant cells (LP cells). They are sometimes known as ‘popcorn cells’ because they look a bit like pieces of popcorn under a microscope.

**Figure: Lymphocyte-predominant cells under a microscope**
LP cells make a protein called ‘CD20’. This is more commonly found in non-Hodgkin lymphomas. Some treatments for NLPHL target the CD20 protein (see page 76).

Ask your medical team what type of lymphoma you have if you’re not sure.

Who gets Hodgkin lymphoma?

Around 2,100 people are diagnosed with Hodgkin lymphoma each year in the UK – more than five people every day. It is slightly more common in males than females.

Hodgkin lymphoma can affect people of any age, including children. In the UK, most people diagnosed are between the ages of 15 and 34, or over 60.

• We have specialist information for younger people: for a copy of our Young person’s guide to lymphoma, call 0808 808 5555 or visit lymphoma-action.org.uk/Books
• You can find us on Facebook, Twitter, Instagram and YouTube.
What causes Hodgkin lymphoma?

Scientists don’t know exactly what causes lymphoma. But they do know that:

• it is not caused by anything you have done
• you can’t catch it from anyone
• you can’t pass it on to anybody else.

Lots of different factors are probably involved in the development of Hodgkin lymphoma.

About 4 in every 10 cases of Hodgkin lymphoma are related to a past infection with Epstein-Barr virus (EBV). EBV is a very common virus that can cause glandular fever. People who have been infected with EBV have a higher risk of developing Hodgkin lymphoma than people who haven’t. **However, most people who have had EBV do not get Hodgkin lymphoma.** Scientists don’t know why some people who have had EBV get lymphoma while most don’t.

Hodgkin lymphoma might also be related to problems with your immune system. For example, people who have HIV or people who are taking medicines that suppress their immune system after a transplant are more likely to develop Hodgkin lymphoma than other people.
Hodgkin lymphoma is not an inherited or contagious condition. You cannot pass it to family members. However, you have a very slightly higher risk of developing lymphoma if you have a close relative who has it.

**Symptoms of Hodgkin lymphoma**

Hodgkin lymphoma can cause a variety of symptoms depending on where in your body it develops.

**Swollen lymph nodes**

The most common symptom of Hodgkin lymphoma is a swollen lymph node or nodes that don’t go down after a couple of weeks. The swollen lymph nodes are not usually painful and have a ‘rubbery’ texture. They typically develop in the neck or just above the collar bones. They can also develop elsewhere in the body, such as the armpit or the groin. In people with NLPHL, this is often the only symptom.

> I noticed a swollen gland near my left collar bone. After a couple of weeks of it not going down, I made an appointment to see the doctor. Zoe, diagnosed with Hodgkin lymphoma in 2014
Many people with classical Hodgkin lymphoma develop swollen lymph nodes inside their chest. This might make you cough or feel breathless but it might not cause any symptoms at all. Occasionally, it can press on large veins in the chest, causing headaches, dizziness and swelling of the face, arms and hands. You might notice prominent veins on the skin of your chest.

I didn’t for a moment think it could be anything serious. I couldn’t understand how a lump in my neck could be connected to this mass in my chest.
Adam P, diagnosed with Hodgkin lymphoma in 2013

Rarely, people with Hodgkin lymphoma have swollen lymph nodes that become painful a few minutes after drinking alcohol. This symptom is unusual – fewer than 1 in 20 people with Hodgkin lymphoma experience it – but it is a strong sign of Hodgkin lymphoma.

It is important to remember that lymph nodes can swell from time-to-time for lots of reasons. Most people with swollen lymph nodes do not have lymphoma.
B symptoms
Around 1 in 4 people with classical Hodgkin lymphoma have symptoms known as **B symptoms**. These are:

**Fever**: a high temperature (above 38ºC) that might come and go

**Drenching sweats**: especially at night

**Unexplained weight loss**: losing weight quickly without trying to.
Other symptoms
Some people with Hodgkin lymphoma have other symptoms, such as:

- **Fatigue**: feeling exhausted or washed out after doing very little. Fatigue is caused by a combination of the lymphoma cells using up your body’s energy, the emotional impact of being unwell, and factors such as disturbed sleep.
- **Itching**: which might be worse in hot weather or at night. This affects around 1 in 3 people with Hodgkin lymphoma. Scientists think it is caused by chemicals released by your immune system as it tries to fight off the lymphoma.
- **Difficulty fighting off infections**: your body is making abnormal lymphocytes, so there are not enough normal lymphocytes left to fight infections. You might have repeated infections before being diagnosed with lymphoma.
Extranodal symptoms
Rarely, Hodgkin lymphoma starts in an organ in your body rather than a lymph node. This is called ‘extranodal’ lymphoma. The exact symptoms depend on where the lymphoma is. For example:

- Lymphoma in the liver might cause a bloated, swollen tummy or a yellow tinge in your skin or the whites of your eyes (jaundice).
- Lymphoma in your bone marrow might cause low blood counts, making you tired and more prone to infections than normal. You might bleed or bruise more easily than you usually do.

What is the outlook for people with Hodgkin lymphoma?
Hodgkin lymphoma usually responds very well to treatment. Most people are cured, even if the lymphoma is advanced when it is diagnosed.

In some people Hodgkin lymphoma comes back (relapses). If this happens, other treatments are available. See page 111 for more information on Hodgkin lymphoma that comes back or doesn’t respond to treatment.
Your lymphoma specialist is the best person to talk to about the likely outcome of your treatment. They consider a range of factors, such as:

- how old you are
- whether or not you have B symptoms
- how much lymphoma you have in your body and where it is (the stage of your lymphoma – see page 38)
- the results of your tests and scans
- your general health.

**Summary**

- There are two main types of Hodgkin lymphoma: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).
- Hodgkin lymphoma develops most often in people aged between 15 and 34 or over 60.
- Doctors don’t know exactly what causes Hodgkin lymphoma.
- The most common symptom of Hodgkin lymphoma is a swollen lymph node or nodes, often in the neck. In some people, Hodgkin lymphoma grows in lymph nodes in the chest.
When I was diagnosed I took things as they came and was actually glad that they’d found the root of my problems. At least it meant I could start getting better. Now in remission, having Hodgkin lymphoma has changed my perspective on life and I make the most of all opportunities that come my way.

Ellie, diagnosed with Hodgkin lymphoma in 2011
Tests, scans and staging

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How is Hodgkin lymphoma diagnosed?

Your GP is usually your first point of contact if you have symptoms of lymphoma. They ask you about your symptoms and examine you. They might take some blood tests. However, it is generally not possible for a GP to confirm whether or not you have lymphoma.

If your GP thinks you might have lymphoma, they will refer you for an urgent appointment with a hospital specialist.

Remember, the symptoms of lymphoma are more commonly seen in other, less serious illnesses, such as infections. Most people who are referred to a cancer service do not have cancer.

What tests might I need?

Your specialist is likely to send you for tests and scans to confirm whether or not you have lymphoma. If you do have lymphoma, you might need more tests to find out exactly what type of lymphoma you have and where it is in your body.

The next sections describe some common tests for lymphoma, but you might not need all of them.
You have most of these tests as an outpatient, so you don’t have to stay in hospital overnight. It might take a few weeks to get all the results.

I was totally shocked when I was told I had NLPHL. It took a while to sink in that I had cancer. But in a weird way, I also felt a bit of relief, because now I knew what the lump was.
Adam F, diagnosed with NLPHL in 2018

For more information about any of the tests and scans described below, visit lymphoma-action.org.uk/Tests

**Lymph node biopsy**

For most people, a lymph node biopsy is the only way to tell for certain whether or not a lump is lymphoma. This means taking a sample from a swollen lymph node to be examined in a lab. The exact procedure depends on where the swollen lymph node is.
There are different types of biopsy.

- An **excision biopsy** involves a minor operation to remove a swollen lymph node. If the lymph node is very large, only part of it might be removed. You usually have this under local **anaesthetic**.

- A **needle core biopsy** takes a small sample of the cells in a swollen lymph node using a special needle. It is often done at the same time as an ultrasound or CT scan (see page 32), under local anaesthetic.

After a biopsy, most people can go home the same day. You might need to go back to hospital about a week later to have stitches removed if you had an excision biopsy.

Arrange for somebody to drive you home after your biopsy.

Your biopsy is sent to a specialist called a ‘pathologist’. They examine your sample under a microscope and do specialised lab tests to find out what type of lymphoma you have.

Biopsy results usually take a week or more to come back.
Blood tests

Blood tests can give your medical team useful information about how lymphoma is affecting your body. They are also used to check how your treatment is affecting you.

You might have blood tests to:

- measure your levels of **red blood cells**, **white blood cells** and **platelets** (your ‘full blood count’)
- find out how well your kidneys, liver and sometimes your **thyroid gland** are working
- look for signs of inflammation in your blood
- measure your levels of vitamin D to see if you need supplements
- check if you have any infections that need treating or that might flare up when you have lymphoma treatment
- test for blood-borne infections, such as HIV and hepatitis.

X-rays and scans

X-rays and scans are used to assess what parts of your body are affected by lymphoma.

For more information about having scans, search for the name of the scan at nhs.uk
**CT scans**

*Computed tomography (CT) scans* use a series of X-rays to make detailed pictures of ‘slices’ through your body.

CT scans don’t hurt and only take a few minutes. You have to lie still during the scan.

- You might be asked not to eat or drink for a few hours before having a CT scan.
- You might be given a special dye (called a ‘contrast agent’) before your scan to help certain parts of your body show up better. This is usually a drink or an injection. Your medical team ask you questions first to make sure you’re not allergic to it.
- You might be asked to hold your breath at certain points during the scan.

Figure: Having a CT scan
• Speak to a member of staff if you are anxious about having a CT scan.
• Tell someone if you feel hot or dizzy during your scan.

PET scans

Positron-emission tomography (PET) scans use a harmless radioactive form of sugar to look at how active the cells in your body are. More active cells, such as lymphoma cells, take up more sugar than less active cells. The radioactivity in the cells is detected with a special camera.

Figure: A PET/CT scan showing Hodgkin lymphoma affecting lymph nodes in the lower neck and chest
Most people with Hodgkin lymphoma have a PET scan to find out which parts of their body are affected by lymphoma.

A PET scan is usually done at the same time as a CT scan – a PET/CT scan.

When you have a PET/CT scan:

• You should not eat for a few hours beforehand.
• When you arrive at your appointment, you have an injection of a harmless radioactive sugar into a vein.
• You then rest for an hour or more while the cells take up the sugar. You need to stay still during this time.
• The scan itself takes about 30 minutes.
• The whole appointment usually takes about 2 to 3 hours.

If you have diabetes, tell your doctor. They will tell you how to look after your diabetes on the day of your scan.
Tell your medical team if you are worried about having a PET scan.
Ultrasound scans

Ultrasound scans can be used to examine swollen lymph nodes that are near the surface of your skin. They can also help find the best place to take a biopsy.

Ultrasound scans use soundwaves to take pictures inside your body. A radiologist or ultrasound technician puts gel on your skin. It might feel a bit cold. They then move the ultrasound probe across your skin. The probe sends signals to a machine that displays a picture of the inside of your body.

Ultrasound scans do not hurt and only take around 15 minutes.

X-rays

X-rays use high energy radiation to take pictures of the inside of your body. You might have a chest X-ray to check for swollen lymph nodes inside your chest.

You have to sit, stand or lie still to have an X-ray. It does not hurt and only takes a few minutes.
**MRI scans**

*Magnetic resonance imaging (MRI) scans* use strong magnets to take pictures of the inside of your body. You might have an MRI scan if you are allergic to the dye used in PET/CT scans, or if you have lymphoma in your brain.

