High-grade
non-Hodgkin
lymphoma

Lymphoma action

High-grade non-Hodgkin lymphoma

Diffuse large B-cell lymphoma

Burkitt lymphoma

Primary CNS lymphoma

Other B-cell lymphoma types

T-cell lymphoma types

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

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

To make a donation towards our work, please visit lymphoma-action.org.uk/Donate

Your lymphoma type, stage and date of diagnosis

Your treatment plan

Key hospital 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 14,000 people are diagnosed with non-Hodgkin lymphoma each year in the UK. This book explains what high-grade non-Hodgkin lymphoma is, how it is diagnosed, and some of the treatment options that might be available to you.

We have information on the more common types in this book, and information about other types on our website at lymphoma-action.org.uk/Types

The book is split into chapters. You can read just the sections that are relevant to you at any given time.

Important and summary points are written in the chapter colour.

★ Lists practical tips.

✎ Gives space for questions and notes.

↖ Lists other resources you might find useful. If you do not have internet access, please contact our Helpline team (page 178).

Words that are in **bold** are explained in the glossary on pages 170 to 176.

The information in this book can be made available in large print.

Contents

Special thanks to Fiona, Geoff, Ian, Jean, Jennie, Kat, Kathleen, Lewis, Miriam, Neil, Nicola, Nigel, Paul, Ros and Tracey for sharing their experiences. Quotations from their stories are featured throughout the book. We would also like to thank health professionals Barbara von Barsewisch and Charlotte Bloodworth, and Lymphoma Action Information and Support Team members Sharon and Nicola, for sharing their thoughts.

Hearing the word 'lymphoma' for the first time was like hearing a foreign word; it wasn't in my vocabulary at all.
Geoff, diagnosed with T-cell lymphoma

What is non-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 your **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.

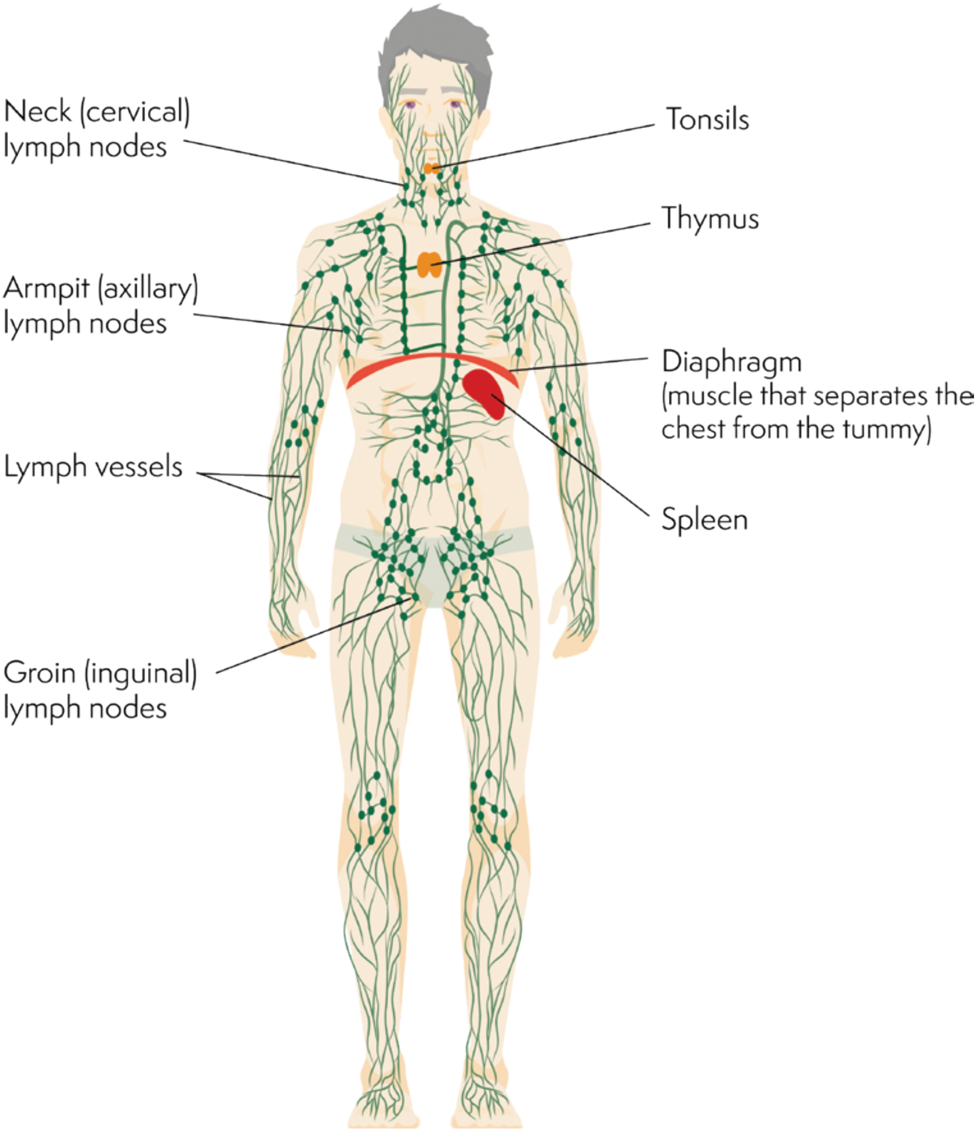
If you have lymphoma, your lymphocytes divide in an abnormal way or do not die when they should. The abnormal lymphocytes build up, usually in lymph nodes in your armpits, neck or groin. However, they can collect in almost any part of your body.

Search 'what is lymphoma?' on our website for more information and to watch an 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 called **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 into your bloodstream.



The lymphatic system

How lymphoma develops

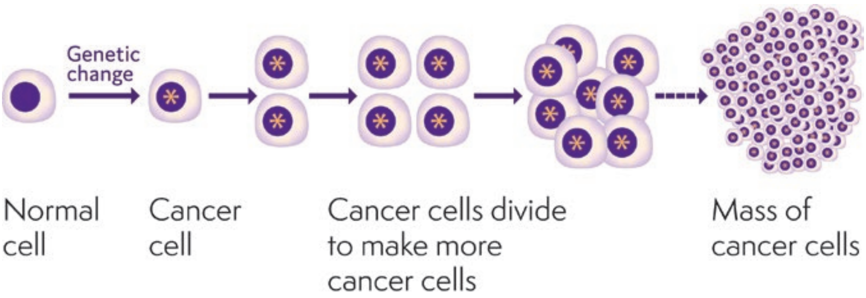
Your body is made up of cells. Some of these cells divide throughout your life. They replace old cells that die off naturally.

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 mutations 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, in high-grade lymphoma it is also common for them to collect in other parts of the body, such as the spleen, liver or **bone marrow**.

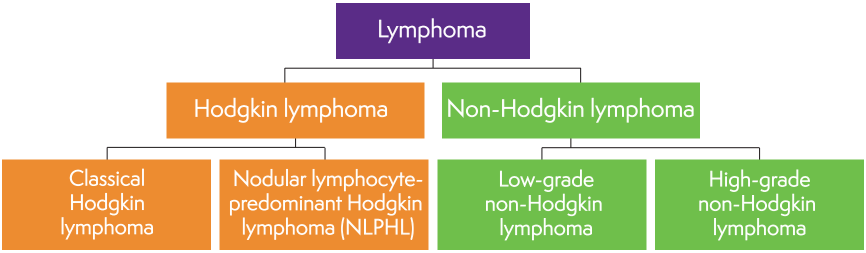


How cancer develops

See page 17 for information about the possible causes and risk factors of **high-grade** non-Hodgkin lymphoma.

