

Hodgkin lymphoma

Classical Hodgkin lymphoma

**Nodular lymphocyte-predominant
Hodgkin lymphoma (NLPHL)**



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



My Hodgkin lymphoma type and stage

My treatment plan

Key contact

Name: _____

Role: _____

Contact details: _____

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

About this book

Over 2,000 people are diagnosed with Hodgkin lymphoma each year in the UK. This book explains what Hodgkin lymphoma is, how it is diagnosed and some of the treatment options that might be available to you.

In this book, we cover classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL). However, please note that the classification of NLPHL is currently under review. This might mean that the name of it changes before the next edition of this book is published.

You might also be interested in our book: *Living with and beyond lymphoma*, which gives tips on coping practically, physically and emotionally. See page 121 for other resources you might find helpful.

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

Important and summary points are written in the chapter colour. Words that are in **bold teal** font are explained in the glossary on pages 116 to 120.

We'd value your feedback on this book – see page 125 for more information.

If you would like a copy of this book in large print, please contact us (page 123).

Contents

● About Hodgkin lymphoma	7
● Symptoms	21
● Tests, diagnosis and staging	29
● Treatment	49
● After treatment	99
● Glossary, useful organisations, information and support	116



About Hodgkin lymphoma

What is lymphoma?	8
How lymphoma develops	11
Who gets Hodgkin lymphoma?	13
Types of Hodgkin lymphoma	14
Possible causes	16
What is the outlook?	18

“ *How was it that I could be diagnosed with what turned out to be the fifth most common cancer in the UK, but yet I'd never heard of it.*
Ian, diagnosed with Hodgkin lymphoma

What is lymphoma?

Lymphoma is a type of blood cancer. It develops when **white blood cells** called **lymphocytes** grow out of control.

Lymphocytes are part of your **immune system**, which helps to fight infection. Lymphocytes travel around your body in the **lymphatic system** surrounded by a fluid called **lymph**. The lymph fluid passes through glands (**lymph nodes**), which are found throughout your body. For this reason, lymphoma is sometimes known as a cancer of the immune system.

If you have lymphoma, your lymphocytes divide in an abnormal way or do not die when they should. The abnormal lymphocytes build up, usually in lymph nodes in your armpits, neck or groin. However, they can collect in almost any part of your body.



Search 'what is lymphoma?' on our website for more information and to watch a short animation about it.

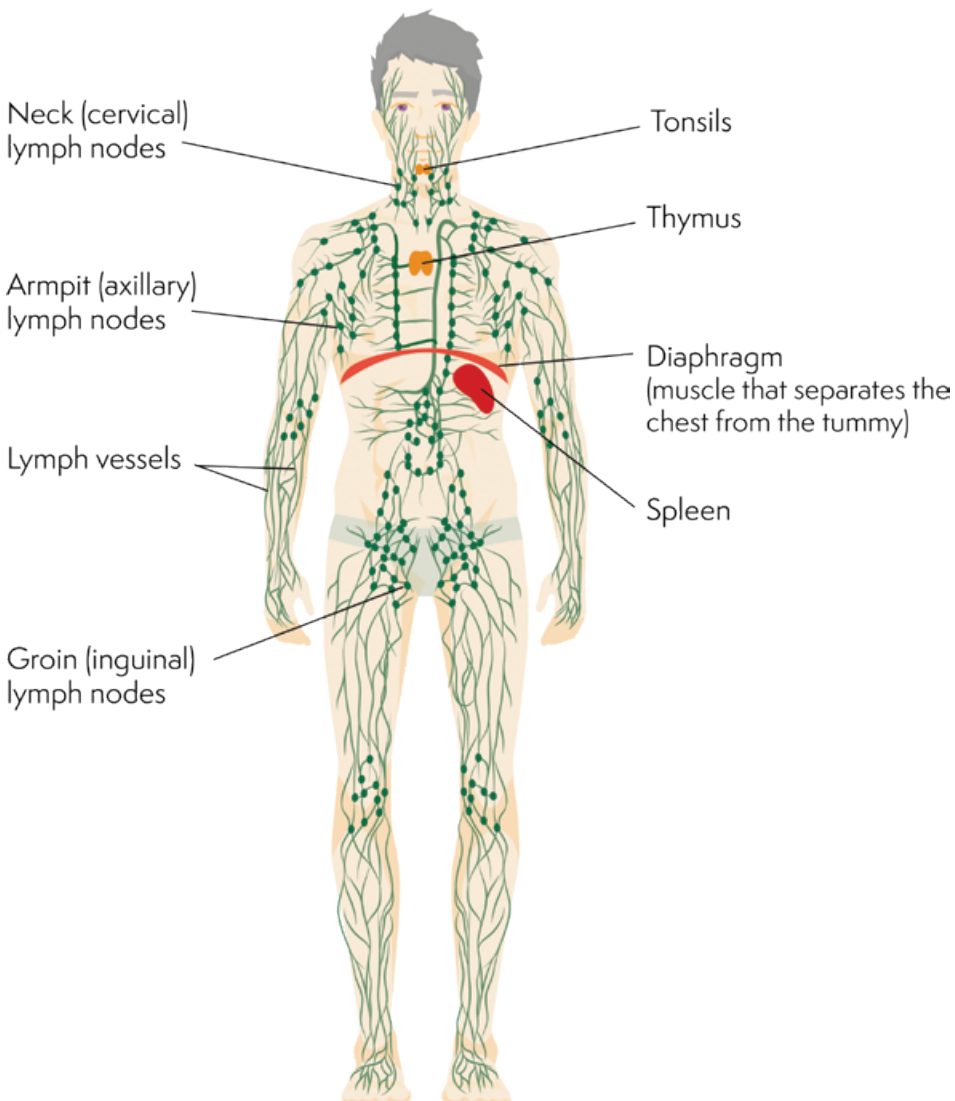
The lymphatic system

Your **lymphatic system** is part of your immune system. It runs throughout your body carrying lymph fluid.

It is a network of tubes (lymph vessels) and **lymph nodes** (sometimes known as lymph glands). It also includes organs, such as your **spleen** (which filters blood) and **thymus** (where some of your immune cells develop).

The lymphatic system has some key functions. It:

- filters out germs (bacteria, viruses and parasites) and poisons (toxins)
- helps to destroy cells that are old, damaged or abnormal
- keeps a healthy balance of lymph, by draining it from your tissues and returning it to your bloodstream
- absorbs fats and vitamins from your digestive system and puts them back to your bloodstream.



The lymphatic system

How lymphoma develops

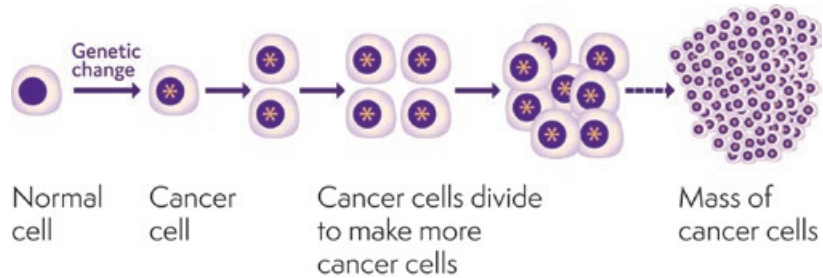
Your body is made up of cells. Some of these cells divide throughout your life. They replace old cells that die off naturally.

Usually, chemical control signals keep cell division and cell death in careful balance. This makes sure that you make only the number of new cells your body needs.

Throughout life, changes (mutations) happen to our DNA (genetic material). Most of the time, these are harmless, but they can sometimes cause disruption. This can lead to abnormal cells that stop responding to the control signals. These cells then might:

- start dividing when they shouldn't
- carry on dividing when they should stop
- stay alive when they should die.

When this happens, it can lead to a build-up of abnormal cells (cancer). It usually takes a number of different mutations for a cancer to develop. With lymphoma, the abnormal cells build up and usually collect in a lymph node. However, they can collect in other parts of the body, such as the spleen, liver or **bone marrow**.

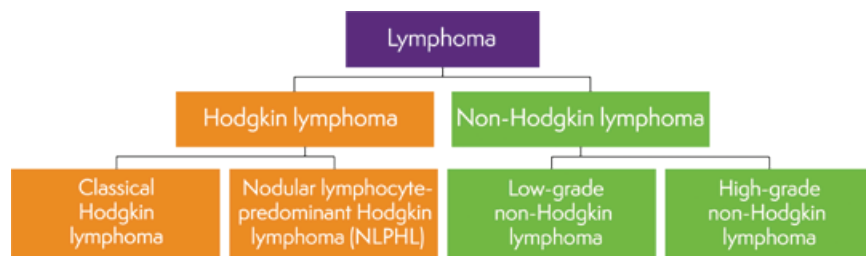


How cancer develops

See page 16 for information about the possible causes and risk factors of Hodgkin lymphoma.

Types of lymphoma

There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphomas and non-Hodgkin lymphomas. Different types of lymphoma behave differently and need different treatment.



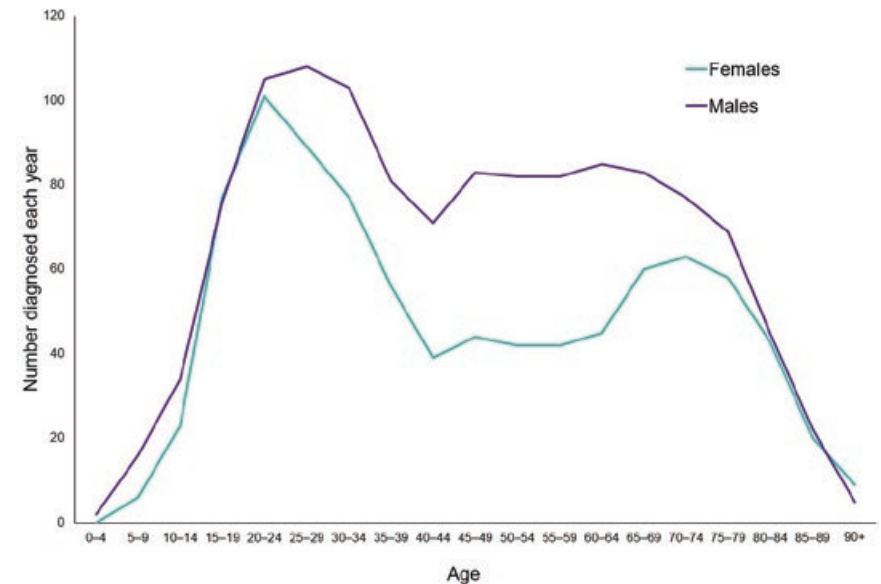
The main types of lymphoma

Who gets Hodgkin lymphoma?

Over 2,000 people are diagnosed with Hodgkin lymphoma each year in the UK – that’s roughly six people every day.

Hodgkin lymphoma can affect:

- any age group, although in the UK, most people diagnosed are between the ages of 15 and 34, or over 60
- people of any ethnicity
- both males and females, although it is slightly more common in males.



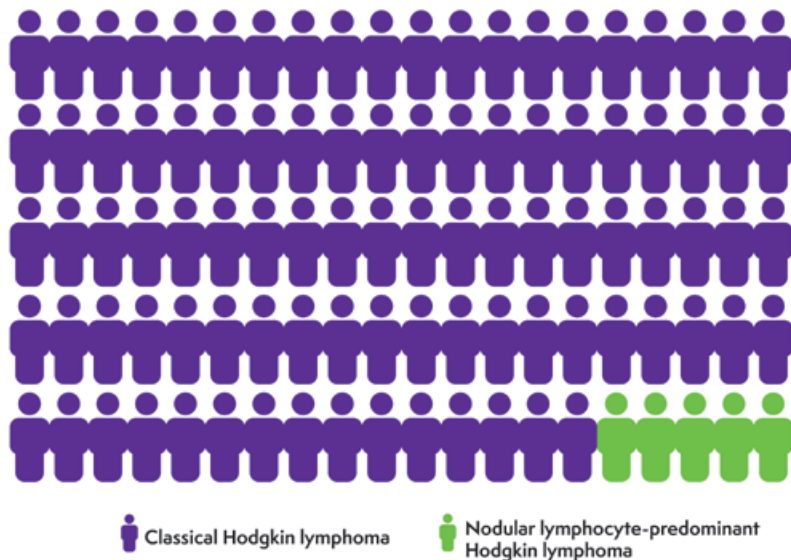
Diagnosed cases of Hodgkin lymphoma each year in the UK. Data source: Cancer Research UK, 2021

Types of Hodgkin lymphoma

There are two types of Hodgkin lymphoma. They are grouped depending on which type of **Reed–Sternberg cell** they contain. These harmful (malignant) cells are large, abnormal cells that look different to healthy cells under a microscope.