When you have an MRI scan:

- You have to take off metal jewellery. Don’t wear clothes that have any metal parts (such as clasps or buttons).
- You lie on a bed that moves into a tube. The tube measures magnetic waves as they pass through your body.
- You have to lie inside the tube for up to an hour.
- The MRI machine is very noisy, but it does not hurt you. However, some people feel hemmed in or claustrophobic. Ask your team if you can wear ear plugs.

- Tell your medical team if you have a pacemaker or any metal implants such as joint replacements.
- Tell your medical team if you feel anxious about your MRI scan.
Bone marrow biopsy

**Bone marrow** is the spongy tissue in the middle of your larger bones. It is where blood cells are made. Your bone marrow can be affected by lymphoma.

Your medical team looks at the results of your PET/CT scan and your blood tests to decide if you need a bone marrow biopsy.

This usually involves taking a sample of bone marrow from your hip bone.

- You have a local anaesthetic to numb the area where the biopsy is being taken.
- The doctor inserts a needle into the middle of the bone and sucks out a sample of liquid bone marrow. They then use another, hollow needle to remove a ‘core’ of bone marrow.
- The doctor removes the needle and puts a dressing over the area.
- The whole procedure usually takes 10 to 15 minutes.

Having a bone marrow biopsy can be uncomfortable but any pain or discomfort is usually brief. You might need painkillers before and after the procedure.

If you are very anxious, you might be able to have a sedative (a drug that relaxes you).
Waiting for your test results

It is natural to feel anxious when you are waiting for tests and their results. It’s very important for your doctors to have all the information they need about your lymphoma so they can plan the most suitable treatment for you.

If you are finding it hard to cope with waiting for your test results, contact our Helpline Services (see page 150 for details). You can also visit lymphoma-action.org.uk/Waiting for tips on how to cope.

Staging of Hodgkin lymphoma

‘Staging’ is the process of working out which parts of your body are affected by lymphoma (in other words, how ‘advanced’ your lymphoma is). The results of your tests and scans help doctors to work out the stage of your lymphoma. Staging lymphoma is important because it helps your medical team plan the most appropriate treatment for you.

There are four main stages of lymphoma. These are numbered 1 to 4; they are sometimes written in Roman numerals as I to IV.
<table>
<thead>
<tr>
<th>Stage 1 (I)</th>
<th>You have lymphoma in only one lymph node or group of lymph nodes. This could be anywhere in your body.</th>
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</thead>
<tbody>
<tr>
<td>Stage 2 (II)</td>
<td>You have lymphoma in two or more groups of lymph nodes but they are all on the same side of your diaphragm.*</td>
</tr>
<tr>
<td>Stage 3 (III)</td>
<td>You have lymphoma in lymph nodes on both sides of your diaphragm.*</td>
</tr>
<tr>
<td>Stage 4 (IV)</td>
<td>You have lymphoma in your bone marrow or in organs outside your lymphatic system.</td>
</tr>
</tbody>
</table>

Sometimes letters are added to the stage.

| A | You don’t have any B symptoms. |
| B | You have one or more B symptoms (weight loss, night sweats or fevers). |
| E | You have lymphoma that started outside the lymphatic system (‘extranodal’ lymphoma). Extranodal lymphoma doesn’t include lymphoma that started in a lymph node and spread to a body organ. |
| X | At least one of your affected lymph nodes is large (more than 10cm across). |

* The muscle separating your chest from your tummy.
Early stage and advanced stage lymphoma

Stage 1 or stage 2 lymphoma is known as ‘early stage’ disease. Stage 3 or stage 4 lymphoma is known as ‘advanced stage’ disease.

The lymphatic system is all over the body, so it is common for lymphoma to be advanced when it is diagnosed. **Unlike many other cancers, advanced stage lymphoma can be successfully treated.**

Ask your specialist if you’re not sure what stage your lymphoma is.

**Summary**

- Hodgkin lymphoma is usually diagnosed using a lymph node biopsy.
- You have other tests such as blood tests and a PET/CT scan to find out which parts of your body are affected by lymphoma (staging).
- The results of your tests and scans help your doctor plan the most suitable treatment for you.
My whole body had flu-like symptoms and I was having night sweats, so my GP referred me to hospital for tests. Two weeks later I was diagnosed with Hodgkin lymphoma with 12 cycles of ABVD chemotherapy planned. I felt so ill, I was relieved to know that something would be done (but I was still surprised by the amount of drugs I was to have).

Pete, diagnosed with Hodgkin lymphoma in 2009
Planning Hodgkin lymphoma treatment

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Where will I be treated? 45
How does my medical team decide what treatment I need? 48
Treatment options for Hodgkin lymphoma 51
How is treatment organised?

Most people have one main consultant who is responsible for their care, usually either an oncologist (a doctor who specialises in treating people who have cancer) or a haematologist (a doctor who specialises in conditions of the blood). The consultant works with a team of other health professionals, sometimes from more than one hospital. This is your multidisciplinary team or medical team. They make sure you get the care and support that is right for you.

Your medical team meets regularly to discuss and plan your treatment, taking your individual needs into account.

You usually have a named ‘key worker’ – a person you can call for advice or if you have any questions or worries about your lymphoma or your treatment. This is usually a clinical nurse specialist (CNS) – a nurse who specialises in looking after people with lymphoma.

Make sure you have a name and contact details for your key worker. You can note this down in the front of this book.
You might find it helpful to take a family member or a friend along with you to your hospital appointments. They might remember parts of the discussion that you don’t, or might think of other questions or concerns. Most doctors encourage people to bring someone along.

Where will I be treated?

You might have your treatment at a local hospital or at a larger hospital with a cancer centre that may be further away. Sometimes people have their treatment shared between the two places.

Children and young people

Children with Hodgkin lymphoma are treated at specialist children’s cancer centres known as ‘principal treatment centres’ (PTCs). These may be some distance away. PTCs work closely with paediatric oncology shared care units (POSCUs), which provide care closer to your home.

Teenagers and young adults with Hodgkin lymphoma are treated at teenage and young adult (TYA) PTCs or at hospitals closer to home that have been approved to treat young people as part of their adult cancer services. Some young people have their treatment shared between a TYA PTC and a more local hospital.
I had the choice of a teenage unit at another hospital, but it was much easier to stay at the hospital where I was diagnosed. I was the youngest by far, but found so much fun and camaraderie on the ward – we actually had a great laugh!
Natalia, treated for Hodgkin lymphoma at the age of 20

- Call 0808 808 5555 or visit lymphoma-action.org.uk/CYP for more information about lymphoma in children and young people, including our Young person’s guide to lymphoma.
- CLIC Sargent: Young Lives vs Cancer (clicsargent.org.uk) and the Teenage Cancer Trust (teenagecancertrust.org) have more information about treatment centres for children, teenagers and young adults.
Questions to ask your medical team

- Where will I be treated?
- Who will be involved in my care?
- How often will I have appointments?
- Does my hospital take part in clinical trials?
- What other experts are there to help if I need them? For example, can I meet with a dietitian or a physiotherapist?
- Does my hospital provide any extra support, such as counselling or complementary therapies?
- Can I get financial support towards my travel costs or hospital parking fees?
- How do I get a medical exemption certificate to claim free prescriptions?
How does my medical team decide what treatment I need?

Hodgkin lymphoma is treated with the aim of sending it into complete remission. This means there is no sign of any lymphoma on tests or scans at the end of treatment.

Your medical team has a meeting where they discuss your case and choose the treatment they think is most likely to achieve complete remission with the minimum possible side effects. They suggest the most appropriate treatment for you based on your test results and circumstances. They consider:

- whether you have classical or nodular lymphocyte-predominant Hodgkin lymphoma
- the stage of your lymphoma
- the symptoms you have
- how old you are
- any other health conditions you have
- your general fitness
- your feelings about your treatment options
- other factors that may be important to you in the future, such as having a family.

Let your medical team know if you have any strong views about your treatment.
Sometimes people with the same type of Hodgkin lymphoma have different treatments.

To help your medical team work out the best treatment for you, you might need more tests to check how well your heart, lungs, liver and kidneys are working.

Your medical team consider any potential side effects of the treatment, including long-term or late effects (health problems that develop months or years after treatment – see page 126). This is important because most people live for many years after their lymphoma has gone into remission. If you might want to have children in the future, your medical team will also consider the possible effects of treatment on your fertility (page 131).

When planning your treatment, your doctors try to balance the chances of your lymphoma coming back against your risk of experiencing side effects during treatment and in the years afterwards.

“I don’t know whether I was in denial, but I left all the worrying to the specialist. I know I am no health expert, so I tried to focus on what I knew about, whenever I could.”
Carol, diagnosed with Hodgkin lymphoma in 2004
Don’t be worried if the people you talk to at the hospital are having treatments different from yours. Your treatment is tailored to you.

**Research and clinical trials**
Clinical trials are medical research studies involving people. They are used to test new treatments or new ways of using existing treatments (for example, different combinations of chemotherapy drugs or lower doses of radiotherapy).

Your doctor might ask you if you would like to take part in a clinical trial.

**Clinical trials are voluntary.** You don’t have to take part in a trial even if you are offered one. You can choose to have standard treatment if you prefer.

If your doctor doesn’t suggest a clinical trial and you are interested in taking part, ask if there is a clinical trial suitable for you. You might be able to be referred to another hospital if there is not a trial running at your hospital.

For more information about clinical trials, or to search our lymphoma clinical trial database, visit lymphoma-action.org.uk/TrialsLink. We also produce a book about clinical trials. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
Treatment options for Hodgkin lymphoma

The exact treatment you need depends mainly on the type and stage of your lymphoma and on the signs and symptoms you have.

There is detailed information about the different treatment options on pages 64 to 82.

Classical Hodgkin lymphoma

Treatment for classical Hodgkin lymphoma usually involves chemotherapy, sometimes followed by radiotherapy. The combination of chemotherapy drugs you have (called a chemotherapy regimen), and whether or not you need radiotherapy, depends on the stage of your lymphoma.

You might have a PET/CT scan after your first few cycles of treatment to check how well you are responding. Your consultant uses the results of the scan to decide how many more cycles of treatment you need, whether you should change to a different chemotherapy regimen and whether radiotherapy might be appropriate for you.
Early stage classical Hodgkin lymphoma
For early stage (stage 1 or 2) classical Hodgkin lymphoma, your doctor considers the signs and symptoms you have before deciding what chemotherapy is most likely to be effective for you and how long you should be treated for. These are sometimes called ‘prognostic indicators’. They include:

• whether you have very enlarged lymph nodes in your chest, or enlarged lymph nodes in several areas of your body
• whether you have B symptoms (fevers, drenching sweats or unexplained weight loss)
• whether your blood tests show you have a high level of inflammation
• how old you are
• whether you have any lymphoma outside your lymphatic system (extranodal disease).

If you don’t have any of these signs, you are most likely to be treated with two to three cycles of a chemotherapy regimen called ABVD (page 69), followed by radiotherapy (page 74).
If you **do** have any of these signs, you are most likely to be treated with:

- four cycles of ABVD followed by radiotherapy **or**
- six cycles of ABVD **or**
- two cycles of a stronger chemotherapy regimen such as BEACOPPesc or BEACOPPDac (page 70) and two cycles of ABVD followed by radiotherapy.

You might have a PET/CT scan after two treatment cycles. If there is no evidence of lymphoma on this scan, a drug called bleomycin might be left out of the rest of your chemotherapy.

You usually have radiotherapy to the areas affected by your lymphoma a few weeks after your chemotherapy finishes.