Types of lymphoma

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



The main types of lymphoma

> **I had heard of lymphoma, but thought there were just two types. What I found when I searched on the internet was just baffling – there was a list of different types as long as my arm.**
> Jennie, diagnosed with
> Burkitt lymphoma

Who gets non-Hodgkin lymphoma?

Around 14,200 people are diagnosed with non-Hodgkin lymphoma each year in the UK – around 38 people every day. About half of people diagnosed with non-Hodgkin lymphoma have high-grade non-Hodgkin lymphoma.

Non-Hodgkin lymphoma can affect:

- any age group including children and young people, although in the UK, most people diagnosed are over 55
- people of any ethnicity
- both males and females, although it is slightly more common in males.

We produce a *Young person's guide to lymphoma* for people aged between 15 and 24. Visit lymphoma-action.org.uk/Shop to order your free copy.

Types of non-Hodgkin lymphoma

Non-Hodgkin lymphomas are grouped based on:

- how fast the lymphoma cells are growing
- the type of lymphocyte they developed from.

Low-grade or high-grade lymphoma

Lymphoma cells can grow slowly or quickly.

- Non-Hodgkin lymphomas that grow slowly are called **low-grade** (or indolent) non-Hodgkin lymphomas.
- Non-Hodgkin lymphomas that grow quickly are called **high-grade** (or aggressive) non-Hodgkin lymphomas.

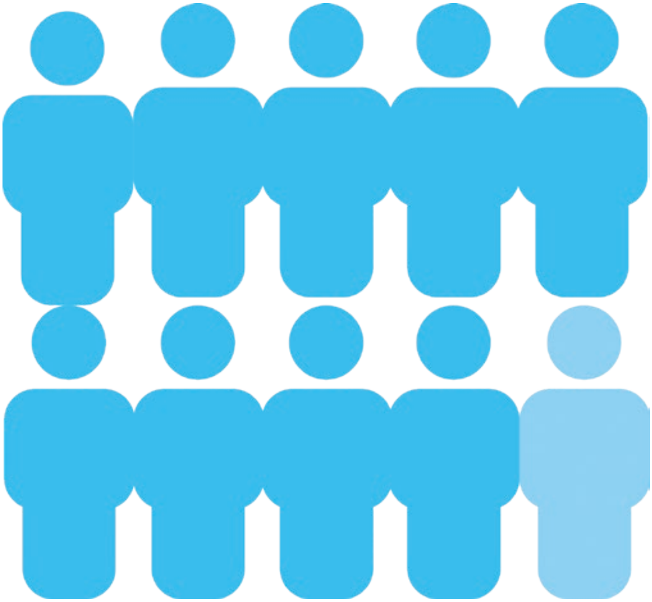
B-cell or T-cell lymphoma

There are two main types of **lymphocyte** in your immune system: B lymphocytes (B cells) and T lymphocytes (T cells). In healthy people, they protect your body from infection and illness.

- T cells recognise and target germs (especially viruses) or cancer cells. They either kill the cell directly, or activate other parts of your immune system to kill it.
- B cells make **antibodies** that stick to specific **proteins** on the surface of cells that don't belong in your body, such as viruses, bacteria or cancer cells. The antibodies can either kill the cell directly, or act like a flag that attracts other immune cells to destroy it.

Either of these types of lymphocyte can grow out of control and cause lymphoma to develop.

- Non-Hodgkin lymphomas that develop from B cells are called B-cell lymphomas.
- Non-Hodgkin lymphomas that develop from T cells are called T-cell lymphomas.



About 9 in 10 people with high-grade non-Hodgkin lymphoma have a B-cell lymphoma

There are many different types of high-grade non-Hodgkin lymphoma.

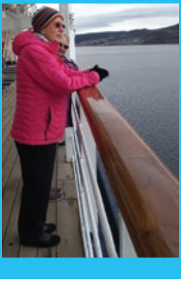
Ask your medical team if you're not sure what type of lymphoma you have.

In this book, we cover the more common types of **high-grade B-cell non-Hodgkin lymphomas** (page 103):

- Diffuse large B-cell lymphoma (DLBCL)
- Burkitt lymphoma
- Primary central nervous system lymphoma
- Other high-grade B-cell non-Hodgkin lymphomas.

We also cover the more common types of **high-grade T-cell non-Hodgkin lymphomas** (page 123).

Further information about the different types of high-grade non-Hodgkin lymphoma can be found on our website. Search 'high-grade non-Hodgkin lymphoma' to find out more.



Venturing into the unknown was frightening, especially when I was told I had a rare cancer that my medical team had not treated before. As for me, I had never heard of the word 'lymphoma'.

Kathleen, diagnosed with Burkitt lymphoma

Possible causes of non-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.

Unlike many other types of cancer, lifestyle factors don't have much impact on your risk of developing lymphoma. Scientists also know that you can't catch lymphoma from anyone or pass it onto anyone else.

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

Genetics

While anyone can develop lymphoma, if you have a close relative (such as a parent or sibling) who has lymphoma, you have a very slightly higher risk of developing it compared with the average person.

Problems with your immune system

Lymphoma is more common in people who have a condition that weakens their immune system, such as human immunodeficiency virus (**HIV**). Lymphoma is also more common in people who are taking medicines that dampen their immune system (immunosuppressants). However, most people who have these conditions do **not** develop lymphoma.

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

What is the outlook for people with high-grade non-Hodgkin lymphoma?

High-grade non-Hodgkin lymphoma generally responds well to treatment. The aim of treatment is complete **remission** (no evidence of active lymphoma in tests and scans).

Most people with high-grade non-Hodgkin lymphoma who go into remission are likely to stay in remission. The longer you're in complete remission, the less likely your lymphoma is to come back.

In some people, the high-grade non-Hodgkin lymphoma gets worse (progressive disease), or comes back after a period of remission (**relapses**). There are other treatments available if this happens.

For more information about high-grade non-Hodgkin lymphoma that doesn't respond to treatment (refractory lymphoma) or comes back after remission, see page 137.

Your lymphoma specialist 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 49)
- the results of your tests and scans
- your general health and fitness.

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.
- Non-Hodgkin lymphoma can be low-grade (slow-growing) or high-grade (fast-growing).
- Non-Hodgkin lymphoma can be grouped into B-cell lymphomas and T-cell lymphomas.
- Most people who are diagnosed with non-Hodgkin lymphoma are over 55, but it can affect anyone.
- In most cases the cause of non-Hodgkin lymphoma is unknown.

Notes

I hadn't had a day off sick for over 8 years. For some time, though, I had been experiencing night sweats. They were so bad that sweat was running off me and within half an hour my duvet was wet. I also noticed that my energy levels had changed dramatically. I always have my head in a book on the way to and from work, but I was falling asleep on the Tube. What finally prompted me to go to my GP, though, was a lump that appeared on my neck.

Kat, diagnosed with double-hit lymphoma

Symptoms of high-grade non-Hodgkin lymphoma

About symptoms of high-grade non-Hodgkin lymphoma

High-grade non-Hodgkin lymphoma can cause a range of symptoms depending on which part of your body is affected. Most people have a mixture of symptoms. Even people with the same type of lymphoma can have different symptoms. Usually, some 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.