Most people diagnosed with Hodgkin lymphoma have classical Hodgkin lymphoma.

- **Classical Hodgkin lymphoma** contains Reed-Sternberg cells.
- **Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)** contains a variant of Reed–Sternberg cells called lymphocyte-predominant (LP) cells.



How common the two types of Hodgkin lymphoma are (all age groups). Data from 2021

Classical Hodgkin lymphoma

There are four subtypes of classical Hodgkin lymphoma, which are listed below. However, they are generally referred to just as 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.

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

Around 1 in 10 people with Hodgkin lymphoma have NLPHL.

NLPHL contains large, abnormal lymphocytes 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. A protein called CD20 is present on the surface of LP cells. The CD20 protein is more commonly found in non-Hodgkin lymphomas. Treatment for NLPHL often includes an antibody that targets the CD20 protein (see page 73).

Possible causes of Hodgkin lymphoma

In most cases, the cause of lymphoma is not known. It's likely that lots of different factors have a part in its development.

Scientists do, however, know that you can't 'catch' lymphoma from anyone or pass it onto anyone else. However, you have a **very slightly** higher risk of developing lymphoma if you have a close relative (such as a parent or sibling) who has it.

Below, we outline some of the things that can increase your chances of developing lymphoma (risk factors).

Epstein-Barr virus (EBV)

EBV is a very common virus that affects B lymphocytes and can cause glandular fever.

EBV infects around 9 in 10 adults, but it is usually mild and many people don't even know they've had it. After you're infected with EBV, the virus stays in your body. Your immune system usually keeps it under control so it does not cause any problems.

People who have been infected with EBV have a higher chance of developing some types of lymphoma, including Hodgkin lymphoma. **However, most people who have had EBV never get lymphoma.**

Problems with your immune system

Hodgkin lymphoma might be related to immune system problems. For example, people who are more likely to develop Hodgkin lymphoma include people who take medicines that dampen the immune system (immunosuppressants), including after a stem cell transplant, and people who have human immunodeficiency virus (HIV).



If you'd like to learn more about some of the possible causes and risk factors of lymphoma, search 'causes' on our website, lymphoma-action.org.uk

What is the outlook for people with Hodgkin lymphoma?

Hodgkin lymphoma usually responds very well to treatment. Most people go into complete **remission** (no evidence of lymphoma in tests and scans) and need no further treatment.

In some people, Hodgkin lymphoma comes back (**relapses**). There are effective treatments if this happens. See page 81 for more information on Hodgkin lymphoma that comes back or doesn't respond to treatment.

Your lymphoma specialist (consultant haematologist or oncologist) is the best person to talk to about the likely outcome of your treatment. In giving you this information, they consider a range of factors, including:

- your age
- how much lymphoma you have in your body and where it is (the **stage** of your lymphoma – see page 43)
- the results of your tests and scans (see page 43)
- your general health.

Summary

- Lymphoma is a type of blood cancer.
- It develops when white blood cells called lymphocytes grow out of control.
- There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma.
- Hodgkin lymphoma is grouped into two main types: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).
- Most people who are diagnosed with Hodgkin lymphoma are aged between 15 and 34 or over 60, but it can affect anyone.
- In most cases, the cause of Hodgkin lymphoma is unknown.
- The long-term outlook for people affected by Hodgkin lymphoma is generally very good.



Symptoms of Hodgkin lymphoma

Common symptoms	22
Extranodal symptoms	26

“ Looking back, I had been feeling unwell for quite a while and I had an awful itch. Having been out for the day, I was in agony with pain at the top of my back. I had a biopsy, which revealed Hodgkin lymphoma, and my consultant explained that my treatment would start straightaway.

Hayley, diagnosed with Hodgkin lymphoma

Common symptoms of Hodgkin lymphoma

Hodgkin lymphoma can cause a range of symptoms. The symptoms you have depend on which part of your body is affected. Usually, symptoms start to go away once you start treatment for lymphoma.

Speak to your medical team for advice to help you manage any symptoms you are experiencing.

“ I had been gradually losing weight, and I'd had a couple of infections needing antibiotics. I put those down to stress, but then I felt a hard lump on my neck just above my collar bone. This definitely set the alarm bells ringing, but the final straw came when I started to feel pain in my chest whenever I took a deep breath.

Sarah, diagnosed with Hodgkin lymphoma



Swollen lymph nodes



The most common symptom of Hodgkin lymphoma is a painless, swollen lump or lumps that don't go down after a couple of weeks.

Usually, swollen lymph nodes develop in the neck or just above the collar bones, but they can develop elsewhere, such as in the armpit or groin. In NLPHL (see page 15), a swollen lymph node or nodes is often the only symptom.

Many people with classical Hodgkin lymphoma get **swollen lymph nodes** inside their chest. This might make you cough or feel breathless. However, it might not cause any symptoms at all. Very occasionally, if a swollen lymph node presses on large veins in your chest, it can cause headaches, dizziness, and swelling of the face, arms and hands. These symptoms usually get better once you have treatment.

Rarely, people with Hodgkin lymphoma have swollen lymph nodes that become painful a few minutes after drinking alcohol. This symptom is unusual, affecting up to 5 in 100 people who have Hodgkin lymphoma.

Fatigue



Fatigue is exhaustion that can be physical, emotional or mental. Sometimes people describe fatigue as feeling 'drained'. You might feel tired after doing very little.

Most people who have cancer get fatigue at some point. This can be a symptom or a side effect of treatment. However, lots of factors can contribute to fatigue, including heightened stress and anxiety.

Itching



Itching affects around 1 in 3 people with Hodgkin lymphoma. It can be worse at night and in hot weather. Scientists think that itching is caused by cytokines. These are proteins that are

released by your immune system when your body is fighting an infection or an illness, such as lymphoma.

Difficulty recovering from infections



Lymphoma can weaken your immune system. Usually, white blood cells fight infections. However, if you have lymphoma, you have some cancerous white blood cells, which can make it harder to fight

infections. The infections you get could be more severe, or last longer than they would if you didn't have lymphoma.

You'll find more on page 90 about signs and symptoms of infection, and when to seek medical attention.

B symptoms

Around 1 in 4 people with classical Hodgkin lymphoma get B symptoms. Your doctors might describe you as having B symptoms if you have one or more of the following:

- **fever:** a high temperature (above 38°C/100.4°F) that might come and go
- **drenching sweats:** especially at night
- **unexplained weight loss:** losing weight quickly without trying to.

Extranodal symptoms

Rarely, Hodgkin lymphoma starts in an organ in your body (rather than in a lymph node), for example the liver, lung or bone marrow. This is called 'extranodal' lymphoma. The symptoms you get depend on where the lymphoma is.



You can find tips to help you cope with symptoms of lymphoma on our website (search 'coping with symptoms') and in our book: *Living with and beyond lymphoma*.

Summary

- The most common symptom of Hodgkin lymphoma is a swollen lymph node or nodes.
- Swollen lymph nodes are often in the neck, but they can be in other places, such as the armpit or groin.
- Doctors consider lots of factors when planning your treatment. This includes whether or not you have B symptoms (fever, drenching sweats and unexplained weight loss).
- Usually, symptoms start to go away once you start treatment for lymphoma.
- Speak to your medical team for advice about how to cope with any symptoms you experience.



Tests, diagnosis and staging

Diagnosis of Hodgkin lymphoma	30
Test results	43
Staging of Hodgkin lymphoma	43

“ I noticed a painless lump on my collarbone, which felt rubbery, so I went to see my GP. He thought it was an infection and that the lump was an inflamed node. However, a few weeks passed and it was still rubbing and wasn't getting any smaller, so my GP referred me for a chest X-ray. This revealed a shadow on my chest; that was the start of numerous tests.

Jamie, diagnosed with classical Hodgkin lymphoma

Diagnosis of Hodgkin lymphoma

Your GP is likely to be the first person you speak to about any symptoms or health concerns.

Your GP asks you about your symptoms and checks for any swollen (enlarged) **lymph nodes**. This alone can't tell them whether or not you have lymphoma – you'll need to have tests and scans to find out more. Usually, you have simple blood tests (see page 31).

You'll be referred to a hospital specialist and seen quickly if your GP thinks there is a possibility that you might have lymphoma.

Once you are referred to a hospital specialist, you're likely to need further tests and scans. It's very important that the health professionals within your medical team get all the information they need about your lymphoma so that they can plan the most suitable treatment for you.

We outline some of the most common tests and scans for lymphoma in this section. You might not need all of them, but you will need a biopsy (page 33) to confirm a diagnosis of lymphoma.

In this section, we cover:

- blood tests (page 31)
- lymph node biopsy (page 33)
- scans and X-rays (page 36)
- bone marrow biopsy (page 41).

You have most of these tests as an outpatient, which means that you don't have to stay in hospital overnight.



For more information about any of the tests and scans outlined in this section, visit lymphoma-action.org.uk/Tests

Blood tests

Most people have blood tests as part of their diagnosis for lymphoma, and then throughout treatment. You continue to have blood tests, though less frequently, after treatment as part of your follow-up (see page 103).

Blood tests can help doctors see how the lymphoma is affecting your body, and to plan the best treatment for you.

Blood tests can also help to check:

- **Your general health.** For example, a 'full blood count' measures your levels of different types of cells: **red blood cells**, **white blood cells** and **platelets**. Lymphoma and its treatment can lower your levels of these cells. This can cause problems that might need treatment. You might also need to take some extra health and safety precautions. If your blood counts are low, your doctors might advise waiting until they are higher before it is safe for you to have treatment.
- **For signs of swelling (inflammation).** This can be a sign of infection and might need treatment.
- **How well your kidneys, liver and thyroid gland are working.** Sometimes, lymphoma and its treatment can affect the functioning of these organs.
- **Your recovery from treatment.** This can include checking for any signs of late effects (health problems that develop months or years after treatment – page 109).
- **For any signs that your lymphoma might be coming back (relapsing).** Your medical team will talk to you about this if they see any.



Search 'blood tests' on our website for more information about having a blood test and when you might need one.

Lymph node biopsy

Most people need a lymph node biopsy to confirm whether or not they have lymphoma.

A lymph node biopsy is a minor operation. It uses a needle to take a sample of cells from a swollen lymph node for examination in a laboratory.

The type of biopsy you have depends on where the swollen lymph node is and how close it is to the surface of your body.

You might have:

- an **excision biopsy**, which removes a whole lymph node
- an **incisional biopsy**, which removes a very small part of a lymph node
- a **core needle biopsy**, which takes a small sample of a lymph node; this type of biopsy is also known as a 'core biopsy' or a 'needle biopsy'
- a **laparoscopic (keyhole) biopsy**, which removes all or part of a lymph node.

In most cases, you'll be given a local anaesthetic so that you do not feel the needle going in. However, laparoscopic biopsy is done under general anaesthetic. In some cases, you might be offered pain relief and a sedative to help you to relax.

“ I called my GP who had a look and referred me to the ENT (ear, nose and throat) department at my local hospital for a biopsy. Two weeks later I was diagnosed with Hodgkin lymphoma.

Lyle, diagnosed with Hodgkin lymphoma



Speak to a member of your medical team in advance of the day of having your biopsy if you feel worried about the procedure.

After your biopsy

Your wound is covered with a protective dressing.