You might not need radiotherapy if:

- you do not have any B symptoms
- you do not have any large lumps of lymphoma
- a PET/CT scan shows all your lymphoma has gone after chemotherapy
- you are a young female and radiotherapy might affect your breast tissue
- the radiotherapy might affect part of your heart.
Chemotherapy without radiotherapy is less likely to cause long-term side effects, but you have a slightly higher risk of your lymphoma coming back (relapsing). If you don’t have radiotherapy, you usually have a total of at least three cycles of chemotherapy. Your doctor should discuss the treatment choices with you and take your views and wishes into account.

**Advanced stage classical Hodgkin lymphoma**

Advanced stage (stage 3 or 4) classical Hodgkin lymphoma is also usually treated with chemotherapy, but you are likely to have more cycles of treatment than people who are diagnosed at an early stage.

The most common treatments for advanced stage classical Hodgkin lymphoma are six cycles of ABVD (page 69) or four to six cycles of BEACOPPesc or BEACOPDac (page 70). Your consultant will discuss the treatment choices with you.
You might have a PET/CT scan after your first few treatment cycles. Depending on the results of your scan, your doctor might recommend changing to a different chemotherapy regimen or adjusting the number of cycles or chemotherapy drugs you need. For example, if there is no evidence of lymphoma on a PET/CT scan after two cycles of treatment, a drug called bleomycin might be left out of the rest of your chemotherapy. Alternatively, if you are on BEACOPPesc, you might only need another two cycles of treatment rather than four.

You might also have radiotherapy if there are any lumps of lymphoma left after your chemotherapy. Most people with advanced stage classical Hodgkin lymphoma do not have radiotherapy.
**Nodular lymphocyte-predominant Hodgkin lymphoma**

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is more often diagnosed at an early stage than classical Hodgkin lymphoma and tends to grow more slowly. It can respond well to gentler treatments.

For more information about NLPHL, visit lymphoma-action.org.uk/NLPHL or contact our Helpline Services (see page 150 for details).

**Early stage NLPHL**

If you have early stage (stage 1 or 2) NLPHL and **no** B symptoms (fever, drenching night sweats or unexplained weight loss), your treatment depends on exactly how much lymphoma you have in your body and where it is.

- **If you only have lymphoma in one group of lymph nodes,** you might have surgery to remove the affected nodes, or you might have radiotherapy or low-dose chemotherapy. If you have surgery, you might not need any further treatment. Instead, you have regular check-ups to make sure your lymphoma is still under control. This is called ‘active monitoring’ or ‘watch and wait’ (page 79). If you have any further signs of lymphoma, you have more treatment.
• If you have lymphoma in two groups of lymph nodes, or if you have any lymphoma left after surgery, you have radiotherapy to the areas of your body affected by lymphoma. If you’re under 19, you might have low-dose chemotherapy instead of radiotherapy.

• If you have lymphoma in more than two groups of lymph nodes, or if the lymphoma is in a place that is not suitable for radiotherapy, you are treated in the same way as more advanced NLPHL.

B symptoms are rare in NLPHL and might suggest that your lymphoma has changed to a faster-growing type. If you have early stage NLPHL and you have B symptoms, you might need stronger treatment. You are most likely to be treated with an antibody therapy called rituximab (page 77) combined with a chemotherapy regimen called CHOP (page 72). This is known as R-CHOP. However, you might be treated with a different regimen, often the same as those used to treat advanced stage NLPHL.
Advanced stage NLPHL

If you have advanced stage (stage 3 or 4) NLPHL but you don’t have any troublesome symptoms, you might not need treatment at first. Instead, you might have active monitoring (page 79) – regular check-ups to make sure your lymphoma is not getting worse. If your lymphoma gets worse or starts to cause problems, you have treatment then.

If your lymphoma is causing symptoms, you are most likely to have chemotherapy (page 64) combined with an antibody therapy called rituximab (page 77). This combination is sometimes called ‘chemo-immunotherapy’.

Chemo-immunotherapy regimens (combinations of drugs) you might have include:

- R-ABVD
- R-CVP
- R-CHOP
- R-CVInbP
- R-OEPA.

See page 67 for more information about chemotherapy regimens.

People who are not well enough to have chemotherapy might have rituximab on its own.
**Treatment for people over 60**

About 1 in 5 people diagnosed with Hodgkin lymphoma are over 60. Age alone may not affect treatment, but people over 60 might be more likely to experience serious side effects than younger people.

Your medical team always aim to give you a treatment that is as safe and effective as possible with the lowest possible risk of causing side effects. They will consider your fitness and any other health conditions you have and might recommend a less intensive treatment if they think you have a higher risk of side effects.

For example, if you have heart or lung problems, there might be some chemotherapy drugs that are not suitable for you. It could take your bone marrow longer to recover from chemotherapy than younger people. This could lead to low blood counts (page 87). You might also be more sensitive to the side effects of radiotherapy.

Some people over 60 who have classical Hodgkin lymphoma are fit enough to have standard treatment with ABVD (page 69). However, if your medical team thinks you have a higher risk of side effects, they will adapt your treatment to suit your individual circumstances.
Your medical team might:

• avoid using particular chemotherapy drugs that are more likely to cause serious side effects
• give you a lower dose of some drugs
• reduce how often you have your chemotherapy, giving your body longer to recover between each cycle
• use a less intensive chemotherapy regimen, such as ChlVPP or VEPEMB (page 71).

People with NLPHL who are not well enough to have chemotherapy might have the antibody treatment rituximab on its own (page 77).

Ask your medical team what treatment they recommend and why they think it is the best option for you.
Summary

- You might be treated at a local hospital or at a cancer centre that may be further away.
- You usually have a named key worker who you can call for advice.
- The exact treatment you need depends on the type and stage of your lymphoma, the signs and symptoms you have, your test results and your individual circumstances.
- Your doctor might ask you if you would like to take part in a clinical trial.
- Treatment for classical Hodgkin lymphoma usually involves chemotherapy, sometimes followed by radiotherapy.
- Treatment for NLPHL usually involves surgery, radiotherapy, or chemotherapy combined with antibody therapy. Some people don’t need treatment straight away.
Treatment wasn’t as bad as I thought it would be. I got away with relatively few side effects, and only remember feeling sick once.

Adam F, diagnosed with NLPHL in 2018
Having treatment for Hodgkin lymphoma

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Chemotherapy

Chemotherapy is treatment that uses drugs to kill cancer cells.

Chemotherapy drugs work by killing cells that are dividing to make new cells. They have little effect on cells that are not dividing.

Cancer cells, including lymphoma cells, are very sensitive to the effects of chemotherapy. Some healthy cells, such as blood cells, hair follicles or skin cells, also divide rapidly and can be affected by chemotherapy. This is responsible for some of the side effects of chemotherapy (page 86).

Visit lymphoma-action.org.uk/Chemotherapy to watch an animation explaining how chemotherapy works.

Chemotherapy usually involves treatment with a number of different drugs (known as a chemotherapy regimen) that work in different ways to kill as many cancer cells as possible.

Having chemotherapy
You usually have chemotherapy for Hodgkin lymphoma as an outpatient in a day case unit or chemotherapy unit. You go to the hospital on treatment days and go home afterwards.
You usually have blood tests beforehand or as soon as you arrive to make sure you are well enough to have your treatment. You might need to stay in hospital if you have side effects such as an infection or very low blood counts (page 87).

In between your treatment days, you usually have lots of medicines to take at home. Some of these might be part of your chemotherapy regimen and some of them might be to help control any side effects you have.

You have chemotherapy in cycles – a round of treatment followed by a rest period before another round of treatment. During each cycle, you might have to go to hospital for treatment on several days or you might only have to go once – it varies depending on the exact chemotherapy you need.

**Why is chemotherapy given in cycles?**
Even when several chemotherapy drugs are used together, they can’t kill all the lymphoma cells in your body in one go. To kill the remaining lymphoma cells, you have several cycles of chemotherapy. You have a rest period between each cycle to give your body time to recover.

A cycle usually takes 3 or 4 weeks. The number of cycles you need and exactly how often you have it depends on the chemotherapy regimen you have.
A whole course of chemotherapy can vary from several weeks to a number of months.

**Having intravenous chemotherapy**

Most chemotherapy is given *intravenously* (as a drip or injection into a vein). You might have it through:

- A ‘cannula’ – a small, soft plastic tube that usually goes into a vein in the back of your hand. You have a new one put in each time you go for treatment.
- A ‘central venous catheter’, ‘central line’ or ‘PICC line’ – a longer plastic tube that goes into a larger vein in the middle of your chest. A central line usually stays in for all of your treatment. You go to a day ward to have your line flushed regularly, or a nurse might show you how to look after it at home.

Your nurse can inject some chemotherapy drugs straight into your cannula or central line over a minute or two. Other chemotherapy drugs have to be given more slowly through a drip (infusion). This could take anywhere from 30 minutes to a number of hours, depending on the drugs you are having.

Tell your nurse if you have any discomfort during your intravenous chemotherapy. They can check the drugs are going in properly.
**Having oral chemotherapy**
You might have some chemotherapy drugs as tablets or capsules that you take orally (by mouth). Your medical team should give you instructions on what to take and when, and how to store the drugs.

**It is important that chemotherapy tablets are not handled by anyone other the person who is taking them to avoid damaging healthy cells.** If you are helping someone take chemotherapy, wear gloves when handling any tablets or capsules.

Use a tablet organiser to make sure you take all your medicines at the right time on the right days of each treatment cycle.

**Chemotherapy regimens for Hodgkin lymphoma**
Most chemotherapy regimens are known by a series of letters, usually the initials of the drugs included.

We include information on the most common chemotherapy regimens for Hodgkin lymphoma but your medical team might recommend a different treatment option for you. Your medical team should tell you about your treatment, including what you have and when.
They should also be able to tell you what side effects to expect from the drugs you are having.

Ask your team questions if there is anything about your treatment that you don’t understand.

Tell your medical team if you feel unwell or have any side effects during your treatment. There are things they can do to help.

Questions to ask your medical team

- What treatment will I have? Why?
- How is the treatment given?
- Where will I have treatment?
- Will I need to stay in hospital overnight?
- Can I drive myself home after my treatment?
- How long does each treatment session last?
- How long does the whole course take?

For information about the common side effects of lymphoma treatment and tips on how to cope with them, see pages 86 to 103.
Common regimens for classical Hodgkin lymphoma

**ABVD** is doxorubicin (also known as Adriamycin®), bleomycin, vinblastine and dacarbazine.

A single cycle of ABVD is 28 days. You have the chemotherapy intravenously on day 1 and day 15 of each cycle followed by 2 weeks without treatment. Depending on how much lymphoma you have in your body and how you respond to treatment, you usually have between two and six cycles of ABVD.

You have ABVD as an outpatient. You have anti-sickness medication first, and then you have the chemotherapy drugs as four separate injections or drips (infusions) into your cannula or central line. It takes around 90 minutes.

“I experienced shakes after my first ABVD treatment, so my infusion was slowed down for future treatments.”

Pete, diagnosed with Hodgkin lymphoma in 2009

“While everyone around me seemed to be struggling with ABVD, I had virtually no side effects. I actually wanted to feel ill to reassure myself that the drugs were working.”

Natalia, treated for Hodgkin lymphoma in 2015
**BEACOPPesc** is bleomycin, etoposide, doxorubicin (also known as Adriamycin®), cyclophosphamide, vincristine (also known as Oncovin®), prednisolone and procarbazine in an escalated dose.

A single cycle of BEACOPPesc is usually 3 weeks. You have all the drugs intravenously except procarbazine and prednisolone, which you have as capsules or tablets. Depending on how much lymphoma you have in your body and how you respond to treatment, you usually have between two and six cycles of BEACOPPesc. It is a stronger treatment than ABVD and is more likely to have both short-term and long-term side effects.

**BEACOPDac** is bleomycin, etoposide, doxorubicin (also known as Adriamycin®), cyclophosphamide, vincristine (also known as Oncovin®), prednisolone and dacarbazine.