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.*

Common symptoms

The common symptoms of lymphoma are outlined in this section. However, it's important to note that these can have other causes. Having one or more doesn't necessarily mean that you have lymphoma.

Swollen lymph nodes

A common symptom of high-grade non-Hodgkin lymphoma is a swollen lump or lumps that don't go down after a couple of weeks.

These swollen **lymph nodes** are not usually painful and have a 'rubbery' texture.

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, or deep inside your body where you can't feel them. Swollen lymph nodes can form large lumps.

It is important to remember that lymph nodes can swell for lots of reasons (for example, if you have an infection). Most people with swollen lymph nodes do not have lymphoma.

Fever

Fever is a high temperature (above 38°C/100.4°F). Fever is almost always caused by an infection, but there are a few other less common causes, including lymphoma. With lymphoma, fevers are usually mild and come and go.

Drenching sweats

Lymphoma can cause sweats that make your nightclothes and bedsheets soaking wet. They are often described as ‘drenching’. They most commonly occur at night, but can sometimes happen during the day.

Your doctor might say you have ‘B symptoms’ if you have one or more of the following symptoms: fever, drenching sweats or unexplained weight loss.

Unexplained weight loss

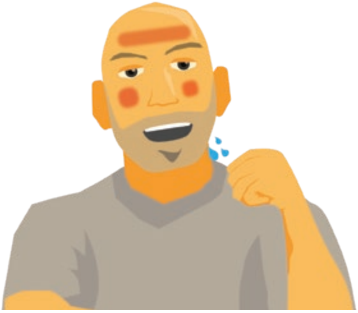
Unexplained weight loss means losing significant weight quickly without trying to.

Fatigue

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

Most people who have cancer get fatigue at some point. This can be a symptom or a side effect of treatment (page 87). However, lots of factors can contribute to fatigue, including other medical conditions, heightened stress and anxiety.

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 92 about signs and symptoms of infection, and when to seek medical attention.**
- **See page 95 for tips to help lower your risk of infection.**

Poor appetite

You might not feel like eating much, or you might feel full after eating only a small amount.

Itching

Itching is not a common symptom of high-grade non-Hodgkin lymphoma but it can be severe and affect most of the body. Itching can be worse at night and in hot weather.

Extranodal symptoms

Sometimes, non-Hodgkin lymphoma starts in an organ in your body rather than a lymph node. For example it might develop in the liver, gut, lung, skin, **bone marrow** or brain. This is called '**extranodal**' lymphoma. The symptoms you might get depend on where the lymphoma is.

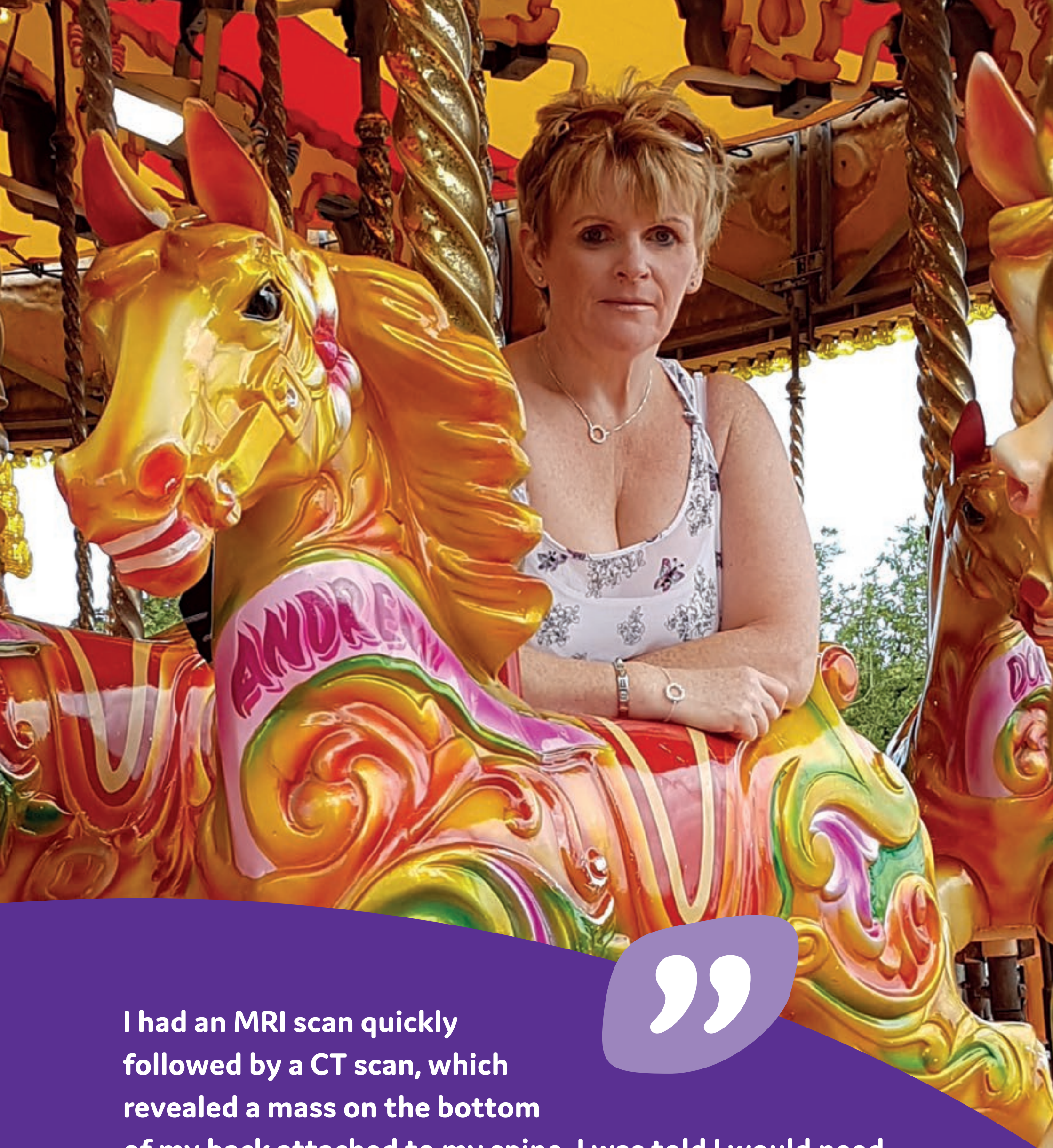
Symptoms of extranodal lymphoma can include:
- unexplained pain
- diarrhoea, constipation or bloating
- a persistent cough or breathlessness
- a rash
- a tendency to bruise or bleed easily
- headaches, memory issues, drowsiness or confusion.

> **I had been on a really enjoyable skiing holiday, but when I got back I started to have several symptoms. I felt really tired, I started to lose weight without trying, was experiencing night sweats and in addition I developed a persistent cough. To add to all this, I was then experiencing really bad back and neck pain.**
>
> Nigel, diagnosed with high-grade non-Hodgkin lymphoma

Summary

- Non-Hodgkin lymphoma can cause different symptoms depending on where it develops.
- The most common symptom of non-Hodgkin lymphoma is a swollen lymph node or nodes, often in the neck, armpit or groin.
- Your medical team consider many factors when planning your treatment, including whether or not you have B symptoms (fever, drenching sweats and unexplained weight loss).