Before you leave the hospital, you should be given clear guidance about how to care for the biopsied area. This is to help prevent infection and to stop the dressing from coming loose.

You can usually go home on the same day as having a biopsy, but check with your doctor in advance. You shouldn't drive yourself home if you have had a sedative or a general anaesthetic. You might be able to drive yourself home if you've had a local anaesthetic.

The general advice is for someone to collect you and drive you home after a biopsy. Speak to a member of your medical team for help organising transport if this is difficult for you to arrange.

It is important to contact your medical team straightaway if you have any problems with the wound or notice any signs of infection. This includes bleeding, swelling, discharge from the biopsied area, fever (a temperature above 38°C/100.4°F), chills and sweating.

Ask your doctor how long it will be before you get the results of your biopsy. Sometimes results come through within a few days. Other times, they take around a week or more.

You can listen to our podcast where Consultant Haematopathologist, Dr Bridget Wilkins, answers some of the most commonly asked questions about biopsies and diagnosis of lymphoma. You can hear it on our website, on Apple podcasts or on Spotify. Search 'pathology podcast' at lymphoma-action.org.uk



Scans and X-rays

Different types of scans are helpful for different things.

They might be used to:

- diagnose and **stage** lymphoma
- guide doctors as to the best place to take a **biopsy** sample from
- plan your treatment
- check your response to treatment
- check for any signs of relapse.

Usually, you have a scan at your local hospital as an outpatient. If your local hospital doesn't have the right scanning machine for you, you might have to travel to a hospital that's further away. Sometimes, it's possible to have a scan at a mobile unit.

PET/CT scans

Computed tomography (CT) scans and positron-emission tomography (PET) scans are among the most common scans doctors use for people affected by lymphoma.

Usually, they're done in the same appointment, as a '**PET/CT scan**'. A PET/CT scan can help give a clear picture of which areas of your body are affected by lymphoma.

CT uses lots of X-rays to take pictures through your body. They're better than regular X-rays at taking pictures of the organs inside your body, including lymph nodes.

PET uses a harmless radioactive sugar to look at the level of activity of cells in your body. Cells that are more active, such as lymphoma cells, take up more sugar than less active cells. A special camera detects the radioactivity and these show up as 'hot spots' on the scan image.



CT scanner

Preparing for a PET/CT scan

You will be given advice, usually from the radiology department, to help to prepare you for your scan.

This might include being:

- asked not to eat or drink (known as 'fasting') for a few hours before you have your scan
- given a special dye (**contrast agent**) as a drink or an injection before your scan – this helps to show up certain parts of your body more clearly on the scan image

- given guidance about if and when to take any medication you usually take – for example, for medicine for diabetes
- advised not to do strenuous physical activity in the 24 hours before your scan.

Staff will ask you to remove any metal you're wearing and whether you could be pregnant.



Find out more about PET/CT scans on our website, including answers to frequently asked questions. Search 'PET/CT' at lymphoma-action.org.uk

Some scans use very low levels of radiation. You will not be radioactive after a CT scan alone. However, with a PET/CT scan, you give off very low levels of radiation for around 6 hours afterwards. As a precaution, you should avoid being close to women who are pregnant during this time. It should be safe to be around adult pets, as long as they are not pregnant.

Scans aren't painful, but you might find it uncomfortable if you have to lie still for a long time. Speak to a member of your medical team if you feel anxious about this or about any aspect of having a scan. You might find it helps to talk through what to expect. In some cases, you might be offered a sedative – but talk to them about this in advance of the day, to see whether it's suitable for you and to give them time to arrange it.

Ultrasound scans

Ultrasound scans use high-energy soundwaves to take pictures of the inside of your body. These soundwaves bounce off tissues and organs inside your body, making echoes. The echoes are recorded and can be used to help build up a picture of the inside of your body.

You might have an ultrasound scan to:

- examine lymph nodes that are near the surface of your skin
- help your doctor find the best place to take a **biopsy**.

You'll be given information about how to prepare for your ultrasound scan. This will include whether to have a full or an empty bladder for the scan. You might also be asked not to eat anything for a few hours beforehand.

Ultrasound scans are quick and painless, and you can go straight home afterwards.

X-rays

X-rays use high-energy waves, similar to radio waves. These take pictures through your body and build an image on a computer screen.

You might have an X-ray to check:

- for swollen lymph nodes inside your chest
- the position of a central line (central venous catheter) if you need one for chemotherapy (page 63)
- your risk of fracture if the lymphoma has weakened your bones.

In some cases, you have a contrast agent. 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 contrast agents used in CT and PET/CT scans
- pregnant, to avoid radiation.

You'll need to take off any metal that you're wearing before your scan.

For the scan, you lie on a bed that moves into a tube, and you have to lie very still for up to an hour. The MRI machine is very noisy – you should be offered earplugs and might be able to listen to music.

Tell your medical team if you:

- have any metal in your body, including a pacemaker, hip replacement, implantable defibrillators, ear (cochlear) implants, staples from surgery and metal clips and plates put in after an injury. Your doctors will find out more about the type of metals in your body and decide on whether it's safe for you to have an MRI scan.
- feel worried about being in an enclosed space (claustrophobic) so that they can help you to manage this. In some cases, you might be offered an anti-anxiety drug before the scan.

Bone marrow biopsy

Bone marrow is the spongy tissue in the middle of your larger bones. It is where blood cells are made.

A bone marrow biopsy checks whether you have lymphoma in your bone marrow. You might also hear it called a 'trephine biopsy', named after the type of needle used to take the sample.

Very often, a PET/CT scan (page 36) is effective in checking for lymphoma in your bone marrow. However, some types of lymphoma can be difficult to see from these types of scans. In this case, you might have a bone marrow biopsy, although this is not often needed.

A bone marrow biopsy sample is usually taken from your hip bone (pelvis).

- You have a local anaesthetic to numb the area where the biopsy is being taken.
- The doctor inserts a biopsy needle into the middle of the bone – either by hand or with a small electronic device that they use to collect a sample.
- The doctor removes the needle and puts a dressing over the area.
- The whole procedure usually takes 10 to 15 minutes.

A bone marrow biopsy is a safe procedure. However, you should contact your medical team if you develop any of the following:

- fever (temperature above 38°C/100.4°F)
- pain where the sample was taken that gets worse or that lasts more than a few days
- redness or swelling where the needle went into your skin
- bleeding that doesn't stop when you put pressure on it.

These could be signs of infection or a complication that needs prompt medical attention.

Test results

Your medical team gather as much information as possible from your tests and scans. You then have a face-to-face appointment to discuss the results of the tests. You can ask to take a family member or a friend to be with you if you would like to.

You can ask your doctor for an idea of how long you'll need to wait for your results. If you are finding it hard to cope with waiting for your test results, call our Helpline freephone.

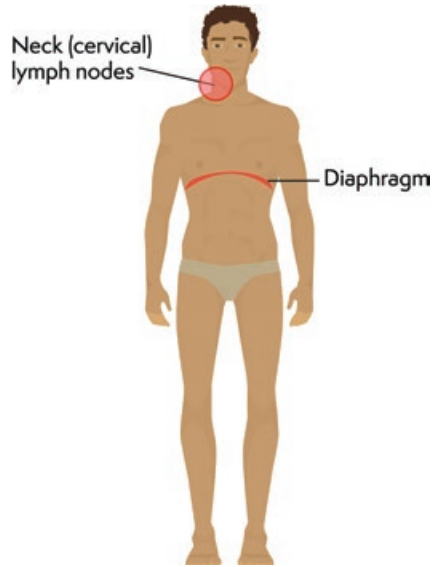
We have tips on coping with waiting for test results and a video where Lucy Whiteman, Lymphoma Clinical Nurse Specialist explains why they can take a while. Visit lymphoma-action.org.uk/Waiting



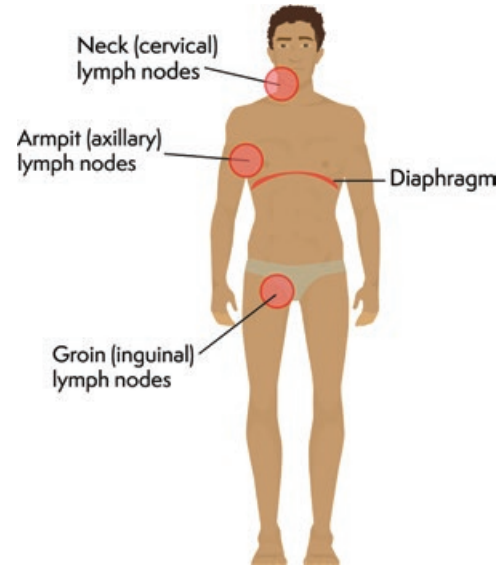
Staging of Hodgkin lymphoma

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

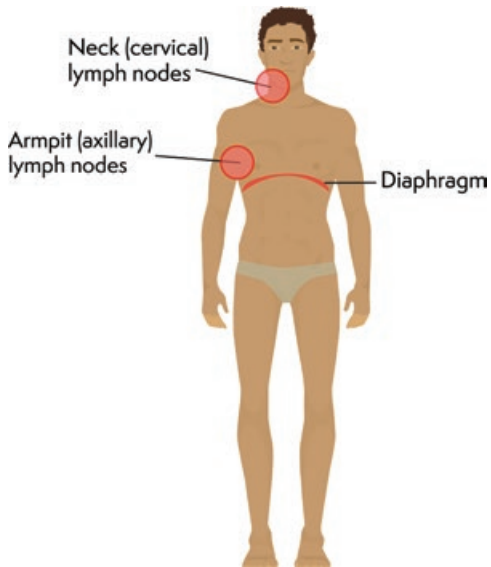
There are four main stages of lymphoma. These are sometimes written in Roman numerals (I, II, III and IV).



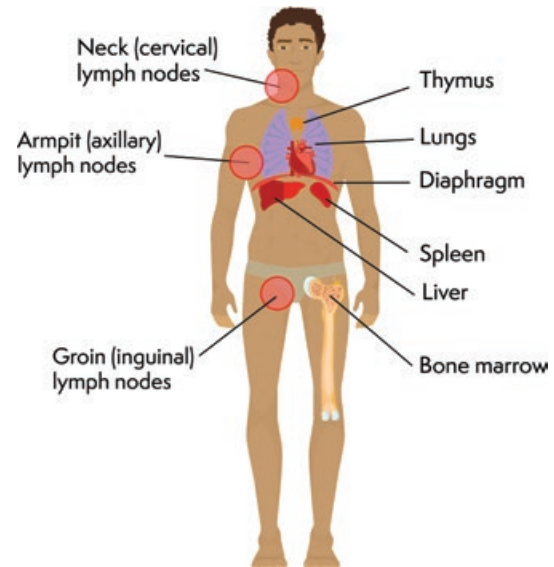
Stage 1
Lymphoma is in only one group of lymph nodes (gland). This could be anywhere in your body.



Stage 3
Lymphoma is in lymph nodes on both sides of your diaphragm.*



Stage 2
Lymphoma is in two or more groups of lymph nodes. These could be anywhere in your body, but all on the same side of your diaphragm.*



Stage 4
Lymphoma has spread from the lymph nodes to an organ outside of the lymphatic system (for example, to the liver, lungs, bone marrow or solid bones)

* The muscle separating your chest from your tummy

You might also have letters after your stage. For example, you might be stage 2A, or stage 3E.

- A** You don't have any B symptoms.
- B** You have one or more **B symptoms** (weight loss, night sweats or fevers).
- E** Extranodal lymphoma means that the lymphoma started outside the lymphatic system.
- S** Lymphoma is in the spleen (part of the lymphatic system).
- X** One or more of your affected lymph nodes is considered to be large or 'bulky'.

Early stage and advanced stage lymphoma

Your doctors might talk about 'early' stage or 'advanced' stage lymphoma.

- 'Early' stage means either stage 1 or stage 2 lymphoma.
- 'Advanced' stage generally means either stage 3 or stage 4 lymphoma.

Your lymphatic system runs throughout your body, so, quite often, Hodgkin lymphoma is advanced when it is diagnosed.