A single cycle of BEACOPDac is 21 days. You have all the drugs intravenously except prednisolone, which you take by mouth. Depending on how much lymphoma you have in your body and how you respond to treatment, you usually have two to six cycles of BEACOPDac. It might have fewer side effects than BEACOPPesc.
**ChlVPP** is *chlorambucil*, *vinblastine*, *procarbazine* and *prednisolone*.

A single cycle of ChlVPP is 28 days. You have vinblastine intravenously and the other drugs as tablets or capsules. ChlVPP is a less intensive chemotherapy regimen that is sometimes used to treat older people or people who aren’t well enough to have ABVD, BEACOPPesc or BEACOPDac.

**VEPEMB** is *vinblastine*, *cyclophosphamide*, *procarbazine*, *etoposide*, *mitoxantrone*, *bleomycin* and *prednisolone*.

A single cycle of VEPEMB is 28 days. You have vinblastine, cyclophosphamide, mitoxantrone and bleomycin intravenously. You have procarbazine, etoposide and prednisolone as tablets. VEPEMB is a less intensive chemotherapy regimen that is sometimes used to treat older people or people who aren’t well enough to have ABVD, BEACOPPesc or BEACOPDac.
Common regimens for NLPHL
The most common regimens used to treat NLPHL are listed here. They are usually given with rituximab (page 77), in which case the letter ‘R’ is added to the name (for example, R-CHOP).

I had six cycles of chemotherapy over a 6 month period and had another scan at the end. The scan came back clear. I remember crying when I heard the news. It was such a relief.
Adam F, diagnosed with NLPHL in 2018

**CHOP** is cyclophosphamide, doxorubicin (also known as hydroxydaunorubicin), vincristine (also known as Oncovin®) and prednisolone.

A single cycle of CHOP is 21 days. You have cyclophosphamide, doxorubicin and vincristine intravenously on day 1 of each cycle. You take prednisolone tablets or capsules for the first 5 days of each cycle.

**CVP** is cyclophosphamide, vincristine and prednisolone.

A single cycle of CVP is 21 days. You have cyclophosphamide and vincristine intravenously on day 1 of each cycle. You take prednisolone tablets or capsules for the first 5 days of each cycle.
CVinP is cyclophosphamide, vinblastine and prednisolone.

A single cycle of CVinP is 2 weeks. You have cyclophosphamide intravenously on day 1 of each cycle and vinblastine intravenously on day 1 and day 8 of each cycle. You take prednisolone tablets or capsules for the first 8 days of each cycle. CVinP is sometimes used to treat children or young adults with NLPHL.

OEPA is vincristine (also known as Oncovin®), etoposide, prednisolone, and doxorubicin (also known as Adriamycin®).

A single cycle of OEPA is 21 days. You have vincristine, etoposide and doxorubicin intravenously on various days of the cycle. You take prednisolone tablets or capsules every day. OEPA is sometimes used to treat children or young adults with NLPHL.

ABVD (page 69) is also sometimes used to treat people with NLPHL.

Search ‘chemotherapy drugs’ at macmillan.org.uk to find out more about particular chemotherapy drugs or regimens.
Radiotherapy uses high-energy X-rays and other types of radiation to kill cancer cells. The high-energy radiation is directed to precise areas of your body so it is usually used to treat lymphoma that is only in one or two places rather than spread throughout your body.

Radiotherapy kills cells by stopping them from dividing. Lymphoma cells are very sensitive to radiotherapy, but it can affect healthy cells as well as cancer cells.
Having radiotherapy

If you need radiotherapy, you are usually treated by a clinical oncologist (a doctor who specialises in treating cancer with radiotherapy). Radiotherapy is only available at specialist centres, so you might need to travel for your treatment.

"After the chemotherapy had finished, I had radiotherapy every weekday for 3 weeks. For me, this was the easiest part of treatment, although I felt more and more tired as the time went on and I had some soreness and redness where the radiotherapy was targeted."
Adam P, diagnosed with Hodgkin lymphoma in 2013

You go to the radiotherapy department to plan your treatment. You might need several visits, including some tests and scans.

Your specialist plans the total dose of radiotherapy you need and how many treatment sessions it should be spread over.

When you have radiotherapy, it is very important that precisely the same area is treated each time. You might have a tiny dot tattooed onto your skin to make sure the X-ray beams target exactly the right place. If you are having radiotherapy to your head or neck, you might need to wear a special mask to make sure you’re in the right position.
You have radiotherapy every day during the week with a rest at weekends. You can usually go home after each treatment. Most people have treatment for 2 to 4 weeks.

Each radiotherapy session takes around 20 minutes. Most of this time is to make sure you are in the correct position. The treatment itself only takes a few minutes. It doesn’t hurt. During the treatment, the radiotherapy staff have to leave the room but they can see you and hear you all the time.

Tell a member of staff if you are worried about anything.

Radiotherapy for lymphoma does not make you radioactive. There is no risk to people close to you after treatment.

For information about the side effects of lymphoma treatment, see pages 86 to 103, which include tips on how to cope with the side effects.

Targeted therapies

Targeted therapies are drugs that interfere with particular proteins or biological processes in cancer cells. They are sometimes called ‘biologic’ therapies.

The main type of targeted therapy used to treat lymphoma is antibody therapy, also called immunotherapy.
Antibodies are naturally made by white blood cells called lymphocytes. They recognise and stick to particular proteins on the surface of cells that don’t belong in your body, such as viruses or bacteria. Once they have stuck to these proteins, they either kill the foreign cell directly or help your immune system to find and destroy it.

Antibodies that stick to proteins on lymphoma cells can be made in a laboratory. These help chemotherapy to work better. Sometimes giving the antibody on its own may be enough to help your body get rid of the lymphoma cells.

Rituximab
Rituximab is an antibody therapy that targets a protein called CD20. NLPHL cells make CD20. Classical Hodgkin lymphoma cells do not.

Rituximab is used to treat NLPHL and many types of non-Hodgkin lymphoma. You usually have it with chemotherapy but some people have it on its own.

Having rituximab
Most people have rituximab as an outpatient and go home afterwards. If you are having it in combination with chemotherapy, you have it on the first day of each treatment cycle. If you are having it on its own, you have it every week for 3 to 4 weeks.
Before you have rituximab, you have medicines to help prevent any reactions to it. You then have rituximab through a drip into a vein. You have your first dose slowly. It might take a few hours. You have the rest of your doses more quickly unless you have serious side effects the first time.

The most common reactions to rituximab treatment are shivers, fevers and flu-like symptoms. You are more likely to get them with your first dose, which is why you have it more slowly.

Occasionally, people have an allergic reaction to rituximab. If this happens, you are monitored in hospital for a while. You might need to have rituximab more slowly in the future, or stop the treatment altogether. Your doctor will talk to you about other options if this is the case.

**Surgery**

If you are having surgery to remove lymph nodes that are affected by lymphoma, your medical team should give you more information about what’s involved. This varies depending on where the lymph nodes are. Ask how long you are likely to be in hospital and what to expect during your recovery.
Active monitoring

Active monitoring (sometimes called ‘watch and wait’ or ‘active surveillance’) is where you have regular check-ups with your medical team to monitor your health and see how your lymphoma is affecting you. You do not have any treatment for your lymphoma unless it is causing significant health problems.

Some people find it difficult to understand why their doctor is suggesting they do not have any treatment. Active monitoring allows you to avoid the side effects of treatment for as long as possible. If your lymphoma gets worse or starts to cause problems, you have treatment then. People with slow-growing lymphoma without troublesome symptoms and who don’t have treatment until they need it, typically do just as well as those who have treatment straightaway.

If are on active monitoring and you notice any change in your symptoms or any new symptoms, contact your medical team straightaway.

We produce a separate book on active monitoring. Visit lymphoma-action.org.uk/Books or phone 0808 808 5555 to order a free copy.
Treatments for symptoms and side effects

You have some medicines that don’t directly treat your lymphoma but are still an important part of your care. They are used to prevent or treat symptoms or side effects and help you feel better in yourself.

Steroids
Steroids are drugs that mimic hormones produced naturally by your body. They are used to treat some types of lymphoma and to help control nausea (feeling sick).

You usually have steroids, such as prednisolone, as tablets. Steroids can have side effects including difficulty sleeping, mood changes, raised blood sugar, and increased appetite. However, these side effects are more likely if you take high doses of steroids or take them for a long time. Side effects should go away after treatment.

Growth factors
Growth factors are hormones that occur naturally in your body. They encourage your bone marrow to make blood cells. Man-made growth factors are sometimes used to boost your blood cell counts (page 87) if they drop too much during chemotherapy.
The growth factor most commonly used is called ‘granulocyte-colony stimulating factor’ (G-CSF). You have G-CSF as an injection into the fatty tissue under your skin (a subcutaneous injection), usually into your tummy, the top of your leg or the top of your arm. You (or a friend or family member) might be taught how to give yourself the injections at home. Alternatively, a community nurse might visit you to give you your injections.

The injections can sting and you might have side effects such as flu-like symptoms, bone pain or headaches. Mild painkillers such as paracetamol can help, but ask your medical team before you take anything. If you feel unwell during your treatment, contact your hospital straightaway.

**Other medicines to help with side effects**
You also have medicines to help prevent side effects developing, and to treat them if they do develop. This might include anti-sickness drugs (sometimes called ‘antiemetics’), pain relieving medicines or antibiotics.
Summary

• Chemotherapy is treatment that uses drugs to kill cancer cells. You usually have chemotherapy as an outpatient and go home afterwards. Most chemotherapy is given intravenously every few weeks.

• Radiotherapy uses high-energy X-rays to kill cancer cells. You usually have radiotherapy as an outpatient and go home afterwards. You have radiotherapy every day during the week with a rest at weekends.

• Rituximab is an antibody therapy that is used to treat NLPHL. You usually have it in combination with chemotherapy.

• Active monitoring involves regular check-ups with your medical team to monitor your health and to see how your lymphoma is affecting you. It allows you to avoid the side effects of treatment for as long as possible.

• You also have medicines to treat or prevent side effects or symptoms. This might include steroids, growth factors and anti-sickness drugs.
The 6 months of chemotherapy were tough. I had treatment every 2 weeks, and had a good day or two, before I was back for the next treatment. A lot of the time I just wanted to sleep, my appetite changed and everything tasted unpleasant. After my third treatment, I began to lose my hair, something that had always been important to me. I still wanted to look myself and found that a good wig and makeup made a big difference to how I felt.

Zoe, diagnosed with Hodgkin lymphoma in 2014
Coping with treatment

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Coping with common side effects of treatment

It is hard to predict exactly how you will feel during your treatment. Some people have few side effects and are able to carry on almost as usual. Others need to make changes, at least for a while.

The side effects you might have depend on what treatment you are having. Your medical team should give you information about your treatment and what to expect, but it is impossible to say what side effects you will get. Each person gets slightly different side effects, even if two people are having the same treatment.

Most side effects are short-term. Some develop soon after starting treatment but some might not develop until later. Sometimes lymphoma treatment can have longer-term effects (page 125). Your medical team should discuss this with you before your treatment starts.

Your doctors and nurses aren’t always going to ask how you are feeling – they might assume you are all right if you don’t say anything.
Tell your medical team about any side effects you have or if you feel unwell during your treatment. There are often things they can do to help.

You can find out more about the potential side effects of lymphoma treatments and how to cope with them at lymphoma-action.org.uk/SideEffects

Questions to ask your medical team

- What side effects might I get? How long might these last?
- Are there any potential late effects (side effects that happen months or years after treatment finishes – see page 126)?
- Will I be able to carry on my normal day-to-day routine during treatment?