Notes



I had an MRI scan quickly followed by a CT scan, which revealed a mass on the bottom of my back attached to my spine. I was told I would need to have a biopsy. I worried it would be painful, but the doctor numbed the area and I didn't feel a thing. It amazed me that they could cut out something so small, and also that these tiny things were causing me so much pain. A week later, I was diagnosed with Burkitt lymphoma.

Jean, diagnosed with Burkitt lymphoma

Tests, diagnosis and staging

Diagnosis of non-Hodgkin lymphoma

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

Your GP will ask you to tell them about your symptoms and check for any swollen (enlarged) **lymph nodes**. This information alone can't tell them whether or not you have lymphoma – you'll need to have tests and scans for them to find out more. Usually, you have simple blood tests (page 35).

You'll be referred to a hospital specialist and seen quickly if your GP thinks there is a possibility that you might have high-grade non-Hodgkin 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 in 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 in almost all cases a **biopsy** (page 37) is needed to confirm a diagnosis of lymphoma.

Most people have these tests as an outpatient, but some people might need to stay in hospital overnight if they have become unwell.

You can find out more on adapting to a diagnosis of lymphoma in our book: *Living with and beyond lymphoma.*

For more information about any of the tests and scans described below, 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 during follow-up (page 153).

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.

- **Whether it's safe for you to have treatment.** 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 162).

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. You might have:

- **an excisional biopsy**, which removes a whole lymph node
- **an incisional biopsy**, which removes a small part of a lymph node

- **a core needle biopsy**, which takes a very 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.

Speak to a member of your medical team 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.

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. Often results come through within a week but they can take longer.

Occasionally, the first biopsy does not give enough information to make a diagnosis and you might need to have another biopsy, but your doctor will talk to you about this.

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 'biopsy 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
- help doctors find 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 another hospital. Sometimes it's possible to have a scan at a mobile unit.

PET/CT scans

Positron-emission tomography (PET) scans and computed tomography (CT) scans are among the most common scans doctors use for people affected by lymphoma. Often, 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.

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 scans use 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**.

Stock 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:

- not eating or drinking (known as 'fasting') for a few hours before the scan
- having 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
- guidance about if and when to take any medication you usually take – for example, medicine for diabetes
- not doing strenuous physical activity in the 24 hours before your scan.

Staff will ask you to remove any metal you're wearing and ask 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. However, with a PET/CT scan, you will 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 – it might be up to an hour. 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.

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, including 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 62)
- 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 scans
- have suspected lymphoma cells in your **central nervous system** or **CNS** (brain and spinal cord)
- are pregnant, to avoid radiation.

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

During 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.

Stock image

MRI scanner

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.

Very often, a PET/CT scan (page 39) 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.

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.
- A biopsy needle is inserted into the middle of the bone to collect the sample.
- The needle is removed and a dressing is put over the area.
- The whole procedure usually takes 10 to 15 minutes.

Remind your medical team if you are taking any blood thinning medication, as this may need adjusting for the procedure.

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.

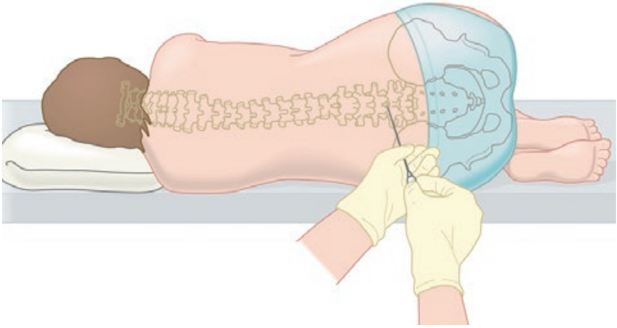
These could be signs of infection or complication that needs prompt medical attention.

Lumbar puncture

Some people with high-grade non-Hodgkin lymphoma might have suspected lymphoma cells in their brain or spinal cord (central nervous system). Your medical team might test for this using a **lumbar puncture**.

A lumbar puncture involves taking a few drops of the fluid that surrounds your brain and spinal cord (called cerebrospinal fluid, or CSF) to be examined in a lab.

- You have a local **anaesthetic** to numb the skin over your lower spine. If you are very anxious, you might also have a sedative to relax you.
- You either lie on your side with your knees bent, or sit up with your arms over a table.
- A doctor puts a small needle into a gap between the bones in your lower back and removes a few drops of CSF.
- The whole procedure takes about 5 to 10 minutes.
- You need to lie flat for about an hour afterwards.
- You might have a headache afterwards.



Having a lumbar puncture

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

Test results

Your medical team gather as much information as possible from the tests and scans you have had. You will then have an 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'd like to.

Many people feel anxious while waiting for tests results. You can ask your doctor for an idea of how long you'll need to wait for your results.

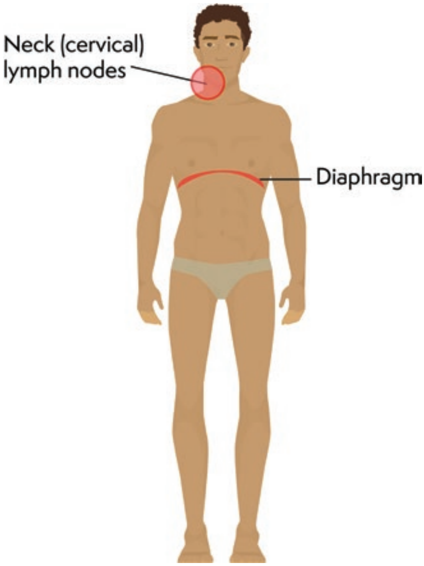
Visit lymphoma-action.org.uk/Waiting for tips on how to cope with waiting for your test results and to watch a video where Lucy Whiteman, Lymphoma Clinical Nurse Specialist, explains why they can take a while.

Staging of non-Hodgkin lymphoma

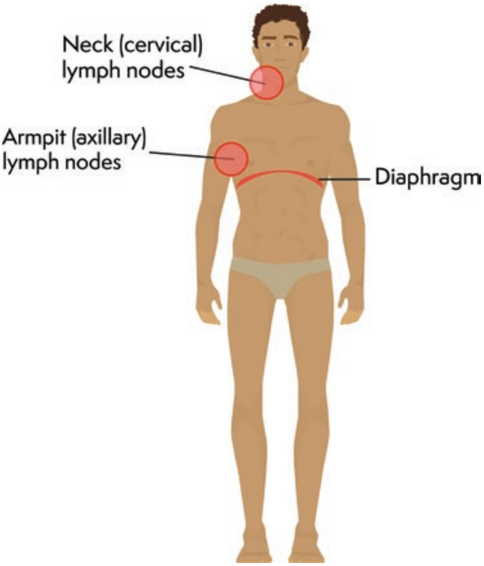
'Staging' is the process of working out which parts of your body are affected by lymphoma (how 'advanced' your lymphoma is). The results of your tests and scans help doctors to work out the **stage** of your lymphoma.

Staging of non-Hodgkin lymphoma is important because it helps your medical team plan the most appropriate treatment for you.