Unlike many other cancers, advanced stage lymphoma can be successfully treated.

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.
- Speak to a member of your medical team if you have questions about any tests you're having, or if you feel worried about having them.
- Your medical team can give you an idea of how long it will be before your test results are available.
- If you would like to, you can take someone with you to your appointment when you get the results of your tests.



Treatment for Hodgkin lymphoma

Treatment aims	50
Your medical team	50
Treatment options	54
Treatment to help with symptoms and side effects	78
If Hodgkin lymphoma comes back or doesn't respond to treatment	81
Side effects of treatment	86
Low blood counts and risk of infection	90

“ *I felt anxious in the weeks leading up to my treatment. My experience was, however, a positive one. On the day of first treatment I was walking into the complete uncertainty of it all. The minute I walked in I felt at peace and I was warmly welcomed.*

Claire, diagnosed with Hodgkin lymphoma

Treatment aims

Usually, Hodgkin lymphoma is treated with the aim of getting rid of all of it so that you go into complete **remission**. This means that there is no evidence of the lymphoma on tests and scans.

Most people treated for Hodgkin lymphoma go into complete remission and do not need any further treatment.

Your medical team

Your treatment is planned by a multidisciplinary team (MDT) made up of different professionals, sometimes from more than one hospital. They each have knowledge and expertise in different specialist areas. This helps to offer you the best care, based on your individual needs. The team meets to discuss and plan your treatment, taking into account your individual needs, general health and preferences. Their decisions are also guided by national treatment guidelines.

The person who has overall responsibility for your care is a doctor who specialises in treating people who have cancer. This is a consultant oncologist or haematologist.

Your key worker

You should have a key worker who you can contact with any questions or concerns you might have about your lymphoma or treatment, including how it affects your day-to-day life.

Usually, your key worker is your lymphoma or haematology clinical nurse specialist (CNS).

You should be given the name and contact details of your key worker – if you're not given this information, ask your lymphoma consultant for it.

Your key worker is often the member of your MDT who helps you to identify and manage any issues that arise from living with lymphoma. This includes any needs that are practical, financial, physical, emotional and social. To help with this, they sometimes use a questionnaire. You might hear this referred to as a Holistic Needs Assessment or 'HNA'.

Children and young people aged up to 25 years

Children and young people with Hodgkin lymphoma are often treated in a specialist children's cancer centre called a Principal Treatment Centre (PTC). There are 21 PTCs across the UK, so your nearest might be some distance from your home.

Some young people (under the age of 25) might be offered a type of radiotherapy called proton beam therapy (PBT). This is available at some UK centres and in other countries.

You can find out more about proton beam therapy on the NHS website. Search 'PBT' on www.england.nhs.uk

It might be possible to have some treatment at a hospital closer to home through a children's community nursing team. Having some appointments at the PTC and some at a local hospital is known as 'joint care' or 'shared care'.

Children and young people aged 16 to 25 have an additional teenage and young adult multi-disciplinary team (TYA MDT). This team consists of health and social care professionals who specialise in treating young people with cancer. It can also include professionals such as play specialists, who help children understand more about their diagnosis, and youth support workers, who organise fun and relaxing activities on the hospital ward.



Find out more about lymphoma in children and young people on our website.

You can download or order a copy of our *Young person's guide to lymphoma* at lymphoma-action.org.uk/books

How does my medical team work out the best treatment for me?

Your medical team meet regularly to discuss the most suitable treatment for you. Sometimes, people with the same type of Hodgkin lymphoma have different treatments. This is because your treatment is planned according to your individual needs.

When planning your treatment, your MDT take into account:

- which type of lymphoma you have (page 14)
- the stage of your lymphoma (page 43)
- your age
- the symptoms you are experiencing
- any other health conditions you have
- your general physical fitness
- the possible side effects of treatment (page 86)
- the possible long-term or late effects of treatment (page 109)
- your feelings and preferences about treatment options
- any other factors that might be important to you in the future, such as having a family.

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

Once you start your treatment, you might have a PET/CT scan (page 36) to check how well you are responding to it. Your consultant uses the results of the scan to guide them in planning the rest of your treatment.

Treatment options for Hodgkin lymphoma

Your medical team plan your treatment specifically for you. They take lots of factors into account to give you the best possible care.

In this section, we outline some of the common treatments for Hodgkin lymphoma. It's unlikely that you will have **all** of these, so you might just want to read the sections that are relevant to you.

- Chemotherapy – page 60.
- Radiotherapy – page 69.
- Antibody therapy treatment – page 73.
- Active monitoring (watch and wait) – page 76.
- Research and clinical trials – page 77.

If you have NLPHL that affects only one group of lymph nodes, you might have surgery to remove them. Radiotherapy is sometimes given afterwards.

“ 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. I started to lose my eyebrows and leg hair but was glad that my hair and beard didn't fall out completely. I returned to work 10 days after my last treatment.

Adam, diagnosed with NLPHL



“ I was put on a six-month course of chemotherapy, given fortnightly. I had very few side effects. But after a couple of months I began to feel unwell again and was very short of breath. It was decided that the bleomycin in the treatment was probably the cause, so it was removed. I got my breath back and finished treatment. I was told that I had responded well to treatment and felt that the worst could be behind me.

John, diagnosed with classical Hodgkin lymphoma



Classical Hodgkin lymphoma

Your medical team should discuss your individual treatment plan with you. It is tailored to your specific needs.

The diagram below gives an overview of the treatment you might have.

Early stage (1 or 2) classical Hodgkin lymphoma

No unfavourable prognostic factors*

Treatment with:

- **ABVD**, with or without radiotherapy, partly depending on the results of a PET scan.

Unfavourable prognostic factors*

Common treatments are:

- **ABVD** with or without radiotherapy or
- **ABVD** (then possibly AVD depending on the results of PET scan) or
- fewer cycles of a stronger chemotherapy regimen such as escalated **BEACOPDac** or escalated **BEACOPP** and **ABVD**, with or without radiotherapy afterwards.

You normally have a PET/CT scan (see page 36) after 2 cycles of treatment. If there is no evidence of active lymphoma, the drug bleomycin might be left out of the rest of your chemotherapy. If there is evidence of active lymphoma, stronger chemotherapy or radiotherapy might be recommended.

See page 60 for more about chemotherapy and page 69 for more about radiotherapy.

*Prognostic factors. See page 60 for more information about prognostic factors.

Advanced stage (3 or 4) classical Hodgkin lymphoma

Chemotherapy, often with more cycles of treatment than someone with early stage classical Hodgkin lymphoma.

Common treatments are:

- **ABVD** (then possibly **ABV**, depending on the results of a PET scan) or
- escalated **BEACOPDac** or escalated **BEACOPP**.

You have a PET/CT scan after your first few treatment cycles. Depending on the results of your scan, your doctor might tweak your treatment plan, for example, which drug/s you have and the number of treatment cycles.

You might have radiotherapy if there are lumps of lymphoma left after chemotherapy; however, this is uncommon.

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

Your medical team should discuss your individual treatment plan with you. It is tailored to your specific needs.

The diagram below gives an overview of the type of treatment you might have. Some centres might offer treatment more commonly given for classical Hodgkin lymphoma.

Early stage (1 or 2) NLPHL

For lymphoma in **one or two groups of lymph nodes** and no B symptoms.

Treatment might involve:

- **Surgery** to remove affected nodes followed by **active monitoring** (watch and wait) if the affected lymph nodes are completely removed.
- **Radiotherapy** if there is lymphoma left after surgery or
- **Chemotherapy** combined with the antibody treatment **rituximab**.

You might have a longer duration of, or possibly stronger chemotherapy that is usually given for advanced stage NLPHL if:

- the lymphoma is in more than two groups of lymph nodes **or**
- you have B symptoms (which is rare in NLPHL).

“ My consultant explained I will start R-CHOP chemotherapy straight away, although with this cancer there could have been a period of active monitoring. He also explained that radiotherapy could have been an option.

Surinder, diagnosed with NLPHL

Advanced stage (3 or 4) NLPHL

For stage 3, options might include:

- **Active monitoring** (watch and wait) if your lymphoma isn't causing symptoms that affect your day-to-day life.
- **Chemotherapy** with the antibody treatment **rituximab**.
- **Rituximab** alone, if you are too unwell for chemotherapy.

For stage 4, options might include:

- **Chemotherapy** with the antibody treatment **rituximab** usually R-CHOP (see page 75) or R-ABVD.

Prognostic factors

If you have classical Hodgkin lymphoma, your medical team considers prognostic factors. Prognostic factors influence treatment outcomes. They help guide your doctors as to how likely you are to recover from lymphoma, and how likely it is to come back (relapse).

The prognostic factors your MDT consider when planning your treatment are your age and whether you have:

- very enlarged lymph nodes in your chest, or enlarged lymph nodes in several areas of your body
- B symptoms (page 25)
- high levels of inflammation, as shown by blood tests
- extranodal lymphoma (page 26).

Chemotherapy

Chemotherapy is treatment with drugs. It works in one or two of the following ways:

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

Lymphoma cells are very sensitive to the effects of chemotherapy, which is why it is often the most suitable treatment.

Chemotherapy has little effect on cells that are not dividing, which is why it is given in **cycles** (see page 62).

Unfortunately, chemotherapy also affects some of your healthy cells, particularly the ones that divide rapidly. This includes blood cells, hair follicles and skin cells, and it's often the cause of some of the common side effects of chemotherapy (see page 86).



Watch our short animation explaining how chemotherapy works. Search 'chemotherapy animation' on our website.

Before chemotherapy

You usually have blood tests when you arrive at the hospital. This is to check that your **blood counts** (page 90) are at a level that is considered to be safe for you to have treatment.

If your blood counts are low, your medical team might advise waiting for a little while (sometimes just a few days) before having treatment, until they are higher. You might also be given treatment to help boost your blood cell counts (pages 79 and 80). You might also stay in hospital during your treatment, so that staff can keep a closer check on your health.

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 can go home afterwards.

Chemotherapy cycles

You usually have chemotherapy as a number of treatments or 'cycles'. After each cycle of treatment, you have a rest period, to allow your body to recover. During each cycle, you might have to go to hospital once, or on a number of days. This depends on the exact chemotherapy you have.

Chemotherapy is given in cycles because the drugs work on cells that are in the process of dividing – they don't have much effect on cells that are not dividing. Having your chemotherapy in a number of treatments at different times increases the chances of it affecting dividing lymphoma cells.

In between your treatment days, you usually have lots of medicines to take at home. Some of these might be part of your chemotherapy treatment plan (**regimen**). Others are to help control any side effects of treatment (page 86).

Intravenous (IV) chemotherapy

Most chemotherapy is given intravenously (as a drip or injection into a vein).

Your nurse can inject some chemotherapy drugs over a minute or two. Other 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 have.

Tell your nurse if you feel any discomfort when you are having IV chemotherapy. They can check that the drugs are going in properly and make any adjustments they need to.

IV drugs are given through a cannula or a central venous catheter.

Cannula

A cannula is a small, soft plastic tube that usually goes into a vein in your arm. You have a new one put in each time you go for treatment.