Low blood counts and risk of infection
Chemotherapy, radiotherapy and targeted treatments can cause temporary damage to your bone marrow. Your bone marrow makes your body’s blood cells.
These include:

- **White blood cells**, which help to fight infection. **Neutrophils** are the most important type of white blood cell.
- **Red blood cells**, which carry oxygen around your body.
- **Platelets**, which help your blood clot to stop bleeding and bruising.

You have regular blood tests to check your blood counts. It is common to have low blood counts during your treatment.

**Low neutrophil count**
A low neutrophil count (neutropenia) is common after many types of chemotherapy and some targeted therapies. It can also develop after radiotherapy to large areas. Depending on the exact treatment you’re having, your neutrophil count is usually lowest about 7 to 12 days after chemotherapy, although it could stay low for longer.

Having a low neutrophil count doesn’t usually cause any symptoms but it means you have a higher risk of infection than normal. If you do get an infection, it can be serious, sometimes even life-threatening. **An infection in someone with neutropenia needs urgent treatment.** You usually have to stay in hospital for intravenous antibiotics and careful monitoring.
Your medical team checks your neutrophil count before each cycle of treatment. If your neutrophil count is too low, your next cycle of treatment might be delayed until you have enough neutrophils. This could just be a day or two later than planned but it could be longer. You might have drugs such as growth factors (page 80) to help boost your neutrophil count.

**Contact your medical team if you have any of the following, no matter how minor they might seem:**

- fever (temperature above 38°C)
- hypothermia (temperature below 35°C)
- shivering
- chills and sweating
- feeling generally unwell, confused or disorientated
- earache, cough, sore throat or sore mouth
- blocked nose
- shortness of breath
- redness and swelling around skin sores, or injuries to intravenous lines
- diarrhoea or vomiting
- a burning or stinging sensation when weeing, or weeing more often than usual
- unusual genital discharge or itching
- unusual stiffness of the neck and discomfort around bright lights
- any new pain.
I developed a high temperature. My mum noticed I was looking red and I had no energy. Just having a shower was taking all my strength. We realised that this was a red flag moment and that I needed to get straight to hospital.

Adam F, diagnosed with NLPHL in 2018

Tips to help lower your risk of infection

- Have a bath or shower regularly.
- Wash your hands before meals, after using the toilet, and after using public facilities.
- Avoid places where you have a higher risk of catching an infection, such as swimming pools, crowded shops and public transport.
- Avoid contact with people who are unwell, for example with a cold, tummy bug or chickenpox.
- Don’t eat anything that is past its sell-by-date.
- Use refrigerated food within 24 hours of opening.
- Take care when handling pets – avoid bites or scratches and wash your hands after any contact with an animal. If possible, get someone else to deal with litter trays and animal poo.
- Wear gloves for gardening.
- Visit your dentist before you start treatment for lymphoma – you may not be able to have any dental work done during or soon after treatment because of increased risk of infection.
Your nurse might advise you to cut out certain foods that might cause infections.

In general, avoid foods that contain lots of live bacteria, such as:

- unpasteurised cheeses and ‘bio’ yoghurt
- takeaways
- raw or undercooked eggs
- undercooked meats and fish
- pâté.

For more information about risk of infection and food safety, visit lymphoma-action.org.uk/Infection

Low red blood cell count
If you have a low red blood cell count, you don’t have enough haemoglobin (the protein that carries oxygen around your body). This is called anaemia. It might make you feel tired or short of breath. If your red blood cell count is very low, you might need a blood transfusion (donated blood or blood products given into one of your veins through a drip).

Tell your doctor if you feel short of breath, unusually tired, dizzy or have new aches and pains.
Low platelet count
A low platelet count is called \textit{thrombocytopenia}. If you have thrombocytopenia, you might bruise easily or bleed more or for longer than usual after minor injuries. You might develop a rash of tiny red spots in your skin or mouth, or notice blood in your wee or poo.

Tell your medical team if you notice any signs of bleeding or bruising or if you feel faint or clammy.

If your platelet count is very low, your medical team might adjust your treatment. You might need a platelet transfusion.

Feeling sick or being sick
Some people who have chemotherapy or radiotherapy might experience nausea (feeling sick) or vomiting (being sick). Sickness can usually be controlled by anti-sickness drugs (antiemetics). There are lots of different anti-sickness drugs available and you might have to try a few to find what works best for you.
Tell your medical team if you feel sick, even if you have already had treatment for it. There are often other medicines you can have.

**Tips to help with sickness**

- Take your anti-sickness drugs regularly as prescribed – don’t wait until you feel sick.
- Tell one of your hospital team if the drugs don’t work.
- Eat several small meals throughout the day when you feel like it. Eat food that appeals to you.
- Avoid cooking food that has a strong smell or ask someone else to prepare meals. Eating meals cold or at room temperature can help.
- Try foods containing ginger, such as ginger biscuits and ginger tea. Sipping a fizzy drink like ginger ale can help.
- Try relaxation techniques such as breathing exercises, meditation or mindfulness.
- Distract yourself by watching a movie, playing a game or talking to someone.
- Try travel sickness wristbands, which you can buy from pharmacies. These might help to stop you feeling sick by using acupressure points.
- Keep your surroundings as peaceful and clean as possible, and get some fresh air regularly.
Sore mouth
Many lymphoma treatments damage the cells lining your mouth. This can be very painful. It can cause mouth ulcers, pain when you swallow or a dry, sore mouth and lips (oral mucositis).

Tell your medical team if you have a sore mouth. They might prescribe painkillers, a special mouthwash, artificial saliva or other treatments to help.

A sore mouth usually gets better once you finish your lymphoma treatment.

Tips to help sore mouth
• Keep your mouth clean, but avoid mouthwashes containing alcohol.
• Use a soft-bristled toothbrush.
• Rinse your mouth after meals.
• Keep your lips moist with lip creams or balms.
• Sip drinks through a straw. Try sucking an ice lolly or ice cubes.
• Avoid smoking and drinking alcohol.
• Avoid hot, spicy foods or foods that are dry or rough in texture. Cool foods that are easy to swallow, such as ice cream and yoghurt, might ease your discomfort.
**Difficulty eating**

Some treatments for lymphoma can reduce your appetite or make you feel full very quickly. Food might taste different or you might be sensitive to particular smells and tastes. If you have a dry mouth, you might find it hard to swallow.

**Tell your medical team if you are struggling to eat.** They might refer you to a dietitian. Talk to your medical team before trying any nutritional supplements.

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**Tips to help with eating**

- Eat little and often or whenever you are hungry, whether it is your usual mealtime or not.
- Avoid foods you don’t like.
- Try foods with a stronger taste, such as savoury foods flavoured with herbs, spices and chutneys.
- Choose high-energy snacks and full-fat foods.
- When you can, eat with others in a pleasant environment.
- Take gentle exercise to stimulate your appetite.

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Once you finish treatment, changes to your taste and appetite should settle down, so try to re-introduce any foods that you stopped enjoying.
Bowel problems
Lymphoma treatments, anti-sickness medicines and painkillers can cause diarrhoea, constipation or wind. Bowel problems are usually mild and get better when your treatment finishes.

**Tell your medical team if you have any bowel problems that aren’t normal for you.** They might be able to give you medicine to help.

**Tips to help with bowel problems**

- If you are constipated, drink plenty of fluids and eat a high-fibre diet containing wholegrain cereals, wholemeal bread and pasta, lentils and pulses, and fruit and vegetables. You might find it helps to have a hot drink in the morning or to take gentle exercise, such as walking.
- If you have diarrhoea, it’s important you drink plenty of fluids to keep yourself hydrated. Try to eat low-fibre foods such as peeled cooked potatoes, white rice, white bread or dry crackers.
- Eating and drinking slowly or drinking peppermint tea might help reduce wind. Avoid fizzy drinks.
Sore skin
If you have radiotherapy, the skin in the treated area might become dry, sore or itchy. This tends to be at its worst a few days after finishing radiotherapy. It usually gets better in a few weeks. You might also notice changes in your finger or toe nails. They might change colour, or become dry and brittle. They might come off completely. They grow back gradually after your treatment ends.

Some lymphoma treatments can make your skin sensitive to sunlight. Take care to protect your skin from the sun.

Ask your medical team how best to look after your skin and if they can recommend any creams or skincare products.

Tips to help sore skin

• Ask for painkillers or other medication to help.
• Avoid using soap, talcum powder or deodorant on sore areas. Try using hypoallergenic products.
• Avoid rubbing your skin. When washing, use lukewarm water and pat yourself dry with a towel.
• Use an electric razor rather than wet shaving, or avoid shaving altogether.
• If your skin is itchy, wear loose-fitting, lightweight clothes made from soft cotton, silk or bamboo.
Hair loss

Many chemotherapy drugs used to treat Hodgkin lymphoma cause hair loss. Radiotherapy also causes hair loss, but only in the area treated.

Your hair usually begins to fall out within a couple of weeks of starting treatment. You should notice it start to grow back within 2 to 3 months of finishing your treatment but it can take longer.

“It was losing my eyebrows that I found most upsetting. It seemed to change my looks completely and I thought it made me look really ill.”
Adam P, diagnosed with Hodgkin lymphoma in 2013

Many people find losing their hair difficult because it is an important part of their identity. It can be helpful to prepare by having your hair (including facial hair, if you have any) cut short beforehand. When your treatment starts, wearing a hairnet or towelling turban to bed helps to collect any hair that falls out at night.

“After my second chemotherapy I lost a dramatic amount of hair. I hated the thought of the wig; it just was not me at all. Instead, I began to comb all my hair back and wear a ponytail.”
Natalia, diagnosed with Hodgkin lymphoma in 2015
Tips to help with hair loss

• Think about if and how you would like to cover your hair loss. There are lots of options, including wigs, scarves, hats and bandanas.
• You might choose not to cover your hair loss at all. Some people try different accessories, jewellery or make up. Experiment to find a look that you feel comfortable with.
• Be gentle with your hair and scalp. Avoid chemical products and exposure to heat and cold. Use a soft hairbrush. If your scalp is dry, try massaging a mild moisturiser or unperfumed natural oil into it.

Talk to your medical team if you are concerned about losing your hair.

Macmillan Cancer Support have information about wigs, hats, scalp care and more to help you deal with hair loss. Visit macmillan.org.uk/HairLoss

Fatigue

Fatigue is extreme tiredness that isn’t related to physical activity and doesn’t necessarily go away after resting. It can happen because of the lymphoma itself or the treatment you are having.
Fatigue affects people differently. Some people find they can’t do as much as they used to. Others feel so tired they can’t do their usual daily activities.

Fatigue usually gets better gradually but it can last for months after your treatment has ended. For some people, it can last a year or more, although it usually gets less troublesome over time.

“I have been shocked by how fatigued I feel; it’s like someone has taken the batteries out.”
Andy, diagnosed with Hodgkin lymphoma in 2009

**Tips to help with fatigue**

- Pace yourself – plan the important things for when you have more energy and don’t get caught up in what is less important.
- Take regular light exercise, such as walking.
- Take short rests throughout the day and try and get into a regular sleeping pattern at night.
- Accept help with day-to-day tasks.
- Make time to see friends and take part in normal social activities.
- Eat a healthy diet.
Nerve damage (peripheral neuropathy)

Some chemotherapy drugs or targeted therapies can damage the nerves that carry information about touch, temperature and pain. The drugs can also cause damage to the nerves involved in muscle movement. This nerve damage is called **peripheral neuropathy**.

Neuropathy most often affects the nerves in your hands and feet, causing symptoms such as numbness and tingling in your fingers and toes. You might feel it in other places, too. Sometimes it affects the nerves of the internal organs, which is known as ‘autonomic’ neuropathy. This can cause symptoms such as abdominal cramps and constipation.