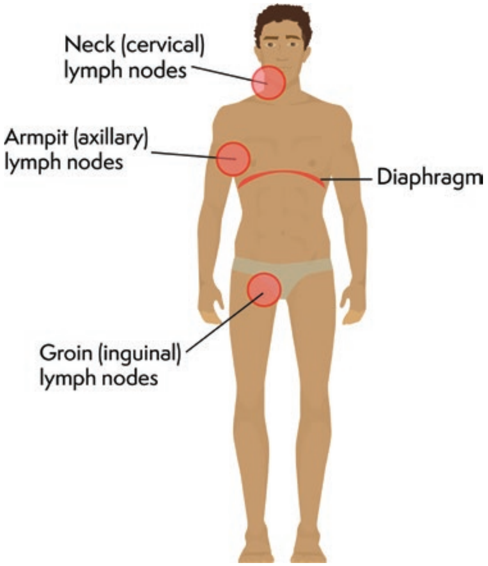
There are four main stages of non-Hodgkin lymphoma. These are sometimes written in Roman numerals (I, II, III and IV).



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

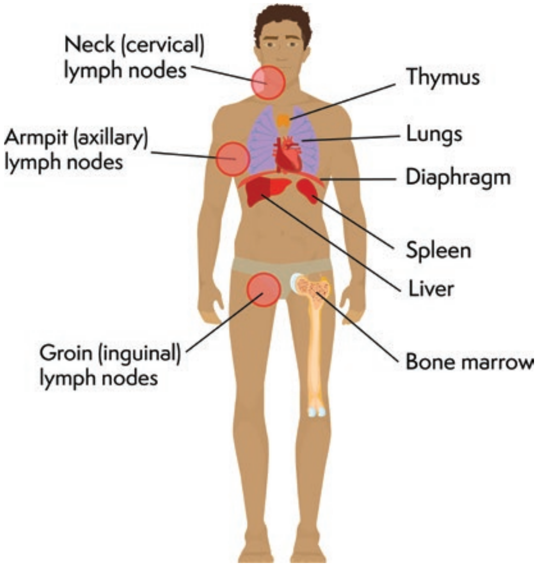


Stage 2
Lymphoma is in two or more groups of lymph nodes. These could be anywhere in your body, but all on the same side of your diaphragm.*



Stage 3

Lymphoma is in lymph nodes on both sides 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.

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 affects an area 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' (**bulky disease**). Not all hospitals use the letter 'X'.

For example, if your lymphoma is stage 3B you have lymphoma in lymph nodes on both sides of your diaphragm, and you have at least one B symptom (weight loss, night sweats or fevers).

Early stage and advanced stage lymphoma

Your medical team might talk about 'early' stage or 'advanced' stage non-Hodgkin 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, non-Hodgkin lymphoma is advanced when it is diagnosed.

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

Summary

- High-grade non-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.
- 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.

My doctor explained my treatment would be six cycles of R-CHOP chemotherapy, probably followed by radiotherapy. I felt nervous about my first chemotherapy but the treatment wasn't as bad as I feared. I had imagined it was going to be awful but there were no dramas and it was not painful. I felt great relief that treatment had started and I imagined the various mechanisms by which the different drugs and my immune system would now be attacking the cancer cells.

Neil, diagnosed with grey zone lymphoma

Treatment for high-grade non-Hodgkin lymphoma

Treatment aims

Usually, **high-grade** non-Hodgkin lymphoma is treated with the aim of complete **remission**. This means that there is no evidence of the lymphoma on tests and scans.

Most people treated for high-grade non-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, including specialists at a University Hospital. They each have knowledge and expertise in different specialist areas, to help offer you the best care. 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 lymphoma. This is either a consultant haematologist or a consultant oncologist.

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).

> **As a clinical nurse specialist, I'm there from the point of diagnosis, through treatment and beyond. I help people affected by lymphoma to understand what's happening, answer questions, and support with any treatment-related and emotional difficulties.**
> Barbara von Barsewisch, Haematology Clinical Nurse Specialist

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. You can write the contact details of your key worker on page 3 of this book.

Your key worker is often the member of your medical team 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'.

We have more information about day-to-day living on our website and in our book *Living with and beyond lymphoma.*

If you're aged up to 25 years old

While most people who are diagnosed with non-Hodgkin lymphoma are over 55, it can affect people of any age.

Children and young people with non-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). At the time of writing, this is available at centres in London and Manchester and in other countries.

You can find out more about PBT on the NHS website. Search 'PBT' at 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'.

Teenagers 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

Planning your treatment

Your medical team meet regularly to discuss the most suitable treatment for you. Sometimes, people with the same type of high-grade non-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 103)
- the **stage** of your lymphoma (page 49)
- your age
- the symptoms you are experiencing
- any other health conditions you have
- your general physical fitness
- the possible side effects of treatment (page 87)
- the possible long-term or **late effects** of treatment (page 162)
- 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.

It can be difficult to weigh up the benefits and risks of the possible treatment options. Talk it through with your medical team and, if you would like to, your family and friends. Ask as many questions as you need to help you make a decision.

Once you have a confirmed diagnosis and treatment plan it is important to consider any long term implications. Dependent on your age you may wish to discuss 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.

If you can, visit your dentist before you start treatment for lymphoma as you might not be able to have dental work done during or soon after treatment.

Once you start your treatment, you might have a PET/CT scan (page 39) 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.

> **The relationship I built with nursing staff, healthcare assistants, pharmacists and junior doctors, as well as the oncologists, was invaluable. On an informative and an emotional level they were always forthcoming.**
> Nicola, diagnosed with diffuse large B-cell lymphoma

Photo credit: Vicki Sharp Photography

Treatment options

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 high-grade non-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 62.
- Targeted treatments, including antibody therapy – page 74.
- Radiotherapy – page 79.
- Stem cell transplants – page 83.
- Clinical trials – page 86.

Chemotherapy

Most people with high-grade non-Hodgkin lymphoma have **chemotherapy**. Chemotherapy is treatment with drugs. It works in one or both of the following ways:

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

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

Chemotherapy can also affect some of your healthy cells, particularly the ones that divide rapidly. This includes blood cells, hair follicles, skin cells, and the lining of the mouth and gut. This is the cause of some of the common side effects of chemotherapy (page 87).

Watch our short animation video that explains how chemotherapy works. Search 'chemotherapy animation' on our website.

Before chemotherapy

You usually have blood tests to check that your **blood counts** 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 high enough. You might also be given treatment to help boost your blood cell counts (page 98).

Having chemotherapy

You usually have chemotherapy for high-grade non-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.

If you are having more intensive chemotherapy, you might have to stay in hospital for your treatment. Even if you are not having intensive therapy, you might need to stay in hospital for your first treatment to make sure you don't develop any serious problems such as **tumour lysis syndrome** (page 90). You might also need to stay in hospital if you develop side effects such as an infection or very low blood counts (page 91).

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 as this allows the drugs to work on more cancer cells. As chemotherapy often only affects dividing cells, some cells will not be targeted during a single treatment.

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 (**chemotherapy regimen**). Other medicines are to help control any side effects of treatment (page 96).

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 tiny, soft plastic tube that is inserted into a vein (usually in your arm) by a small needle. 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 all of your treatment.

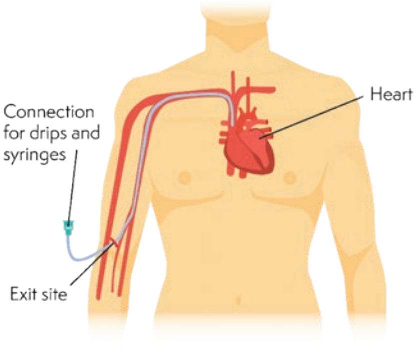
A line can also be used to:

- 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. Examples include a Hickman® line and a Groshong® line.
- **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. An example is a 'port-a-cath'.