Central venous catheter ('line')

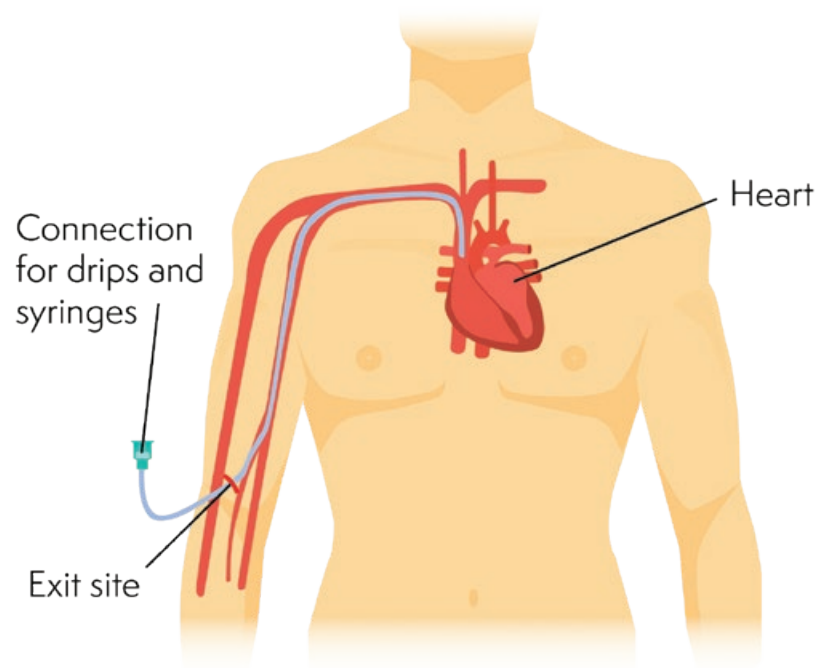
A central venous catheter (or 'central line') is a longer plastic tube that goes into a larger vein near your heart. A central line usually stays in for the whole of your treatment.

A line can also be used to:

- give you drugs and other fluids
- take blood samples for blood tests more easily
- save you the discomfort of repeated needle pricks.

There are different types of line:

- **PICC line** (peripherally inserted central catheter), which goes in through a vein in your arm, above the bend of your elbow. It is held securely in place by a dressing.
- **Tunnelled central line**, which is usually positioned on your upper chest. Part of it runs in a 'tunnel' under your skin.
- **Totally implantable line**, a thin, soft tube that runs under the skin before going into a vein in your chest. It can be used to deliver long-term chemotherapy while lowering the risk of infection.



Person with a PICC line fitted

Lines are put in during a small operation done under local or general **anaesthetic**. Once it's in place, a line isn't usually painful. However, if you feel any discomfort, tell a member of your medical team.

Once it's fitted, your line is covered with a simple dressing to protect it. You will be given instructions on how to care for it once you go home. This includes how to take baths and showers while it is in place.

Lines can sometimes become infected. Occasionally, a blood clot can develop around them. Contact your hospital immediately if you develop any symptoms of infection, including:

- redness or heat around the area (site) of the line
- a high temperature (above 38°C/100.4°F)
- swelling in your arm.

Oral chemotherapy

You might have some or all of your chemotherapy by mouth (orally) as a tablet or capsule. You should be given guidance about how to store and take any chemotherapy drugs that you're given to take at home. If you are not told how to do this, ask your clinical nurse specialist or another member of your medical team.

Unless you've been told to by a member of your medical team, do not crush or open the tablets or capsules.

It is important that other people don't handle your chemotherapy drugs. If you are helping someone to take chemotherapy, wear protective gloves when handling the drugs.

Your chemotherapy treatment plan

Chemotherapy drugs for lymphoma are usually given as a regimen – a treatment plan that includes more than one type of drug. You have these drugs all at once so that the different drugs can work on different phases of the cell cycle. Having them together helps to kill as many lymphoma cells as possible.



Find out more about chemotherapy, including answers to commonly asked questions, on our website. Search 'chemotherapy' at lymphoma-action.org.uk

Common chemotherapy regimens for Hodgkin lymphoma

Your treatment is planned specifically for you. However, the most common chemotherapy **regimens** used to treat Hodgkin lymphoma are ABVD and BEACOPDac.

ABVD

The regimen ABVD is made up of doxorubicin (**Adriamycin®**), **bleomycin**, **vinblastine** and **dacarbazine**. It is usually given in 4-week cycles where you have treatment every 2 weeks, followed by a 2 week rest period. Bleomycin is given by injection into a muscle (intramuscularly) or by drip (infusion) into a vein (intravenously). The other drugs are given intravenously (page 62).

BEACOPDac

Usually, you have it as an 'escalated' regimen, known as escalated BEACOPDac or escBEACOPDac. The drugs are given at higher doses than in standard BEACOPDac.

BEACOPDac is made up of **bleomycin**, **etoposide**, doxorubicin (**Adriamycin®**), **cyclophosphamide**, **vincristine** (sometimes known as **Oncovin®**) **prednisolone** (a steroid) and **dacarbazine**. You have all these drugs every 3 weeks. You have most of these drugs through a drip into a vein. However, you take prednisolone by mouth (orally), as capsules or tablets.

Escalated BEACOPDac is more effective than ABVD at sending Hodgkin lymphoma into complete remission. However, it is more likely to have both short-term and long-term side effects. Your medical team should discuss these with you before you start treatment.

If you have advanced stage NLPHL that needs treatment, you might be offered a chemotherapy regimen together with antibody therapy (page 59).

If you are over 60 years old

Your medical team might offer you treatment that avoids chemotherapy drugs that are more likely to cause serious side effects if you are over 60. For example, they might recommend a regimen such as:

- **ChlVPP**, which is **chl**lorambucil, **vin**blastine, **pro**carbazine and the steroid **pred**nisolone. You have vinblastine through a drip into a vein. You have the other drugs as tablets or capsules that you take by mouth. Each treatment cycle is 28 days.
- **AVD**, which is ABVD without bleomycin. It is made up of doxorubicin (**Adriamycin**®), vinblastine and dacarbazine. Each treatment cycle is 28 days and is given through a drip into a vein.



Search 'chemotherapy drugs' at macmillan.org.uk to find out more about particular chemotherapy drugs or regimens.

Safety precautions while you are on chemotherapy

Your medical team will give you guidance about any safety precautions you should take while you are having chemotherapy.

- **Infection:** Take steps to lower your risk of infection. Be aware of the possible signs and symptoms of infection and who to contact if you notice any (page 91).

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

Talk to your medical team if you want to have a baby. People who have had lymphoma are usually advised to wait for up to 2 years after finishing treatment before trying to start a family.

Radiotherapy

Radiotherapy uses high-energy X-rays (a type of radiation) to destroy cancer cells. It stops them from dividing, so that they die off in time. Lymphoma cells are very sensitive to radiotherapy.

The radiation is directed to precise areas of your body. This targets as many lymphoma cells as possible, while causing as little damage as possible to surrounding healthy cells.

Radiotherapy is a 'local' treatment, which means that it affects only the parts of your body being treated. It is therefore usually used to treat lymphoma that is only in one or two places in your body.

Having radiotherapy

You'll need to go to hospital for your radiotherapy treatment to be planned, and each time you have it. Not all hospitals have a radiotherapy department, so you might need to travel a bit further to one that does.

Many people who have radiotherapy have it with the aim of getting rid of the lymphoma – this is known as 'curative radiotherapy'. Sometimes, radiotherapy is given to help shrink the lymphoma. This can help control symptoms such as pain and is known as 'palliative radiotherapy'.

Planning your radiotherapy

Your treatment is carefully planned by a radiotherapy team, led by a clinical oncologist. Very often, they use a **computed tomography (CT) simulator scan** to help them work out:

- **the total dose of radiotherapy** to give you
- **how many separate treatments** (fractions) you should have
- **exactly where the lymphoma is**, so that they can direct radiotherapy to precisely this area.

Your radiotherapy team only give radiation that is known to be within safe limits. They also plan your treatment to avoid damaging critical structures such as your brain, heart and salivary glands.

To help make sure that radiotherapy goes to exactly the same place each time you have treatment, you might have some tiny permanent dot-like marks made to your skin, using a needle and ink. These are lined-up with the X-ray beams on the radiotherapy treatment machine to help make sure that the radiotherapy goes to exactly the right place.

If you are having radiotherapy to your head, neck, armpit or chest, you might instead have a plastic radiotherapy mask (sometimes called a 'shell') to wear each time you have treatment so that the radiotherapy goes to exactly the right place.



“ *I had to have a head and neck 'shell' or 'mask' made to ensure I received radiotherapy to exactly the same position each time. A mesh-like material was placed in warm water and then placed over my head, neck and shoulders – I could just about see through it. It was then massaged into me like quick-setting plaster. It's semi-hard (pliable but retains its shape) and felt tight, but I could breathe easily. I found the best way to cope was to think about totally different things.*

Julian, who had radiotherapy for lymphoma

Each radiotherapy session takes around 10 to 20 minutes. Most of this time is spent getting you into position – the radiotherapy treatment itself takes only a few minutes. Having radiotherapy 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.

Radiotherapy treatment does not make you radioactive. People around you, including children, are not at any risk from being near to you after you've had treatment.

Typically, you have radiotherapy treatment Monday to Friday for 2 to 3 weeks. However, your schedule might differ from this as your treatment plan is designed specifically for you.

It can be helpful to take someone with you to the hospital for emotional support. They'll need to wait outside the treatment room to avoid unnecessary radiation.



Read more about radiotherapy for lymphoma, including answers to frequently asked questions, on our website. Search 'radiotherapy' at lymphoma-action.org.uk

Targeted treatments

Targeted treatments attack particular **proteins** on lymphoma cells. The proteins are much more common in lymphoma cells than in healthy cells. They are often important in helping the cancer cells grow and survive.

There are lots of different types of targeted treatment and they each attack particular proteins. We outline some of the common antibody therapy treatments for Hodgkin lymphoma on the following pages.



Search 'targeted treatments' on our website to find out more about specific targeted treatments for people with lymphoma.

Antibody therapy

Antibody therapy is a type of targeted treatment.

Your **lymphocytes** make antibodies. The antibodies recognise and stick to particular proteins on the surface of cells that don't belong in your body (foreign cells), such as viruses or bacteria. They then either kill the foreign cell or help your **immune system** find and destroy it.

With antibody therapy, antibodies are made in a laboratory.

You might have antibody therapy on its own, or alongside chemotherapy. This is called 'chemoimmunotherapy' (or CIT).

Antibody therapy works through your immune system. This is why it is also known as 'immunotherapy'.

Rituximab

Rituximab is a type of antibody therapy that targets a protein called CD20.

NLPHL cells make CD20, which is why rituximab can be used to treat NLPHL. You usually have rituximab with chemotherapy but some people have it on its own.

Having rituximab

Most people have rituximab as an outpatient and go home afterwards.

Before you have rituximab, you have pre-medication to help prevent any reactions to the drug. You are likely to be given:

- paracetamol tablets
- antihistamines, taken by mouth (orally) or given intravenously (IV), by a drip into a vein
- steroids, taken orally or by IV.

You have rituximab intravenously or as an injection just underneath your skin (subcutaneously).

Your first dose is given very slowly, so that your medical team can check for any reactions – these are more common the first time you have rituximab.

Side effects of rituximab vary from person to person. They can include shivers, fevers and flu-like symptoms. If you experience any side effects, speak to a member of your medical team. They can give you advice on how to manage them.

Chemotherapy with antibody therapy for advanced stage NLPHL

If you have advanced stage NLPHL that needs treatment, you might be offered one of the following regimens. Chemotherapy drugs are given **together** with the antibody therapy rituximab.

In the following regimens, R stands for rituximab:

- **R-ABVD**, which is doxorubicin (**Adriamycin**®), bleomycin, vinblastine and dacarbazine
- **R-CHOP**, which is cyclophosphamide, doxorubicin (or hydroxydaunorubicin®), vincristine (**Oncovin**®) and the steroid prednisolone
- **R-CVP**, which is cyclophosphamide, vincristine and prednisolone.

You'll find an overview of common treatments on pages 56 and 57 (classical Hodgkin lymphoma) and pages 58 to 59 (NLPHL).

Macmillan Cancer Support has an online tool where you can search for a chemotherapy regimen and find out more about it. Search 'treatment and drugs' on macmillan.org.uk

Active monitoring for NLPHL

Lymphoma doesn't always need treatment straightaway. Instead, your medical team might recommend that you have regular check-ups to keep checks on your health and to see how the lymphoma is affecting you. This approach is called 'active monitoring' or 'active surveillance'. You might also hear it called 'watch and wait'.

You then have treatment if your lymphoma begins to cause significant health problems. Some of the advantages of this approach can include avoiding side effects from treatment for as long as possible, and only needing to go into hospital for outpatient check-ups.