Symptoms of neuropathy usually develop after you have had several cycles of treatment.

**Tell your medical team straight away if you have symptoms of peripheral neuropathy.** They can suggest things to help with symptoms. They might adjust your treatment to stop your symptoms getting worse.

For most people, peripheral neuropathy starts to get better after you finish treatment, but it can take weeks or months. For some people, it never goes away completely.

**You must notify the Driver and Vehicle Licensing Agency (DVLA) if you have peripheral neuropathy.**
Tips to help with peripheral neuropathy

- Take extra care to avoid injuring your fingers and toes – they will be less sensitive than usual. Avoid extreme temperatures and take care when cooking.
- Keep your hands and feet warm. Cold can make symptoms worse.
- Try gently massaging or exercising your fingers and toes by flexing and stretching them for a few minutes, four times a day.
- Wear gloves for gardening.
- Wear comfortable shoes and avoid high heels.

‘Chemo brain’ (cancer-related cognitive impairment)
Some people have trouble remembering things or concentrating properly when they have lymphoma. This is probably due to the effects of both the lymphoma itself and the lymphoma treatment.

“I felt really fatigued and also found that I could no longer concentrate or focus on things, something the doctor told me is known as ‘chemo brain’.
Adam P, diagnosed with Hodgkin lymphoma in 2013
Although this is often called ‘chemo brain’, it doesn’t only affect people being treated with chemotherapy. Some people describe it as a ‘mental fog’ or feeling slightly detached from the world around them. Its medical name is cancer-related cognitive impairment.

The effects of chemo brain usually get better gradually after finishing treatment, although it often takes many months and occasionally years.

**If you are affected by chemo brain, tell your medical team.** They can offer you advice and support.

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**Tips to help with chemo brain**

- Don’t take on too much and stick to one thing at a time.
- Write things down: use a diary, app or notebook to remind you what you need to do, and when and where you need to do it.
- Plan your day so that you do difficult things when you feel at your best.
- Ask for help where you can.
- Try to keep your mind active by playing games, reading or solving problems.
Coping with day-to-day life

It is hard to predict how your treatment will affect your everyday life. You might need to adjust to changes in your physical or emotional health. This might make it more challenging to deal with day-to-day practicalities, such as work, studying and socialising.

"I take each day at a time and try not to look too far ahead."
Adam P, diagnosed with Hodgkin lymphoma in 2013

Working and finances

Some people carry on working during treatment for lymphoma. Others need to take time off.

Your employer must, by law, make any ‘reasonable adjustments’ you need during and after your treatment. You might need to reduce or change your working hours, alter the work you do, or take time off to attend appointments. If you are unable to work, you might be entitled to sick pay.

"Physically, work was hard and sometimes I found it difficult even to walk up flights of stairs. But mentally it did me so much good and helped me recover."
Carol, diagnosed with Hodgkin lymphoma in 2004
Talk to your employer about the support you might need during and after your treatment. You can also discuss work-related concerns with your medical team.

If you are self-employed, think about how you will manage your work and finances. If you’re not able to work, you might qualify for financial support from the government. Your specialist nurse might be able to help you access this.

If you’re unemployed and you’re receiving financial support, let the government know about your lymphoma to make sure you get the right payment each month. You can usually do this through your online account or through your local Jobcentre Plus.

Macmillan Cancer Support produce detailed information about work and cancer. Visit macmillan.org.uk/Work

**Studying**
If you’re at school, college or university, you’re likely to need time off from your studies, particularly during treatment. Let your school, college or university know what is happening so that they can support you.
If you are at school, your school and local council should support you to make sure your education doesn’t suffer. Universities and colleges should be flexible and understanding, too. You might only want to take a short break from studying and do work when you can. You might prefer to take a longer time out and return to studying the next academic year when you have fully recovered.

“I’d been determined from the start to keep up my education, as it was an element of my life I felt I maintained control over.”

Ellie, diagnosed with Hodgkin lymphoma in 2011

**Hobbies and socialising**

While you’re being treated for lymphoma, allow yourself time to do the things you enjoy. When you feel well enough, seeing friends, getting out or doing a hobby can make you feel more like yourself and improve your emotional and physical wellbeing.

Try to pace yourself. You might find it harder to do something than you used to or get tired more easily.

Remember that there may be times when you should avoid crowds and public places because of the risk of infection – your hospital team should give you advice about this.
Holidays and special events

Talk to your medical team before planning any holidays or special events. They can advise you based on your individual situation.

It might be advisable to stay close to home during certain times of your treatment and recovery. For example, if you have a low blood count, your risk of getting an infection is high and you should try not to be exposed to lots of people.

If you are thinking about going on holiday once you have finished treatment, talk to your team. You might need to consider where you travel to, your accommodation and whether you need any vaccinations. Depending on where you are going, finding travel insurance at a reasonable price can also be difficult, so it is important to plan ahead.

Visit lymphoma-action.org.uk/Travel for more information about travelling outside of the UK.
**Sex and contraception**

There is no reason you shouldn’t have sex during treatment if you feel like it, but be aware that you need to take extra precautions.

Use contraceptives throughout your treatment if there is any chance that you or your partner could become pregnant. Some treatments can damage sperm or eggs and could be harmful to a developing baby. If you do become pregnant, it can make it more difficult to treat your lymphoma.

While you are on chemotherapy, use a condom to avoid passing chemotherapy to your partner during vaginal, anal or oral sex. This also protects you against infection.

People who have had lymphoma are usually advised to wait for up to 2 years after finishing treatment before trying to start a family. There is more information on lymphoma treatment and fertility on page 131.

Everybody’s circumstances are different, so it is important to discuss these issues with your medical team. They can give tailored advice on what they feel would be best for you.

You might not feel like having sex when you are going through treatment or for some time afterwards. Be open with your partner and let them know how you feel.
Summary

• You are likely to experience side effects but it’s difficult to predict what side effects you’ll get and how they will affect you. Your medical team should tell you the most common side effects of your treatment.
• There are lots of things you can do to help you cope with side effects.
• Talk to your medical team about the support available to you.
• No one can tell you exactly how treatment for Hodgkin lymphoma will affect your day-to-day life. You might need to make changes to your work or studies, personal life, or holiday plans.
Initially to be told that I needed 6 months of treatment and then to find that it had not worked was fairly emotional. It was quite a rollercoaster. At that point, stem cell transplants were thrown into the mix.

Hannah, diagnosed with Hodgkin lymphoma in 2014
What happens if Hodgkin lymphoma comes back or doesn’t respond to treatment?

What is relapsed or refractory Hodgkin lymphoma? 112

How is relapsed or refractory Hodgkin lymphoma treated? 112
What is relapsed or refractory Hodgkin lymphoma?

Many people go into long-term remission after treatment for Hodgkin lymphoma. In a small number of people, the lymphoma does not respond to treatment (refractory lymphoma) or comes back after treatment (relapsed lymphoma). In either case, there are other treatment options that your doctor can suggest.

Lymphoma is most likely to come back within 2 years of the end of your first treatment. However, it can happen later, too. Later relapses are more common in NLPHL than in classical Hodgkin lymphoma.

How is relapsed or refractory Hodgkin lymphoma treated?

If your lymphoma doesn’t respond to treatment or comes back after treatment, it can be very upsetting. However, there are several treatment options that can be successful. The treatment you have depends on:

- the type of treatment you’ve already had and how your lymphoma responded to it
- how well you coped with the treatment
- how quickly your lymphoma came back
- how old you are
- how fit you are.
**Radiotherapy**
If your lymphoma is only in one place in your body, you might have radiotherapy to the affected area (page 74). However, most people need different treatments.

**Salvage chemotherapy**
Most people with Hodgkin lymphoma that has come back or has not responded to treatment have more chemotherapy. This is not usually the same as your first treatment.

If you are fit enough, you are likely to have stronger chemotherapy than you had before. This is sometimes called ‘salvage chemotherapy’.

Lots of different treatment regimens are used for salvage chemotherapy. Your medical team should explain which one they think is best for you. You might have to stay in hospital to have some salvage chemotherapy regimens.

If salvage chemotherapy reduces your lymphoma and you are well enough, your doctor is likely to suggest that you have a stem cell transplant to give you the best chance of a longer-lasting remission.

If you have NLPHL, you might need a less intensive chemotherapy regimen. You are unlikely to have a stem cell transplant.
**Stem cell transplant**

If you respond to salvage chemotherapy and you are fit enough, your doctor might recommend a **stem cell transplant**. This involves having very high-dose chemotherapy.

High-dose chemotherapy can often work when initial treatment didn’t. However, it can permanently damage your stem cells (special cells in your bone marrow that make all your red and white blood cells). This stops you making all the normal blood cells your body needs.

A stem cell transplant is a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells.

Usually, the stem cells are collected from your own bloodstream before your high-dose chemotherapy and are given back to you afterwards. This is known as an ‘autologous’ (self) stem cell transplant. Occasionally, the stem cells come from a donor. This is called an ‘allogeneic’ stem cell transplant.
Having a stem cell transplant

The most common high-dose chemotherapy regimen used to treat relapsed or refractory Hodgkin lymphoma is BEAM: carmustine (also called BiCNU® or BCNU), etoposide, cytarabine (also called Ara-C) and melphalan.

You have these chemotherapy drugs every day for 6 days and then you have your stem cells. You have them through a drip, a bit like a blood transfusion. The stem cells settle in your bone marrow where they start to make new blood cells. While they are settling into your body, you have a very high risk of infection.

Stem cell transplants are very intensive. You usually stay in hospital for several weeks. You need tests beforehand to make sure you are fit enough to have one.

If your medical team thinks a stem cell transplant is suitable for you, they will talk to you in detail about it.

We have separate information on stem cell transplants, including a book on autologous (self) stem cell transplants. Visit lymphoma-action.org.uk/SCT or phone 0808 808 5555 to learn more.
**Targeted drugs**

If you have relapsed or refractory classical Hodgkin lymphoma, you might have treatment with a targeted drug. This might be brentuximab vedotin, or a checkpoint inhibitor such as nivolumab or pembrolizumab.

**Visit lymphoma-action.org.uk/TargetedDrugs for the latest information on targeted drugs for Hodgkin lymphoma.**

**Brentuximab vedotin**

Brentuximab vedotin is an antibody joined to a chemotherapy drug. The antibody sticks to a protein called ‘CD30’ on classical Hodgkin lymphoma cells and carries the anti-cancer drug directly to them, like a guided missile.

Brentuximab vedotin is used to treat some people with relapsed or refractory classical Hodgkin lymphoma. You have it through a drip into a vein every 3 weeks. The most common side effects of brentuximab vedotin are peripheral neuropathy (page 101) and a low neutrophil count (page 88).

It is not suitable for people who have NLPHL because NLPHL cells do not make CD30.
**Checkpoint inhibitors**

Lymphoma cells can interact with your own immune cells to turn your immune cells off. Checkpoint inhibitors are drugs that block this interaction, allowing your immune cells to recognise and destroy the lymphoma cells.

Checkpoint inhibitors called nivolumab or pembrolizumab are used to treat some people with relapsed or refractory classical Hodgkin lymphoma who need more treatment. You have them through a drip into your vein every 2 or 3 weeks. You usually carry on having treatment for at least 2 years as long as you are responding to it. The most common side effects of nivolumab and pembrolizumab are diarrhoea and lung inflammation.
Clinical trials
Your medical team might ask if you’d like to take part in a clinical trial to help find out what the best treatment is for Hodgkin lymphoma that has relapsed or has not responded to treatment.

New treatments for Hodgkin lymphoma are often tested first in clinical trials in people with relapsed or refractory disease. You might be able to access new, experimental treatment by taking part in a clinical trial.