> **I had a Hickman® line fitted, which was a great piece of equipment. It made everything so much easier.**
> Jennie, diagnosed with Burkitt lymphoma



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 or 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 deal with these, 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.

Intrathecal chemotherapy

If you have lymphoma that has spread to your **central nervous system** (CNS), or there is a high risk that it might spread to your CNS, you might also have **intrathecal** chemotherapy.

This is chemotherapy that is injected into the fluid around your spinal cord through a **lumbar puncture** (page 47).

Intrathecal chemotherapy can be used to give drugs that cross from your bloodstream into your brain and spinal cord in lower doses than having them intravenously.

Your chemotherapy treatment plan

Chemotherapy drugs for lymphoma are usually given as a treatment plan that includes more than one type of drug. This is known as a **chemotherapy regimen**. 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 frequently asked questions, on our website. Search 'chemotherapy'

Common chemotherapy regimens for high-grade non-Hodgkin lymphoma

Your treatment is planned specifically for you. The most common chemotherapy regimens for high-grade non-Hodgkin lymphoma are known as:

- **CHOP** – made up of **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin), vincristine (**O**ncovin®) and **p**rednisolone.
- **CHP** – made up of **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin) and **p**rednisolone.

For some types of non-Hodgkin lymphoma, the chemotherapy regimen also includes another therapy, such as:

- an **antibody therapy**, rituximab (a type of **targeted treatment**, page 74). This is called **chemo-immunotherapy**, and the regimen is referred to as R-CHOP or R-CHP. 'R' is short for rituximab.
- an **antibody-drug conjugate**, polatuzumab vedotin. This is added to the R-CHP regimen and is referred to as Pola R-CHP.
- an antibody-drug conjugate, brentuximab vedotin. This is added to the CHP regimen and is referred to as BV-CHP.

The chemotherapy regimen is usually given in a 21-day **cycle**. You have all drugs except prednisolone (a **steroid**) as a drip (infusion) or injection into a vein on day 1 of each cycle. You take prednisolone orally (by mouth) every day for the first 5 days of each cycle. You have a rest period on days 6 to 21.

Depending on how much lymphoma you have in your body and how you respond to treatment, you usually have between three and six cycles of the chemotherapy regimen.

- Early stage (stage 1 or 2) high-grade non-Hodgkin lymphoma can often be treated with a shorter course of chemotherapy or chemo-immunotherapy (usually three to four cycles).
- Most types of advanced stage (stage 3 or 4) high-grade non-Hodgkin lymphoma can be treated with a longer course of chemotherapy or chemo-immunotherapy (usually six cycles).

> **I started to recognise the pattern of how I would feel after treatment. For the first five days the steroid prednisolone helped, but by days 6-7 the effects of that drug had worn off and I felt really rubbish and tired.**
> Neil, diagnosed with grey zone lymphoma

Intensive chemotherapy regimens for high-grade non-Hodgkin lymphoma

Some types of high-grade non-Hodgkin lymphoma, such as primary central nervous system lymphoma and some types of peripheral T-cell lymphoma, have a higher risk of relapsing after initial treatment or might not respond well to standard chemotherapy (**refractory** lymphoma).

These types of lymphoma might need to be treated with more intensive chemotherapy, if you are fit enough. This may be combined with rituximab.

More intensive chemotherapy regimens include:
- **DA-EPOCH**: **d**ose-**a**djusted **e**toposide, **p**rednisolone, vincristine (**O**ncovin®), **c**yclophosphamide and doxorubicin (or **h**ydroxydaunorubicin)
- **CODOX-M**: **c**yclophosphamide, vincristine (**O**ncovin®), **dox**orubicin and **m**ethotrexate; this is sometimes alternated with IVAC

- **IVAC**: **i**fosfamide, etoposide (also known as **V**P-16) and cytarabine (also known as **A**ra-**C**)
- **MATRix**: **m**ethotrexate, cytarabine (also known as **A**ra-C), **t**hiotepa and **ri**tu**x**imab.

> **I was told my lymphoma would be treated aggressively with full-time stays in hospital.**
> Kathleen, diagnosed with Burkitt lymphoma

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

Intensive CNS prophylaxis

Rarely, some types of high-grade non-Hodgkin lymphoma can spread to your brain or spinal cord (your **central nervous system** or CNS). If you are at high risk of this, chemotherapy called '**CNS prophylaxis**' might help to prevent it.

CNS prophylaxis involves having a chemotherapy drug that is able to cross from your bloodstream to your CNS, such as methotrexate. Treatment can be given into a vein (intravenously) or into your spinal fluid during a lumbar puncture (page 47).

> **I had six cycles of R-CHOP and three doses of intrathecal methotrexate (CNS prophylaxis). The chemo days weren't too bad, but I struggled with side effects (mainly fatigue and appetite loss) and a terrible headache after the first lumbar puncture.**
> Miriam, diagnosed with DLBCL

To find out more about the side effects of lymphoma treatment see pages 87 to 96 or visit lymphoma-action.org.uk/SideEffects

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 92).
- **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, as well as acting as contraception to avoid conceiving a child.

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.

Targeted treatments

Targeted treatments ‘target’ particular **proteins** on lymphoma cells. These proteins can be much more common in lymphoma cells than in healthy cells and may be 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 treatments for high-grade non-Hodgkin lymphoma on the following pages.

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

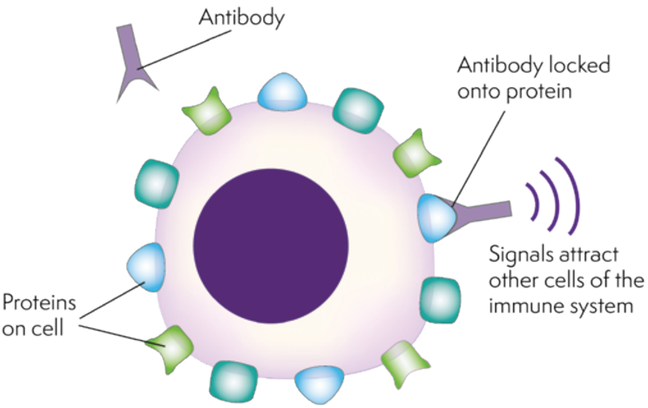
Antibody therapy

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.

Antibody therapy uses antibodies that have been made in a laboratory.

You might have antibody therapy on its own, or alongside chemotherapy. This is called **chemo-immunotherapy** (or CIT).



Antibody therapy: antibodies stick to particular proteins on lymphoma cancer cells

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 on the surface of B cells.

T cells do not have CD20 on their surface, so rituximab is only used to treat non-Hodgkin B-cell lymphomas. You usually have rituximab with chemotherapy.

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 orally (by mouth) 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). Most people have rituximab as an outpatient and go home afterwards.

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 slow down the treatment to reduce the side effects and give you advice on how to manage them.

Antibody–drug conjugated therapy

An antibody–drug conjugated treatment is a type of **targeted treatment**. It is an **antibody** joined to a chemotherapy drug. The antibody is designed to stick to a protein on lymphoma cells and carry the chemotherapy drug directly to them. These therapies are only used for certain types of high-grade non-Hodgkin lymphoma and your exact treatment will depend on many factors. You have medication before the treatment to prevent any reactions to the medicine.