Treatment for Hodgkin lymphoma is just as effective if it is kept until it is needed.

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

We have a book called *Active monitoring (watch and wait) for lymphoma*. You can download or order a free copy. Visit lymphoma-action.org.uk/books

Research and clinical trials

Clinical trials are medical research studies involving people. They often test new treatments, or new ways of giving them (for example, together with another treatment). They can also be used to find out about other aspects of a disease, such as how it develops, the best way to diagnose it, or how it affects quality of life.

Your doctor might ask you if you would like to take part in a clinical trial – it's completely up to you whether you do or not. If your doctor doesn't offer you a trial but you think you might be interested in taking part in one, ask them if there's one that might be suitable for you.

“ Jo was offered two chemotherapies: the standard ABVD chemotherapy, or a clinical trial. It was a difficult decision, and Jo decided he wanted to do the clinical trial in the hope that he might be able to help others in the future.



Nichola, whose son Jo was diagnosed with Hodgkin lymphoma



Search 'clinical trials' at lymphoma-action.org.uk for more information.

Treatments to help with symptoms and side effects

Some of your medicines might not be given to treat your lymphoma but to help improve your overall health and wellbeing. For example, you might be offered anti-sickness drugs (antiemetics), painkillers or antibiotics. Some people have low-dose chemotherapy to help control some of the symptoms of lymphoma.

Steroids

Steroids are chemical messengers (hormones) that are made naturally in your body. If you have steroids as medication, the drugs copy the effects of these hormones. They are used to treat some types of lymphoma and to help control sickness (nausea and vomiting). The type of steroids most commonly used in the treatment of lymphoma are corticosteroids.

Side effects of steroids are usually short-term and improve once you stop taking them. They can include: muscle aches and weakness, increased risk of infection, fluid retention, changes in metabolism, increased appetite, difficulty sleeping, and changes in mood.

Take any steroid medication you're given exactly as prescribed. Don't stop taking steroids suddenly, as withdrawal symptoms can be severe. Your medical team can help you to stop taking steroids gradually.

Depending on your type of steroid medication and how long you are taking it for, you might be given one or both types of a card:

- **Steroid treatment card**, which reminds you that you should not stop taking steroids suddenly, and what to do if you become unwell. It also tells health professionals the details of the steroids prescribed to you.
- **Steroid emergency card**, to help spot the signs of a serious condition called 'adrenal crisis'. This is where you have a lack of the hormone cortisol in your body.

If you are given either or both of these cards, carry them with you for all the time you are on steroids and for some time after completing treatment with them. This is usually 12 months, but your medical team will advise you based on your individual circumstances.

Growth factors

Growth factors are chemical messengers (hormones) that encourage cells to divide and develop.

Your body makes growth factors naturally. Growth factors can also be made in a laboratory and are sometimes used to boost your blood cell counts (page 90) if they drop to low levels 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 (subcutaneous injection). This is usually into your tummy, the top of your leg or the top of your arm.

You (or a friend or family member) can be taught how to give the injections so that you can have them at home. Other options can include having a community nurse visit you to give you the injections at home. Sometimes, it's possible to have them at your GP surgery.

“ After treatment I developed a high temperature. My mum noticed I was looking red and I had no energy. We realised that this was a red flag moment and that I needed to get straight to hospital. I had developed neutropenic sepsis and needed to be treated with antibiotics and G-CSF injections to help my neutrophil count recover faster. I was in hospital for a week and my next chemotherapy was delayed until I was well enough to have it.

Adam, diagnosed with NLPHL



The injections might sting a bit and cause side effects such as flu-like symptoms, back and pelvic pain, aches or headaches.

Seek advice from your medical team about how to cope with any side effects you experience – mild painkillers such as paracetamol often help, but check first that it's safe for you to take these.

Contact your doctor urgently if you develop an itchy rash, swelling of your face, lips, tongue or throat, difficulty breathing or feeling faint after the injections. These side effects are uncommon.

If Hodgkin lymphoma comes back (relapses) or doesn't respond to treatment (refractory)

For most people, Hodgkin lymphoma goes into complete remission and needs no further treatment.

In a small number of people, Hodgkin lymphoma does not respond to treatment (**refractory lymphoma**) or comes back after treatment (**relapsed lymphoma**).

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

If your lymphoma relapses or is refractory, your treatment options depend on a number of factors:

- the type of treatments you've already had
- how your lymphoma responded to treatment and how treatment affected you
- how soon after treatment the lymphoma came back
- your age
- your general health and fitness.

If your lymphoma relapses or is refractory, your medical team will plan the most appropriate treatment for you. We outline some of the treatment options that you might be offered below. These include radiotherapy, chemotherapy, and targeted treatments. You can read more about these treatment types on page 54. You might also be offered a stem cell transplant.

Radiotherapy

If your lymphoma is only in one place in your body, you might have radiotherapy to the affected area (page 69). However, most people need other treatments.

Chemotherapy

Most people with Hodgkin lymphoma that has come back or has not responded to treatment have more chemotherapy. Usually, this is a different type of chemotherapy than the one you had as your first treatment. Depending on your general health and fitness, it might also be stronger.

Chemotherapy given to treat relapsed or refractory lymphoma is sometimes called 'second-line' or 'salvage' therapy. You might have to stay in hospital to have some salvage chemotherapy regimens.

Stem cell transplant

Stem cells are special cells in your bone marrow that make all of your red and white blood cells.

If your lymphoma responds to salvage chemotherapy and you are fit and well enough, your medical team might recommend a stem cell transplant using your own stem cells (autologous stem cell transplant). This is to help make your remission last as long as possible – which might be for the rest of your life.

Having a stem cell transplant involves having very high-dose chemotherapy. This type of chemotherapy can be very effective.

Stem cell transplants are very intensive. You need tests beforehand to make sure you are fit enough to have one. You usually stay in hospital for several weeks. If your medical team thinks a stem cell transplant is suitable for you, they will talk to you in detail about it.

A stem cell transplant 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.

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. The stem cells settle in your bone marrow where they start to make new blood cells.

Risk of infection

For a few weeks after an autologous stem cell transplant, you have very low blood counts (page 90). Having a lower number of neutrophils, which are a type of white blood cell that helps to fight infection, puts you at very high risk of developing an infection. This is called neutropenia. Your blood counts start to rise after a few weeks but it can take several months for your immune system to recover.

While you are in hospital, your medical team take precautions to reduce your risk of infection. They also keep close checks on you for any signs of infection.

Although there are things you can do to help lower your risk of infection, it's impossible to completely avoid all sources of infection. Tell a member of your medical team as soon as you notice any signs or symptoms of infections (page 91) so that you have the best possible chance of effective treatment for it.

When you go home, your medical team should tell you what signs to look out for and who to contact if you are worried you might have an infection.



We have separate information about stem cell transplants, including a book on *Autologous stem cell transplants*. Visit lymphoma-action.org.uk/SCT.

Targeted treatments

If you have relapsed or refractory classical Hodgkin lymphoma, you might have treatment with a targeted drug, for example:

- brentuximab vedotin
- nivolumab or pembrolizumab.

Brentuximab vedotin

You have brentuximab vedotin through a drip into a vein every 3 weeks. **Neutropenia** is a common side effect of brentuximab vedotin. You might also experience damage to some of your nerves (peripheral neuropathy), which can lead to symptoms such as 'pins and needles' in your hands and feet, and being more or less sensitive to touch and temperature.

Nivolumab or pembrolizumab

You have these drugs through a drip into your vein at intervals of between 2 to 6 weeks. As long as your lymphoma is responding to it, you usually continue treatment for up to 2 years.

Most people tolerate these drugs well. The most common side effects of nivolumab and pembrolizumab are diarrhoea and lung inflammation, known as 'pneumonitis'.

Clinical trials

New treatments for Hodgkin lymphoma are tested first in clinical trials in people with relapsed or refractory lymphoma. You might be able to try a 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.

Side effects of treatment

Treatment destroys lymphoma cells but it can also damage healthy cells, causing unwanted side effects.

Your medical team can give you information about any side effects you might experience. They base this on lots of factors, including the type of treatment you have, how much of it, and how often, as well as 'individual factors', such as your age. However, different people can get different side effects, even if they're having the same treatment.

Usually, side effects are short-term and start to go away once you finish treatment. However, they can have a significant impact on your day-to-day life, including your emotional wellbeing. Speak to your medical team for advice about how to manage them.

Your medical team can offer suggestions about how to cope with side effects and might also offer suitable prescriptions to help. In some cases, you might also be offered a referral to a specialist who can offer further support.

“ *The image of who I thought I was became unfamiliar, almost alien. I was losing my hair and so much weight, I was unable to recognise my reflection in the mirror, which I avoided at all costs. The hospital staff and doctors became like a family to me. My identity felt crushed, yet I didn't mind because I knew this perception of a helpless human being was not really me.*

Carly, diagnosed with Hodgkin lymphoma



Some of the common side effects of treatment include:

- **Fatigue** – extreme tiredness that can be physical, mental or emotional. This can be worsened by the emotional impact of living with lymphoma.
- **Low blood counts and risk of infection** – treatment can have a short-term effect on the number of blood cells you have. This can lead to anaemia, thrombocytopenia and neutropenia (page 92).
- **‘Chemo brain’** – cancer-related cognitive impairment, which affects thinking processes such as memory and attention. Some people describe this as a ‘mental fog’. You might find it difficult to plan, keep up with a conversation or remember things.
- **Hair loss** – some people experience hair loss or thinning. This can happen to the hair on your head, as well as elsewhere on your body.
- **Sickness** – nausea (feeling sick) and vomiting (being sick). There are effective anti-sickness medicines (antiemetics) that can help.
- **Nerve damage (peripheral neuropathy)** – damage to the nerves of the peripheral nervous system (network of nerves outside of the brain and spinal cord). It can cause symptoms such as increased or decreased sensitivity to touch and temperature, and numbness and tingling (pins and needles) in your hands and feet.
- **Bowel problems** – diarrhoea, constipation (particularly with ABVD chemotherapy) and wind (flatulence).
- **Skin problems and irritations** – you might get dry, sore and itchy skin in some areas of your body.

- **Sore mouth (oral mucositis)** – which can cause symptoms such as pain when you swallow, mouth sores (ulcers), which can lead to infection, dry, sore mouth and lips.
- **Reduced fertility** – your doctors should talk to you about whether your lymphoma treatment is likely to affect your fertility. In general, fertility preservation is more effective if you take measures early, so it’s a good idea to talk to your medical team about your fertility **before** you begin treatment. If you are a parent of a child with lymphoma, speak to your child’s medical team before his or her treatment begins.



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

Low blood counts and risk of infection

Treatment for lymphoma can temporarily damage 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.

It is common to have low blood counts during your treatment. Your medical team regularly check your blood counts and make any adjustments to your treatment plan as necessary.

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 (IV) antibiotics and careful monitoring.

Possible symptoms and signs of infection include, but are not limited to:

- fever (temperature above 38°C/100.4°F)
- hypothermia (temperature below 35°C/95°F)
- shivering (even if you do not have a fever, which is more likely if you're taking steroid medication)
- chills and sweating
- feeling generally unwell, confused or disoriented
- blocked nose, earache, sore throat or mouth,
- cough, yellow or green phlegm or snot (mucus), difficulty breathing
- redness and/or swelling of the skin, pain and redness around intravenous (IV) lines
- diarrhoea or vomiting
- a feeling of burning or stinging when you wee, or needing to wee more often than usual
- vaginal discharge or itching
- unusual and new stiffness of the neck with discomfort around bright lights
- new and increasing pain.

Contact your medical team if you have any of these signs or symptoms, no matter how minor they might seem.

Anaemia (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) in 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 treatment with a blood transfusion – a drip (infusion) of donated blood or blood products given into one of your veins.

Tell your doctor if you feel short of breath, unusually tired, dizzy or have new aches and pains. This could be a sign of anaemia that needs treatment.

Thrombocytopenia (low platelet count)

Thrombocytopenia is a shortage of platelets. You might bruise easily, bleed more or bleed for longer than usual if you hurt yourself if you are thrombocytopenic.