If you do consider entering a clinical trial, your medical team will talk to you about this in detail.

• We have a clinical trials information service called Lymphoma TrialsLink. For more information about clinical trials, or to search for a trial that might be suitable for you, visit lymphoma-action.org.uk/TrialsLink
• We also produce a book about clinical trials. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
Summary

• Refractory lymphoma is lymphoma that does not respond to your first treatment.
• Relapsed lymphoma is lymphoma that responds to treatment but then comes back.
• If you have relapsed or refractory Hodgkin lymphoma that is only in one place in your body, you might have radiotherapy to the affected area.
• Most people with relapsed or refractory Hodgkin lymphoma have treatment with a more intensive chemotherapy regimen. This is sometimes called ‘salvage chemotherapy’.
• If you respond to salvage chemotherapy and you are fit enough, you might have high-dose chemotherapy and a stem cell transplant.
• Some people might have treatment with targeted drugs called brentuximab vedotin, nivolumab or pembrolizumab.
• Your doctor might ask you if you’d like to take part in a clinical trial of an experimental drug.
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 with Hodgkin lymphoma in 2015
What happens after treatment?

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How you might feel after treatment

Instead of being delighted to finish treatment, I began to feel angry, asking ‘Why me?’ I also felt like I was being left behind.
Adam P, diagnosed with Hodgkin lymphoma in 2013

You might expect to feel happy and relieved when you finish treatment but many people have mixed feelings. This can come as a surprise. Occasionally, people can feel anxious and low once their treatment has finished, even if they are in remission. This might be because:

• you only start to think deeply about what has happened once your treatment has finished
• you may need to make changes to your life because of your lymphoma or its treatment
• you miss the reassurance of frequent contact with your hospital team
• you are worried about the future and find it difficult to plan ahead.

Now that I feel I am through it, I get a lot more emotional. Before, I don’t recall crying, and was just focused and determined. Perhaps that was my coping mechanism. But now I get tearful about lots of things.
Carol, diagnosed with Hodgkin lymphoma in 2004
It is important to realise that these feelings are all natural, even if others expect you to feel happy. Talk to people, including your GP and medical team, about how you are really feeling.

If you’d like to talk about how you’re feeling, contact our Helpline Services (see page 150 for details).

Follow-up

When you finish your lymphoma treatment you have an appointment with your medical team to talk about your physical, emotional and social needs. Your team uses the information from this appointment to create a care and support plan that’s specific to you.

You are likely to have a follow-up appointment every 2 to 3 months at first. After a while, your appointments may become less frequent. Some hospitals have a self-management system, which means that instead of having regular, pre-booked appointments, you arrange your own follow-up appointments as-and-when you feel you need one.

I had follow-up checks every 3 months, then 6 months, then annually.
John, diagnosed with Hodgkin lymphoma in 2008
Your follow-up appointments are to monitor your recovery from treatment, check that your lymphoma has not come back and to look out for late effects (page 126).

At your follow-up appointments, you might see your consultant, clinical nurse specialist, or another member of your medical team. They talk to you about how you’re feeling, any symptoms you have and how you’re adjusting to life after treatment. They might examine you. You might also have some blood tests. You are unlikely to have a scan unless there is a particular reason to have one.

You can contact your hospital team at any time. Don’t wait until your next appointment is due if you are worried about your lymphoma.

You might feel anxious before your follow-up appointments. They are an inevitable reminder of your lymphoma at a time when you are trying to move on. It can help to talk through your concerns with a friend or family member. Remember that if you have no new symptoms, it is unlikely your lymphoma has come back.
Your follow-up appointments are an important part of your care. They give you a chance to talk about anything that might be on your mind.

Before your appointment, write down any concerns or questions you’d like to discuss with your medical team. Remember that appointments are a two-way process and give you an opportunity for a collaborative discussion with your medical team.

Most hospitals offer follow-up appointments for at least 2 years after you finish treatment. This is an important time in terms of your recovery from treatment and the risk of relapse. Some hospitals offer follow-up for 5 years or longer.

After your follow-up period ends, your GP usually becomes your main point of contact if you have any concerns or notice anything unusual. Your GP should have a record of your diagnosis and all the treatment you’ve had – but it’s a good idea to remind them that you have had treatment for lymphoma.
Late effects of treatment

Late effects are health problems that may develop months or years after treatment for lymphoma. Most people are treated successfully for Hodgkin lymphoma with few late effects.

You may have a higher risk of developing late effects if you’ve had more than one treatment for lymphoma. The risk of developing late effects might seem worrying, but knowing what conditions you might be at risk of gives you the best chance of preventing late effects or getting treatment early if they develop.

We cover the most common late effects of lymphoma treatment on the next few pages. Your medical team should talk to you about the possible late effects of your treatment before it starts.

Questions to ask your medical team

• What late effects might I develop?
• How will I be monitored for these effects?
• How can I reduce my risk of being affected?
• What signs should I look out for?
• Are there any screening programmes I should take part in?
Lung problems
Radiotherapy to your chest or treatment with bleomycin (a component of the ABVD, BEACOPP and BEACOPDac chemotherapy regimens) can cause scarring of your lungs. Brentuximab vedotin can make this worse if it is given with bleomycin. This combination is usually avoided.

If the lung damage is mild, it can be seen on X-rays or scans, but it doesn’t cause any symptoms. If there is more scarring, you might get short of breath. If you are affected, you might not be able to do as much exercise as you used to before you feel out of breath. You might be advised to avoid scuba diving because high-flow oxygen could potentially increase your risk of developing lung problems. Ask your medical team.

If you have been treated with bleomycin and you need surgery, tell the anaesthetist about your treatment so they can take any necessary precautions.

You are more likely to develop lung problems after lymphoma treatment if you smoke. **If you are a smoker, try to give up.**

**Talk to your GP or visit nhs.uk/smokefree for free support to help you quit smoking.**
Heart problems
Radiotherapy to your chest and some chemotherapy drugs can damage your heart. This includes doxorubicin, a component of the ABVD, BEACOPP, BEACOPDac and CHOP chemotherapy regimens commonly used to treat classical Hodgkin lymphoma and NLPHL.

Heart problems generally start 10 years or more after your lymphoma treatment but they can develop sooner. Your risk of heart problems stays higher than usual for several decades after your treatment.

People who have been treated for lymphoma also have a higher than usual chance of developing ‘metabolic syndrome’ – a combination of diabetes, high blood pressure and obesity. Metabolic syndrome also increases your risk of developing heart disease.

You can lower your risk of developing heart problems by making lifestyle choices that aim to keep your heart healthy. These include maintaining a healthy weight, eating well and staying active. You should also have your blood pressure, blood sugar level and cholesterol level checked regularly. If you are a smoker, try to give up.

Visit the British Heart Foundation’s website (bhf.org.uk) for information about heart problems and advice on keeping your heart healthy.
Other cancers

Treatment for Hodgkin lymphoma can increase your risk of developing another cancer in the future. However, this risk is small. **Most people who have been treated for lymphoma never develop another cancer.**

The type of cancer you might be at risk of depends on the exact treatment you had, the dose you had, how old you were when you were treated and how old you are now.

- Radiotherapy is linked to an increased risk of developing solid tumours (in other words, not blood cancers) in parts of your body that were exposed to radiation during your treatment.
- In general, chemotherapy is linked with an increased risk of developing leukaemia (a type of blood cancer) and non-Hodgkin lymphoma. Some chemotherapy might also increase your risk of certain solid tumours (for example, lung cancer, stomach cancer or pancreatic cancer).

Lifestyle factors also affect your risk. You should do what you can to reduce your risk. Try to eat a healthy diet, stay active and maintain a healthy weight. Protect your skin from the sun. If you are a smoker, try to give up.
Ask your medical team what cancers you might be at higher risk of developing. Make sure you know the symptoms of these cancers. Cancer is usually more treatable if it is diagnosed early.

**Underactive thyroid gland**

If you’ve had radiotherapy to your neck, your thyroid gland might become underactive (known as ‘hypothyroidism’). This makes the cells in your body slow down. It can make you feel very tired and be more sensitive to cold. You might also put on weight.

Hypothyroidism can develop any time after treatment, even many years later. It can be diagnosed by a simple blood test at your GP surgery. It is easily treated with tablets.
Effects on fertility

Some chemotherapy drugs or radiotherapy to your tummy (abdomen) or the area below your belly button (your pelvis) can damage your ovaries or testicles. This might lead to early menopause in women, and reduced fertility in both men and women. Different treatments have different effects on your fertility. **ABVD, the most common chemotherapy regimen used to treat Hodgkin lymphoma, does not usually affect your fertility in the long-term.**

Your medical team should tell you if your treatment is likely to affect your fertility. If it is, and you think you might want to have children in the future, they can refer you to a fertility specialist to discuss options for preserving your fertility.

• We have more information on early menopause and reduced fertility after lymphoma treatment at lymphoma-action.org.uk/SideEffects
• Visit the Fertility Network at fertilitynetworkuk.org for advice and support about fertility issues.
• The Daisy Network (daisynetwork.org.uk) and Menopause Matters (menopausematters.co.uk) offer support and information for people experiencing early menopause.
Future blood transfusions
If you need to have a blood transfusion in the future, there is a very small risk that white blood cells in the donor blood could react against your own cells. This is called ‘transfusion-associated graft-versus-host disease’. It can be very serious.

To prevent this happening, you should only have a blood transfusion that has been irradiated (treated with X-rays) to destroy any white blood cells.

Your medical team should mark your notes and tell the hospital blood bank that you need irradiated blood. They should give you an alert card in case you need a blood transfusion at a different hospital. **Make sure you always have your card with you.**
Summary

• It is normal to experience mixed feelings when you finish treatment.
• You have regular follow-up appointments to monitor your recovery, check your lymphoma has not come back and to look out for late effects.
• Late effects are health problems that may develop months or years after treatment for lymphoma. It is important to know what late effects you’re at risk of.
• Possible late effects of lymphoma treatment include lung problems, heart problems, other cancers, underactive thyroid, reduced fertility and early menopause.
• If you need a blood transfusion in the future, you need to have irradiated blood.
Both my wife Maria and I developed a healthy lifestyle after my treatment finished. We looked more closely at our diet and introduced more exercise. For me, I have a more positive mindset and feel much better physically.

John, diagnosed with Hodgkin lymphoma in 2008
Living with and beyond Hodgkin lymphoma

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When someone close to you has lymphoma 140
Your feelings

No one can tell exactly how you will feel when you are diagnosed with Hodgkin lymphoma, when you have treatment or afterwards. You will probably have different feelings at different times. This is natural and there is no ‘right’ or ‘wrong’ way to react. You might feel:

- shocked – you may feel numb and find it hard to accept things at first
- sad – your life and plans, at least for a while, are going to have to change
- scared – often this is fear of the unknown, so finding out more about what to expect can help
- angry – you may feel you’ve lost control of your life and resent that this has happened to you.

These feelings are natural. It is important to accept them and deal with them. It can help to talk about your feelings, especially during times when you are finding it harder to cope.

Talking to people closest to you can sometimes be difficult – particularly if they are dealing with their own feelings about your illness. Your specialist nurse is often a good person to talk to if you’re looking for help – they know the kind of feelings people often have and how to approach them.
Depression
You might feel there are times when you don’t want to talk to anyone and just want to be alone. It is not unusual to feel low from time-to-time but if you feel like this a lot of the time, you might be experiencing depression.

People who are affected by depression might feel hopeless, guilty or worthless. They might lose interest in hobbies or normal activities, or find it difficult to concentrate on things. They might also have trouble sleeping; this can include difficulty falling asleep, waking up early or sleeping all the time.

If you, or those around you, think you might be affected by depression, talk to someone. Your GP is a good first contact. There is a lot of support, treatment and counselling available for people with depression. There are also things you can do to help yourself.