Brentuximab vedotin

Brentuximab vedotin is an antibody–drug conjugate that targets a protein called CD30.

You have brentuximab vedotin through a drip into a vein (intravenous infusion), either as an outpatient or during your stay in hospital. It usually takes about 30 minutes. It is often given in combination with CHP chemotherapy regimen (page 68), every 3 weeks for up to 16 cycles.

Polatuzumab vedotin

Polatuzumab vedotin is an antibody–drug conjugate that targets a protein called CD79b.

You have polatuzumab vedotin through a drip into a vein (intravenous infusion), either as an outpatient or during your stay in hospital. It is given in combination with other drugs, every 21 days for 6 cycles.

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 responsive to radiotherapy.

The radiation is directed to precise areas of your body. This targets the lymphoma cells, 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. Therefore, it is usually used to treat lymphoma that is only in one or two places in your body.

In high-grade non-Hodgkin, radiotherapy might be used to treat:

- localised (early-stage) lymphoma – most often after a short course of chemotherapy (page 62) or chemo-immunotherapy
- lymph nodes that were very large at the time of diagnosis – usually after a full course of chemotherapy or chemo-immunotherapy

- areas of lymphoma that are affecting critical parts of your body (for example, pressing on the spinal cord)
- a single area of lymphoma that is remaining following chemo-immunotherapy.

Children and young people under the age of 25 might be offered a type of radiotherapy called proton beam therapy.

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.

Stock image

Having radiotherapy

Your treatment is carefully planned by a radiotherapy team, led by a clinical oncologist (sometimes known as a radiation oncologist), who will work out:

- **the total dose of radiotherapy** to give you
- **how many separate treatments** (fractions) you should have
- **exactly where the lymphoma is**, using a radiotherapy CT planning scan, 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 or heart.

Your clinical oncologist will explain the side effects you might experience during and shortly after your radiotherapy treatment, as well as possible late effects which might occur months to years after treatment.

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 that the best way to cope was to think about totally different things.**
>
> Julian, who had a radiotherapy mask fitted

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.

Typically, you have radiotherapy treatment Monday to Friday for up to 5 weeks. However, your schedule might differ from this as your treatment plan is designed specifically for you.

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

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**
- **Listen to our podcast where Consultant Clinical Oncologist, Professor George Mikhaeel, explains what radiotherapy is and when it is used in the treatment of lymphoma. You can hear it on our website, on Apple podcasts or on Spotify. Search 'radiotherapy podcast' at lymphoma-action.org.uk**

Stem cell transplant

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

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

Your medical team might recommend a stem cell transplant if you have:

- some types of T-cell lymphoma (page 123)
- primary or secondary **CNS** lymphoma (page 113)
- other types of high-grade non-Hodgkin lymphoma that have either **relapsed** after treatment, or not responded to initial treatment (**refractory**).

In these circumstances, a stem cell transplant might increase your chance of having a longer-lasting **remission** from lymphoma.

Having a stem cell transplant

A stem cell transplant is a form of treatment that involves a number of different steps. Stem cell transplants need a lot of preparation.

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

If you are having a stem cell transplant using your own stem cells (**autologous**), the cells are collected from your bloodstream. Occasionally, the stem cells come from a donor. This is called an **allogeneic** stem cell transplant.

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

Before your infusion of stem cells you are given high doses of a chemotherapy regimen in hospital to make sure that your lymphoma is completely eliminated. On the day of your stem cell transplant, the stem cells are given back to you through your central line, just like a blood **transfusion**.

Once the new stem cells are in your bloodstream they make their way to your bone marrow. They then settle into your bone marrow and start dividing to make new blood cells.

For 10 to 14 days after an autologous stem cell transplant, you have very low blood counts (page 91). Having a low **white blood cell** count, especially a type of blood cell called '**neutrophils**' (neutropenia), puts you at very high risk of developing an infection. Your blood counts start to rise after 10 to 14 days 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 92) 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.

Clinical trials

New treatments for non-Hodgkin lymphoma are tested first in clinical trials. 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.

Visit lymphoma-action.org.uk/TrialsLink for information about clinical trials, or to search for a trial that might be suitable for you.

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.

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

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** (pages 91 to 93).
- **'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.

Macmillan Cancer Support have information about wigs, hats, scalp care and more. Visit macmillan.org.uk/HairLoss

- **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. Rarely, it can cause pain in your jaw.

- **Sickness** – Nausea (feeling sick) and vomiting (being sick). There are effective anti-sickness medicines (antiemetics) that can help.
- **Bowel problems** – Diarrhoea, constipation and wind (flatulence).
- **Skin problems and irritations** – You might get dry, sore and itchy skin in some areas of your body, changes might also occur in your finger or toe nails.
- **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.
- **Difficulty eating** – Food might taste or smell different, you might get indigestion or heartburn or feel full very quickly.
- **Reduced fertility or early menopause** – Your doctors should talk to you about whether your lymphoma treatment is likely to affect your fertility.

> **There is the frustration of not being able to do things I could do before. Some of this I have put down to 'chemo brain', which causes me problems with concentration and with finding the correct word.**
> Kathleen, diagnosed with Burkitt lymphoma

Tumour lysis syndrome

Chemotherapy is often very effective against fast-growing cancer cells, killing a large number of lymphoma cells very quickly. These cells release chemicals as they break down. If a lot of lymphoma cells break down at once, your body might struggle to get rid of the extra chemicals. This can cause serious problems for your kidneys and heart. This is called **tumour lysis syndrome**.

Tumour lysis syndrome is often asymptomatic and detected on blood tests, but symptoms might include:

- feeling or being sick
- low appetite
- weeing less than usual
- muscle cramps
- heart palpitations.

If your medical team think you are at risk of developing tumour lysis syndrome, they will prescribe medicines to help prevent it. During your treatment, your medical team monitors you closely for any signs that it might have developed.

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. The most important type of white blood cells are **neutrophils.**
- **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.

Neutropenia (low white blood cell count)

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 or rigors (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). 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 of thrombocytopenia:

- 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).
- **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**, by using refrigerated food within 24 hours of opening. You can find out more about food safety on the World Health Organisation (WHO) website and the Food Standards Agency website.
- **Take care when handling pets**, to 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**, as 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.

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).

Side effects of steroids are usually short-term and improve once you stop taking them. They can include:
- muscle aches and weakness
- indigestion or heartburn
- increased risk of infection
- fluid retention
- changes in metabolism including higher blood sugar levels
- weakening of bones
- difficulty sleeping
- changes in mood.

Take any steroid medication you're given exactly as prescribed. Don't stop taking steroids suddenly without seeking medical advice, 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 cards:
- **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' - 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 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 usually have your first dose of G-CSF in hospital to check for any reactions to it. You (or a friend or family member) might then be taught how to give the injections so that you can have the rest 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.

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 the uncommon side effects of an itchy rash, swelling of your face, lips, tongue or throat, difficulty breathing or feeling faint after the injections.

Anti-sickness medication

There are many different types of anti-sickness medication (**antiemetics**) available, which work in different ways. Your medical team will consider which type, how much and how frequently you might need to take antiemetics based on your risk of sickness. You might have to try a few to find out what works best for you.