Thrombocytopenia often gets better on its own quite quickly. However, if your platelet count is very low, or you are at particular risk of bleeding, your medical team might adjust your treatment or offer treatments to help your blood clot. In some cases, a transfusion of platelets is needed.

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

- nosebleeds
- bleeding gums after brushing your teeth
- heavier or longer periods than is usual for you
- bleeding for longer than you'd expect after a cut or scratch
- bruising more easily than usual
- red or purple patches or spots called 'purpura' or 'petechiae' on your skin (often on your legs), your lips or in your mouth
- blood in your sick (vomit)
- blood in your wee
- blood in your poo (this might be obvious, bright red blood or it can make your poo black and sticky)
- persistent headache, blurred vision or a change in your level of consciousness.

If you have a low platelet count, take precautions to reduce your risk of bleeding. For example, avoid contact sports (such as rugby) and high-impact sports (such as football and martial arts). Wear gloves to protect yourself from injury while doing activities such as gardening, DIY and crafts such as sewing.

Tips to help lower your risk of infection

Keep good personal hygiene

- **Wash your hands before eating and after using the toilet.** Take antibacterial hand sanitiser gel or wipes with you if you are out and about.
- **Have a warm bath or shower each day.** Check with your medical team for advice about bathing and showering if you have a chemotherapy central line (central venous catheter) in place.
- **Keep good dental hygiene.** Use a soft toothbrush and an alcohol-free antiseptic/antibacterial mouthwash.

Minimise contact with germs

- **Avoid places where you have a higher risk of catching an infection,** such as swimming pools, busy shops and public transport at peak times.
- **Avoid contact with people who are unwell,** for example with a cold, tummy bug or chickenpox.
- **Prepare food safely and don't eat anything that is past its sell-by-date** – use refrigerated food within 24 hours of opening. You can find out more about food safety on the World Health Organization (WHO) website and the Food Standards Agency website.

- **Take care when handling pets** – avoid bites or scratches and wash your hands after any contact with an animal. If possible, ask someone else to deal with pet care jobs that involve animal poo, such as cleaning out litter trays.
- **Visit your dentist before you start treatment for lymphoma** – you might not be able to have any dental work done during or soon after treatment because of increased risk of infection.

Protect your skin

- **Protect yourself from cuts and scratches** by wearing gloves for gardening, wearing shoes when you are outside and avoiding walking barefoot indoors.
- **Keep your skin moisturised** with a body lotion or moisturiser if it becomes dry or cracked.
- **Allow spots and scabs to heal** without picking at them.

Summary

Having treatment

- Hodgkin lymphoma is usually treated with the aim of getting rid of all of it (complete remission) and needs no further treatment.
- Your treatment is planned specifically for you by a multidisciplinary team (MDT) made up of different professionals.
- You should be given the name and contact details of your key worker, who you can talk to about any concerns or questions you have – ask your consultant for it if you're not given this information.

Treatment types

- Chemotherapy is treatment that uses drugs to kill cancer cells. You 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.
- Targeted treatments attack proteins on cancer cells. There are different types of targeted treatments.
- Rituximab is an antibody therapy that is often 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.
- As well as your treatment for lymphoma, you also have medicines to treat or prevent side effects or symptoms. This might include steroids, growth factors and anti-sickness drugs.

Side effects

- Different treatments cause different side effects. However, even people who have the same treatment might get different side effects.
- Your medical team should talk to you before you begin treatment about the side effects you might experience.
- Treatment for lymphoma can temporarily affect your blood counts. This can lead to neutropenia (which can increase your risk of infection), anaemia (which can make you feel tired and breathless) and thrombocytopenia (which can make you bruise and bleed more easily).
- It's important to know the signs of infection (page 91) and who to contact if you notice any.



After treatment

Feelings after treatment	100
Follow-up	103
Healthy living and day-to-day life	106
Late effects of treatment	109

“ I finished my treatment and was back at work the following month. For my mental wellbeing I really needed to get back to some sort of normality. One problem I had was that the backs of my legs felt very stiff since starting the chemotherapy. As a result, I have reduced my hours as my legs simply won't take it past 4.30pm.

Surinder, diagnosed with NLRPHL

Feelings after treatment

Finishing treatment for lymphoma can bring a range of emotions. Some of these are likely to be positive but others might be harder to cope with. You might feel differently at different times.

“ We often hear from people when they finish their treatment. They might expect to feel relieved, elated, happy, but often, there is a mixture of different feelings they weren't expecting. We're here for anyone who would like to talk these through.

Sharon, Lymphoma Action Information and Support team member

Some people feel anxious and low once their treatment finishes. You might start to really think about the reality of what you and those close to you have experienced, which can bring a new sense of shock, anger or sadness.

Many people miss the reassurance of frequent contact with their medical team after treatment. You might worry about the future and any changes you need to make to your plans. It can be an added difficulty if friends and family expect you to feel happy – for some people, this leads to feeling irritated and isolated, as though those around them don't understand that this continues to be a challenging time.

“ I found the aftermath of cancer really hard to deal with. When I was told I was in remission, I remember feeling euphoric. I was very excited the whole day. But very soon afterwards I felt numb – and then I felt bad for feeling that way.

Raveen, diagnosed with Hodgkin lymphoma



Talking to someone about how you feel can help you to make sense of challenging feelings. You could speak to a family member or friend, or you might like to talk to someone who's been affected by lymphoma – our Helpline team might be able to link you with a peer-support buddy who has personal experience of lymphoma (see page 123).

You could also speak to a member of our Helpline team about how you're feeling, or consider getting support from a counsellor. Speak to your GP or clinical nurse specialist if you're interested in counselling. They might be able to offer you a referral on the NHS. You can also search for a private therapist in your area using the British Association of Counsellors and Psychotherapists online tool: bacp.co.uk/search/Therapists



- Search 'health and wellbeing' on our website to find a range of resources to help with your physical and emotional wellbeing.
- We have information about recovery from treatment, including about adjusting to life after treatment. Search 'recovery' on our website.
- You might also be interested in our tips to help you communicate with the people around you. Search 'communicating' on our website.
- Search 'Live your life' on our website to find out about our self-management programme, designed for people who have just finished treatment or are on active monitoring.



We also have a list of useful organisations on our website, including those that can help with aspects of emotional wellbeing. Search 'useful orgs' at lymphoma-action.org.uk

If you'd like to talk about how you're feeling, call our Helpline freephone on 0808 808 5555. Find out more about how we can support you on page 123.

Follow-up

After finishing treatment for lymphoma, your medical team are there to support you in your physical and emotional recovery.

End-of-treatment appointment

You have an end-of-treatment appointment with your clinical nurse specialist or another health professional.

- You'll be asked about your health and wellbeing, for example, about how you're feeling, any symptoms you have and how you're adjusting to life after treatment. To help guide the conversation, your clinical nurse specialist might use a questionnaire, which is sometimes called a holistic needs assessment (HNA).
- You might also be examined and have blood tests.
- You usually have a scan at the end of your treatment to check how well your lymphoma has responded. However, scans aren't routinely used as part of ongoing follow-up as there is no evidence to suggest that they change lymphoma treatment or outcomes. Doctors prefer to keep scans for when they're considered to be helpful, which minimises radiation.

Your end-of-treatment appointment is also a chance to ask any questions you might have about your lymphoma and the impact it has on your life.

Some people find it helps to write down any questions they have before their appointment. You could also note down the answers or key points of discussion during the appointment.

Our *Introduction to lymphoma* book includes suggested questions you might like to ask your medical team, including about follow-up and recovery after treatment. See page 124 for information about how to get a copy.

Personalised care plan

Together, you and your medical team put together a care and support plan that is specific to your individual needs. This is known as personalised care and support. It includes needs that are physical, emotional, social or financial, for example, about day-to-day life, work, vaccinations and travel.



As well as the support your medical team offer, there might also be a health and wellbeing event of interest to support you in your recovery. For example, we have a peer-led self-management Live your Life self-management programme. Find out more at lymphoma-action.org.uk/LyL

During your follow-up period

Your follow-up appointments might be in person, over the phone or by video call. The aims are to check:

- your recovery from treatment
- for any signs that your lymphoma has come back (**relapsed**) – though, most of the time, these are noticed first by the person with lymphoma
- for any late effects (page 109).

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 is the time when risk of relapse is higher. You usually have check-ups every 3 to 4 months at first, then every 6 months.

If it is suitable for you, you might be offered a supported self-management system, although this isn't available at all hospitals. The idea is that you are supported to develop the skills, knowledge and confidence to book your own follow-up appointments, as-and-when you feel you need one.

Whichever way you are followed-up, you can contact your medical team at any time. Don't wait until your next appointment is due if you are worried about your lymphoma.

After your follow-up period

Your GP usually becomes your main point of contact if you have any concerns or notice any new symptoms. Most hospitals also offer a phone number to call if you have any concerns about relapse. If you are not given this information, ask for it.

Depending on the usual practice of your hospital, you might be referred back to your GP for health checks after a certain number of years in remission. This depends on factors such as your lymphoma type, the treatment you have had and how long it's been since you completed treatment. Follow-up might also differ if you were treated as part of a **clinical trial**.

Your GP should have a record of your diagnosis and all the treatment you've had. However, it's a good idea to remind them that you have had treatment for lymphoma. You should also tell any health professional who treats you in the future, including your dentist.

Healthy living and day-to-day life

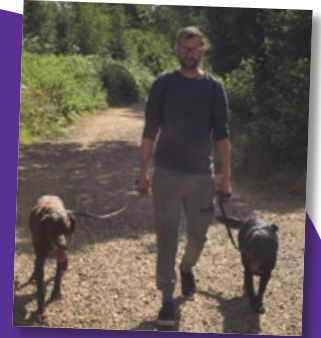
Following a healthy lifestyle puts you in the best position to live well, with and beyond lymphoma. This includes:

- eating a healthy, balanced diet
- getting regular physical activity
- being a healthy weight
- not smoking
- getting enough sleep
- managing stress
- protecting yourself from the sun
- keeping up-to-date with any vaccinations your medical team recommend
- taking up any screening programme checks you're invited to.

Your medical team can also tell you about any late effects to be aware of (page 109) and give you advice about other aspects of your life, such as safety precautions to take if you travel to another country.

“ *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. They were always so pleased to see me and they stopped me from thinking too much about the lymphoma. They really made me feel much better.*

Adam, diagnosed with NLPHL



We have more information about these lifestyle factors on our website and in our book: *Living with and beyond lymphoma*.



Practicalities

You might need to make some short-term or longer-term changes in your day-to-day life. For example, with practicalities such as work, studying and social activities. Your medical team should support you in finding ways to manage these aspects of your life.

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

There is a range of possible sources of support available to people who are looking after a family member or friend who has lymphoma. For example, you might be entitled to financial support. If you are employed, you could also speak to your employer about making adjustments to your work and about taking time out, for example, to support the person you care for by going to medical appointments with them.



“ Before my diagnosis I worked as an apprentice in financial services. The organisation was incredibly supportive, giving me six months off during my treatment and ensuring the timescales were expanded so that I could complete my studies.

Lyle, diagnosed with Hodgkin lymphoma



Search 'day-to-day' on our website for more information about where to find support with practicalities.

If you are a young person, you can find information about adjusting to life after treatment for lymphoma in our *Young person's guide to lymphoma* (see page 124)

If you drive and you are diagnosed with peripheral neuropathy (page 88), it's important to tell the Driver and Vehicle Licensing Agency (DVLA). You can find information on the UK government's website about how to notify them. Search 'peripheral neuropathy driving' at www.gov.uk



If someone close to you has lymphoma, we have information for you on our website – search 'caring for someone who has lymphoma' at lymphoma-action.org.uk. We also have a book for family and friends: *When someone close to you has lymphoma*, which offers practical tips and emotional support.

Late effects of treatment

Late effects are health problems that develop months or years after treatment for lymphoma. Your medical team should talk to you about the possible late effects of your treatment before it starts.