- Visit nhs.uk/Moodzone for tips to help you cope with depression, anxiety and stress, or nhs.uk/oneyou/every-mind-matters for tips, tools and apps to help you look after your mental health.
- Mind (mind.org.uk) have lots of information on mental health and where you can seek support.
- If you are in crisis, call the Samaritans on 116 123.
Healthy living

Many people find that having cancer makes them think about their lifestyle. Changes that you make after your diagnosis could help you to live a longer and healthier life after treatment.

It is important that you:

• eat a healthy diet
• keep a healthy weight
• stop smoking
• exercise regularly
• drink plenty of liquids, especially if you are having chemotherapy
• keep up-to-date with your vaccinations, including the annual flu vaccine
• take part in any health screening programmes you are invited to attend.

We have more information and tips on living well with and beyond lymphoma, including diet, exercise, vaccinations and travel insurance. We also have a book called Living with lymphoma. To learn more, visit lymphoma-action.org.uk/LWL or contact our Helpline Services (see page 150).
I’m fairly sure that the dog walking helped me recover more rapidly. Even on bad days, I had to take the dogs out, which helped keep my fitness up, and probably helped with potential fatigue.
Adam F, diagnosed with NLPHL in 2018

You might look at other aspects of your life, too, such as your responsibilities, your job or finances, or how you spend your free time. Many people find having lymphoma makes them value the simple things in life, such as spending time with family and friends and doing the activities they enjoy. Some people find it prompts them to travel or do the things they’ve always wanted to do.

Making informed choices

You might find it useful to learn more about your type of lymphoma and the treatment you’ve had. This could help you:

• take steps to avoid or limit problems during and after treatment
• cope with side effects
• recognise when to call the hospital if a problem occurs
• make decisions about your health and wellbeing
• reduce any fears and anxieties you might have
• feel more in control of what is happening to you.
When I was first diagnosed, I wanted to keep it to myself, but now I think it is important to learn as much as I can about lymphoma and to raise awareness of it.
Adam F, diagnosed with NLPHL in 2018

When someone close to you has lymphoma

When someone close to you has lymphoma, it can be a difficult time for you, too. You might feel helpless watching someone you love going through tests and treatments. You might not know how best to support them – but there are lots of things you can do.

I can still remember so clearly my Dad’s face when we came out of that consultation – thinking back about that makes me feel tearful even now.
Carol, diagnosed with Hodgkin lymphoma in 2004

Don’t forget to take care of yourself. If you become run down or ill, you will not be able to support your loved one. Make sure you look after your own health, eat well and get plenty of rest.

You probably have many of the same emotions as your loved one. You need time to deal with your feelings, too. Talk to someone – friends, family, or a specialist – especially if you are finding it difficult to cope.
People are often unsure what to say to someone affected by cancer or worry that they might say the wrong thing. Often, you don’t need to say anything. Just being ready to listen can be a huge help. Be guided by the person with lymphoma and what they want to talk about – they might just want to have a ‘normal’ conversation about a television programme, or anything that isn’t their lymphoma.

My mum coped by talking about my lymphoma to everyone. My dad and I coped by shutting down.
Natalia, diagnosed with Hodgkin lymphoma in 2015

Let the person with lymphoma know that you love them. Care for them in whatever way you can. Remember that a smile or a hug may say much more than any words.

Practical things you could do to help include:

- providing transport to and from hospital
- going to hospital appointments with them to help remember what is being said
- helping with shopping or preparing meals
- taking care of other family members
- encouraging them to spend time seeing other people or doing things they enjoy
- organising fun things to do when they feel up to it.
A carer is someone who looks after a person with an illness or disability without getting paid for it. You might not feel like it, but you are a carer if you’re looking after a relative or a friend with lymphoma. Carers UK (carersuk.org) and Carers Trust (carers.org) are helpful sources of support.

**Summary**

- You might experience a mix of emotions at different times during your experience of lymphoma. This is normal.
- If you feel down a lot of the time, it could be a sign of depression. Talk to your GP to find out about support available to you.
- Try and live a healthy lifestyle, following a healthy diet and exercising regularly.
- You might find it useful to learn about your type of lymphoma and the treatments you’ve had.
- If you are caring for someone with lymphoma, remember to look after yourself, too.
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td><strong>Anaemia</strong></td>
<td>shortage of red blood cells or haemoglobin in the blood</td>
</tr>
<tr>
<td><strong>Anaesthetic</strong></td>
<td>drugs given to make a part of the body numb (local anaesthetic) or put the whole body to sleep (general anaesthetic)</td>
</tr>
<tr>
<td><strong>Antibody</strong></td>
<td>a protein made by white blood cells that recognises and sticks to proteins that don’t belong in your body, such as viruses or bacteria</td>
</tr>
<tr>
<td><strong>Antibody therapy</strong></td>
<td>treatment that uses antibodies made in a laboratory to target cancer cells</td>
</tr>
<tr>
<td><strong>B symptoms</strong></td>
<td>fever, drenching night sweats and unexplained weight loss</td>
</tr>
<tr>
<td><strong>Biopsy</strong></td>
<td>a test that involves looking at a sample of tissue under a microscope</td>
</tr>
<tr>
<td><strong>Bone marrow</strong></td>
<td>the spongy material at the centre of larger bones</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>-------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>treatment that uses drugs to kill cancer cells</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>a combination of chemotherapy drugs</td>
</tr>
<tr>
<td>regimen</td>
<td>given at a particular dose and schedule</td>
</tr>
<tr>
<td>CT scan</td>
<td>computed tomography: a scan that uses X-rays to take pictures of ‘slices’ through your body</td>
</tr>
<tr>
<td>Cycle</td>
<td>a round of treatment followed by a rest period to allow your body to recover before the next round of treatment</td>
</tr>
<tr>
<td>DNA</td>
<td>deoxyribonucleic acid: the genetic make-up of a cell</td>
</tr>
<tr>
<td>HIV</td>
<td>human immunodeficiency virus: the virus that causes AIDS</td>
</tr>
<tr>
<td>Immune system</td>
<td>the system in your body that fights off and prevents infection</td>
</tr>
<tr>
<td>Immunotherapy</td>
<td>treatment that works through your immune system</td>
</tr>
<tr>
<td>Intravenous</td>
<td>into a vein</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td><strong>Late effects</strong></td>
<td>side effects that might develop months or years after treatment</td>
</tr>
<tr>
<td><strong>Lymph nodes</strong></td>
<td>small, bean-shaped structures spread throughout your lymphatic system that filter lymph fluid</td>
</tr>
<tr>
<td><strong>Lymphatic system</strong></td>
<td>a network of tubes, nodes and organs that filters out germs and toxins, helps destroy cells that are old or damaged and drains waste fluids from your tissues</td>
</tr>
<tr>
<td><strong>Lymphocytes</strong></td>
<td>specialised white blood cells that are part of your immune system</td>
</tr>
<tr>
<td><strong>MRI</strong></td>
<td>magnetic resonance imaging: a scan that uses magnetic waves to produce a picture of the body</td>
</tr>
<tr>
<td><strong>Neutropenia</strong></td>
<td>shortage of neutrophils in the blood</td>
</tr>
<tr>
<td><strong>Neutrophils</strong></td>
<td>a type of white blood cell that is important in fighting infections</td>
</tr>
<tr>
<td><strong>Peripheral neuropathy</strong></td>
<td>damage to the nerves of your peripheral nervous system, which carries signals and messages between different parts of your body</td>
</tr>
</tbody>
</table>
**PET scan**  
positron-emission tomography: a scan that uses a radioactive form of sugar to look at how active cells are

**PET/CT scan**  
a test that combines a PET scan and a CT scan

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

**Radiotherapy**  
treatment that uses high-energy X-rays and other types of radiation to kill cancer cells

**Red blood cell**  
blood cells that carry oxygen around your body

**Reed–Sternberg cells**  
large, abnormal cells that look like owls’ eyes; characteristic of classical Hodgkin lymphoma

**Refractory lymphoma**  
lymphoma that doesn’t respond to treatment

**Relapsed lymphoma**  
lymphoma that comes back after treatment

**Spleen**  
a pear-sized organ behind your ribcage on the left-hand side; it filters blood
<table>
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<tr>
<th>Term</th>
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</thead>
<tbody>
<tr>
<td><strong>Subcutaneous</strong></td>
<td>underneath the skin</td>
</tr>
<tr>
<td><strong>Stage</strong></td>
<td>a measure of how much of your body is affected by lymphoma</td>
</tr>
<tr>
<td><strong>Stem cell transplant</strong></td>
<td>a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells</td>
</tr>
<tr>
<td><strong>Targeted therapies</strong></td>
<td>drugs that interfere with particular proteins or biological processes in cancer cells</td>
</tr>
<tr>
<td><strong>Thrombocytopenia</strong></td>
<td>a shortage of platelets in your blood</td>
</tr>
<tr>
<td><strong>Thymus</strong></td>
<td>a small, butterfly-shaped gland behind your breastbone where some immune cells develop</td>
</tr>
<tr>
<td><strong>Thyroid gland</strong></td>
<td>a gland at the front of your neck that produces a hormone called thyroxine, which controls how fast the cells in your body work</td>
</tr>
<tr>
<td><strong>Ultrasound scan</strong></td>
<td>a scan that uses soundwaves to take pictures inside your body</td>
</tr>
<tr>
<td><strong>White blood cell</strong></td>
<td>a cell that helps your body fight infections; several different types exist including lymphocytes and neutrophils</td>
</tr>
</tbody>
</table>
Useful organisations

**Bloodwise** provides a range of information about blood cancers.
0808 2080 888 www.bloodwise.org.uk

**British Association for Counselling and Psychotherapy** provides a list of accredited private counsellors in your area.
01455 883300 www.bacp.co.uk

**Cancer Research UK** offers information on all types of cancer, a searchable database of clinical trials and a helpline staffed by nurses.
0808 800 4040 www.cancerresearchuk.org

**Carers UK** offers expert advice, information and support for carers.
0808 808 7777 www.carersuk.org

**CLIC Sargent: Young Lives vs Cancer** provides emotional and practical support for young people with cancer and their families.
0300 330 0803 www.clicsargent.org.uk

**Macmillan Cancer Support** provides practical, emotional and financial support to people affected by cancer.
0808 808 0000 www.macmillan.org.uk
Maggie’s Centres provides free practical, emotional and social support to people with cancer and their family and friends.
0300 123 1801       www.maggiescentres.org

Teenage Cancer Trust provides cancer services and support for young people affected by cancer.
hello@teenagecancertrust.org       www.teenagecancertrust.org

Working with Cancer provides advice about remaining in work, returning to work or finding work for people with cancer.
07919 147784       www.workingwithcancer.co.uk

Visit lymphoma-action.org.uk/UsefulOrgs for a list of other organisations you might find helpful.
Information and support

If you’d like to talk to someone about anything to do with lymphoma, get in touch.

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

Come to one of our **Support Groups**. Find one near you at lymphoma-action.org.uk/SupportGroups.

Use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details.

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

Check out our **YouTube channel** to watch personal stories and medical films.

See our website for full details of our services. For our latest news and updates, follow us on social media:
We produce many other publications that give information about lymphoma. Visit our website at lymphoma-action.org.uk or call 0808 808 5555 for more information.

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

**How you can help us**

Volunteering is at the heart of what we do. If you’d like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

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

**References**

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.
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This book is about Hodgkin lymphoma. It describes how Hodgkin lymphoma typically affects people, how it is treated and what to expect during and after treatment.

Lymphoma Action is the UK’s only charity dedicated to lymphoma, the fifth most common cancer. Our mission is to make sure no one faces lymphoma alone.

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