Note that if you need to have a blood transfusion in the future, you should only have blood that has been irradiated (treated with X-rays). This is to help prevent transfusion-associated graft-versus-host disease (TA-GvHD), which is a rare but very serious complication.

While it's not possible to say for certain whether you'll develop late effects, your medical team can give you an idea based on your specific lymphoma, the treatment you've had and individual risk factors, such as your age and lifestyle.

You can't always prevent late effects. However, noticing problems early gives you a better chance of treating or managing them effectively if they do arise.

We outline some of the possible late effects of treatment for Hodgkin lymphoma below. You'll find more information on our website. Search 'late effects' at lymphoma-action.org.uk

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with radiotherapy to the chest and with the chemotherapy drug bleomycin. If the damage is slight, you might not have any symptoms. If it is more severe, it can affect the type and amount of physical activity you're able to do. For example, if you've been treated with bleomycin, you might be advised to avoid certain activities (such as scuba diving) that expose you to oxygen levels that might be unsafe for you

and increase your risk of developing lung problems. Your medical team can give you advice about exercise that is suitable for you.

You are more likely to develop lung problems after lymphoma treatment if you smoke. If you smoke and would like free support to help you stop, talk to your GP or visit nhs.uk/smokefree

Heart problems

Radiotherapy to your chest and some chemotherapy drugs can damage your heart. This includes doxorubicin, a component of the ABVD, BEACOPP and CHOP chemotherapy regimens commonly used to treat classical Hodgkin lymphoma and NLPHL.

Heart problems generally don't start until at least 10 years after treatment, but they can develop sooner. Your risk of heart problems stays higher than usual for several decades after your treatment.

You can lower your risk of developing heart problems by not smoking, maintaining a healthy weight, eating well and staying active. You should also have your blood pressure, blood sugar level and cholesterol level checked regularly. Ask your GP surgery for information about how to book these.

Visit 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.

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.

Lifestyle can be a significant protective or risk factor, so take steps to follow a healthy lifestyle (page 106).

You can also ask your medical team about any screening programmes you should be aware of.



Find information online about screening programmes available in your region of the UK. Go to lymphoma-action.org.uk and search 'useful orgs'.

Hormone problems

Treatment for lymphoma can affect the production of chemical messengers (hormones) in your body. This can lead to problems including:

- underactive thyroid (hypothyroidism) – see below
- reduced fertility – page 114.

Underactive thyroid

If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid (hypothyroidism). This is where your thyroid gland makes less of the hormone thyroxine than it should. Thyroxine controls how your body uses energy. If you have too little of it, you might feel tired, sensitive to the cold and constipated. You might also gain weight easily.

The risk of developing hypothyroidism is highest within the first 5 years of having treatment. It stays increased after this time compared to if you had not ever had treatment for lymphoma.

Hypothyroidism is diagnosed by a blood test and is easily treated with thyroxine tablets. You might be offered regular blood tests to keep checks on your thyroid functioning.



You can find out more about hypothyroidism on the British Thyroid Foundation's website: www.btf-thyroid.org

Reduced fertility

Some treatments for lymphoma can affect women's ovaries and men's testicles, leading to reduced fertility. This can happen with radiotherapy given to your tummy (abdomen) area or to the area below your belly button (pelvis). It can also happen with chemotherapy. Less is known about the effects of newer, targeted treatments.

In women, treatment can also lead to an early menopause.



We have information about reduced fertility on our website. This includes about fertility preservation options for men and women, and about early menopause. Search 'fertility' on our website.

Summary

- Many people feel a wide range of emotions when they finish treatment. There is support available to help you through this time.
- After treatment, you have a follow-up period. This is to check your recovery and to help you manage any side effects or late effects of treatment. It also gives you a chance to talk to your medical team about questions or concerns you might have.
- A healthy lifestyle helps in your recovery and to live well, with and beyond lymphoma.
- After treatment, you might need to make some short or longer-term adjustments to your day-to-day life. This might include to your work or studies.
- Late effects are health problems that can develop months or years after treatment. Your medical team should talk to you before you begin treatment about any you might experience.
- There is support available to help you live well, with and beyond lymphoma. This includes with support needs that are physical, emotional, social, financial and practical. Speak to your medical team for advice. We are also here to support you – see page 123 to find out how.

Glossary

Anaemia	shortage of red blood cells, which means you don't have enough haemoglobin (the protein that carries oxygen around your body)	CT scan	computed tomography scan: uses X-rays to take pictures or 'slices' through your body
Anaesthetic	drugs given to make a part of the body numb (local anaesthetic) or put your whole body into a sleep-like state (general anaesthetic)	Contrast agent	a type of dye given as a drink or injection to help show up internal structures clearly on scan images
Antibody	a protein made by white blood cells that sticks to proteins on things that don't belong in your body, such as viruses, bacteria and some cancer cells	Cycle	a round of treatment followed by a rest period to give you time to recover before the next round of treatment
B symptoms	a set of symptoms: fever, drenching sweats and unexplained weight loss	Immune system	the system in your body that fights off and prevents infection
Biopsy	a biopsy looks at a sample of cells under a microscope to check for lymphoma cells	Intravenous (IV)	into a vein
Bone marrow	the spongy material at the centre of larger bones	Late effects	health problems due to treatment that develop months or years after treatment
Chemotherapy	treatment with anti-cancer drugs	Lymph nodes	small, oval swellings (glands) that are spread throughout your lymphatic system; they help your body fight infections and drain away waste fluids from tissues
Chemotherapy regimen	a chemotherapy treatment plan	Lymphatic system	part of your immune system, the lymphatic system is 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

Lymphocytes	specialised white blood cells that are part of your immune system	Reed–Sternberg cells	large, abnormal cells that are characteristic of classical Hodgkin lymphoma
MRI scan	magnetic resonance imaging: a scan that uses magnetic waves to take pictures of the inside of your body	Refractory lymphoma	lymphoma that doesn't respond to treatment
Neutropenia	shortage of neutrophils in the blood	Relapsed lymphoma	lymphoma that comes back after treatment
Neutrophils	a type of white blood cell that is important in fighting infections	Remission	no evidence of lymphoma in tests or scans
PET/CT scan	a test that combines a PET scan and a CT scan	Spleen	an organ that filters blood
PET scan	positron-emission tomography: a scan that uses a radioactive form of sugar to look at how active cells are	Stage	a measure of how much of your body is affected by lymphoma
Platelets	small cells in your blood that help your blood to clot when you cut yourself	Stem cell transplant	a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells
Protein	proteins have different roles, including controlling how our cells work and helping to fight infections	Subcutaneous	underneath the skin
Radiotherapy	treatment that uses high-energy X-rays (a type of radiation) to destroy cancer cells	Targeted therapies	drugs that attack particular proteins on lymphoma cells
Red blood cell	cells that carry oxygen around your body	Thrombocytopenia	shortage of platelets in the blood
		Thymus	a small gland behind your breastbone where some of your immune cells develop

- Thyroid gland** a gland at the front of your neck that produces a hormone called thyroxine, which controls how fast the cells in your body work
- Ultrasound scan** a scan that uses high-energy soundwaves to take pictures of the inside of your body
- White blood cell** a cell that helps your body fight infections; there are different types, including lymphocytes and neutrophils

Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites. You can find more useful organisations on our website. If you don't find what you're looking for, please get in touch with our Helpline team (page 123).

British Association for Counselling and Psychotherapy provides a list of accredited counsellors and an online tool to search by area.

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.

Carers UK offers advice, information and support for carers.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer and their family and friends.

Maggie's Centres provides practical, emotional and social support to people with cancer and their family and friends.

Mental Health Foundation have a set of podcasts that are designed to give you skills and techniques that can help improve your mental wellbeing.

Relate offers relationship information and support, including face-to-face and remote counselling.

Teenage Cancer Trust provides cancer services and support for young people affected by cancer.

Working with Cancer provides advice about remaining in work, returning to work or finding work for people with cancer.

Young Lives vs Cancer provides emotional and practical support for young people with cancer and their families.



Visit lymphoma-action.org.uk/Useful-Organisations for a list of other organisations you might find helpful.

Information and support

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



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



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



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



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



Visit lymphoma-action.org.uk/TrialsLink to search for clinical trials.



@lymphomaaction



lymphoma_action

If you're interested in finding out more about any of the topics in this book, we have information on our website. We also produce books, which are available free of charge. You might find the following titles helpful:

- *Introduction to lymphoma*
- *Active monitoring (watch and wait) for lymphoma*
- *Autologous stem cell transplant*
- *Living with and beyond lymphoma*
- *When someone close to you has lymphoma*
- *Young person's guide to lymphoma*

We also produce a series of Easy Read books.

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

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



How you can help us

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 scan the QR code to complete our short survey. Alternatively, visit our website at lymphoma-action.org.uk/BookFeedback, email us at publications@lymphoma-action.org.uk or call our Information and Support Team on 0808 808 5555.



References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

Disclaimer

Although we make reasonable efforts to ensure the content of our publications is accurate and up-to-date at the time of going to press, we make no representations, warranties or guarantees, whether express or implied, that the content is accurate, complete or up-to-date, particularly in relation to medical research which is constantly changing.

The content of this publication has been developed for people living in the UK and is provided for general information only and primarily for personal and educational use. It is not intended to amount to advice on which you should rely. You must obtain professional, medical or specialist advice before taking, or refraining from, any action on the basis of the content of this publication. Lymphoma Action cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information referenced in it.

©Lymphoma Action 2022. All rights reserved. No part of this publication may be reproduced or transmitted without permission. Go to lymphoma-action.org.uk/Legal for permitted use and reproduction of this book

Check our website for the most up-to-date details of our services, including opening times.

Notes



Notes



Notes





Acknowledgements

We would like to acknowledge the continued support of our Medical Advisory Panel and other expert advisers as well as our Reader Panel. In particular we would like to thank the following people for their assistance with this book:

- Professor Graham Collins, Consultant Haematologist, Oxford University Hospitals NHS Foundation Trust.
- Professor Peter Johnson, Professor of Medical Oncology, University of Southampton. Professor Johnson has provided consultancy for Takeda and Bristol-Myers Squibb.
- Dr Pam McKay, Consultant Haematologist and Honorary Clinical Associate Professor, Beatson West of Scotland Cancer Centre, Glasgow. Dr McKay has received honoraria and travel support to attend meetings from Roche and Takeda.
- Dr Nick Morley, Consultant Haematologist, Sheffield Teaching Hospital NHS Foundation Trust. Dr Morley receives support to attend conferences by Takeda UK Ltd.
- Dr Bridget Wilkins, Consultant Haematopathologist, St Thomas' Hospital, London and Royal Hampshire County Hospital, Winchester.

Special thanks to Adam, Carly, Claire, Hayley, Ian, Jamie, John, Julian, Lyle, Nichola and her son Jo, Raveen, Sarah, Sharon and Surinder for sharing their experiences. Quotations from their stories are featured throughout the book.

With thanks to Bristol Myers Squibb, Eli Lilly & Company, Gilead Sciences Ltd, Incyte Biosciences Ltd, Janssen and Takeda UK Ltd for funding this book. As per our policy, they have no influence over our content.

This book gives tips to help you manage the physical, practical and emotional aspects of living with and beyond lymphoma.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years.

We're here for you.



Freephone helpline **0808 808 5555**
(Mon to Fri, 10am to 3pm)



information@lymphoma-action.org.uk



www.lymphoma-action.org.uk



Live Chat via our website
(Mon to Fri, 10am to 3pm)

Inform | Support | Connect

Lymphoma Action
Unit 3, Bell Business Park
Smeaton Close, Aylesbury
Bucks HP19 8JR
General enquiries 01296 619400

✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users



This book is 100% recyclable

Company Registration No 03518755
Charity Registration (England and Wales) No 1068395
(Scotland) No SC045850

© Lymphoma Action 2022
9th edition produced November 2022
9th edition rebranded March 2024
Next revision due November 2025
LYM0009HodgLymphBk2002v9.1
ISBN 978-1-914948-03-9