Anti-infection prophylaxis

If you are at high risk of developing an infection, you might have treatment to help prevent you from getting infections. This is known as anti-infection prophylaxis.

Blood transfusions

If your red blood cell count is low (anaemia), you might need a blood **transfusion**. If your **platelet** count is low (**thrombocytopenia**), you might need a platelet transfusion.

Keeping active and maintaining a healthy diet can help during treatment. We have information about coping practically, physically and emotionally on our website and in our book *Living with and beyond lymphoma*.

Summary

- High-grade non-Hodgkin lymphoma is usually treated with the aim of getting rid of all of it (complete remission).
- 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 usually have chemotherapy as an outpatient and go home afterwards. Most chemotherapy is given intravenously every few weeks.
- Targeted treatments attack proteins on cancer cells.
- Rituximab is an antibody therapy often used to treat B-cell lymphomas. You usually have it with chemo.
- Radiotherapy uses high-energy X-rays to kill cancer cells.

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 92) and who to contact if you notice any.
- 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.

After a barrage of blood tests, scans and biopsies, I was diagnosed with primary mediastinal diffuse large B-cell lymphoma, a type of high grade non-Hodgkin lymphoma.

Lewis, diagnosed with primary mediastinal diffuse large B-cell lymphoma

Types of high-grade non-Hodgkin lymphoma

About this chapter

There are many different types of **high-grade** non-Hodgkin lymphoma. In this chapter, we cover some of the more common types, including any specific symptoms and treatments. Use the chapter contents on page 103 to navigate to the section that is relevant to you.

We have not included every type of high-grade non-Hodgkin lymphoma. Some types have more than one name, so check with your medical team to see whether we include your type under a different name.

We have more information on most types of high-grade non-Hodgkin lymphomas on our website. View or download our information sheets at lymphoma-action.org.uk/Information or call 0808 808 5555 to request a copy.

If your type of high-grade non-Hodgkin lymphoma isn't covered here or on our website, check with your medical team for where to get detailed information. They might be able to tell you if we have included a lymphoma similar to yours in this book.

For more detailed information about general symptoms see page 23 to page 30.

For more information about treatments see page 55 to page 101.

Diffuse large B-cell lymphoma

Diffuse large B-cell lymphoma (DLBCL) is the most common type of high-grade non-Hodgkin lymphoma. It typically affects people over 65, but it can develop at any age. It is slightly more common in men than women.

Rarely, there is an association between DLBCL and conditions affecting the immune system. These include:
- autoimmune conditions like rheumatoid arthritis
- HIV
- organ transplantation
- taking immunosuppressive therapy for other conditions.

Sometimes DLBCL develops in people who have had a low-grade lymphoma in the past. This happens when a low-grade lymphoma transforms (changes) into a quicker growing DLBCL.

Symptoms of DLBCL

People with DLBCL might have:

- swollen lymph nodes that grow quickly, often in the neck, armpit, groin, or abdomen, or deep inside your body. Often, DLBCL develops outside lymph nodes (**extranodal** disease)
- **B symptoms** (fevers, night sweats, weight loss)
- symptoms specific to where the DLBCL is, for example nausea or diarrhoea if it is in your stomach or bowel.

Treatment for DLBCL

Treatment differs depending on whether you have early-stage (1 or 2) or advanced stage lymphoma (3 or 4) (page 49).

Early stage (1 or 2) DLBCL

- Usually, a short course (three to four cycles) of **chemo-immunotherapy**, such as: **R-CHOP** (**r**ituximab plus **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin), vincristine (**O**ncovin) and **p**rednisolone) followed by **radiotherapy**.
- **Pola-R-CHP** (**pola**tuzumab vedotin, **r**ituximab, **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin) and **p**rednisolone) may be used in some cases.
- If radiotherapy is not possible (usually because the areas involved with lymphoma are too far apart), a full course (six cycles) of R-CHOP is recommended.
- Radiotherapy can sometimes be avoided if you are 'low-risk', or have a complete response to chemo-immunotherapy.

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

Advanced stage (3 or 4) DLBCL

- Usually, a full course (six cycles) of **chemo-immunotherapy**, such as: Pola-R-CHP or R-CHOP.
- If you're not well enough to have full strength chemo-immunotherapy, you might have an adjusted regimen, such as:
    - a dose reduced regimen, for example 'R-mini-CHOP'
    - **RGCVP** (**r**ituximab, **g**emcitabine, **c**yclophosphamide, **v**incristine, **p**rednisolone)
    - treatment on a clinical trial.
- If you're at high risk of your lymphoma relapsing, or have a more aggressive type of DLBCL, you might have a more intensive treatment, such as:
    - **R-CODOX-M/R-IVAC**: **r**ituximab plus **c**yclophosphamide, vincristine (**O**ncovin®), **dox**orubicin, **m**ethotrexate/**r**ituximab plus **i**fosfamide, etoposide (**V**P-16), cytarabine (**A**ra-**C**)
    - **DA-EPOCH-R**: **d**ose-**a**djusted **e**toposide, **p**rednisolone, vincristine (**O**ncovin®), **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin) plus **r**ituximab.
- If you have responded to chemo-immunotherapy, you might have radiotherapy if there is lymphoma left in only one area of your body, or you have **bulky disease**.
- If you're at high risk of your lymphoma affecting your your central nervous system (CNS), you might be given 'CNS prophylaxis' (chemotherapy at a high dose sometimes using a lumbar puncture).

Rare types of DLBCL and other large B-cell lymphomas

Primary mediastinal large B-cell lymphoma (PMBL)

Primary mediastinal large B-cell lymphoma typically affects people in their 20s and 30s. Although it is rare, it is more common in women than men. It develops from B cells in the **thymus** where it tends to grow as a large lump inside the chest. It is a rare type of DLBCL.

Symptoms of PMBL

People with PMBL might have:

- breathlessness, cough, difficulty swallowing
- swelling of the neck and face
- headaches, dizziness.

Treatment for PMBL

Treatment for PMBL is similar to treatment for DLBCL, with chemo-immunotherapy (R-CHOP) being the typical treatment usually followed by **radiotherapy** to the chest area. Your medical team may suggest a stronger treatment such as DA-EPOCH (page 71) plus rituximab. You might be asked if you'd like to take part in a clinical trial (page 86).

Search 'Primary mediastinal large B-cell lymphoma' at lymphoma-action.org.uk for more information

T-cell/histiocyte-rich large B-cell lymphoma

T-cell/histiocyte-rich large B-cell lymphoma can develop at any age but it more commonly affects middle-aged men. It is a rare type of DLBCL.

Symptoms of T-cell/histiocyte-rich large B-cell lymphoma

People with T-cell/histiocyte-rich large B-cell lymphoma might have:

- swollen lymph nodes
- swelling of the liver or spleen, which can cause tummy swelling and discomfort

- a feeling of being generally unwell
- B-symptoms (fever, night sweats, weight loss).

Treatment for T-cell/histiocyte-rich large B-cell lymphoma

Treatment for T-cell/histiocyte-rich large B-cell lymphoma is similar to that for DLBCL (page 106).

Search 'T-cell/histiocyte-rich large B-cell lymphoma' at lymphoma-action.org.uk for more information.

EBV-positive DLBCL not otherwise specified (NOS)

Epstein-Barr virus (EBV) is a very common virus that affects B **lymphocytes** and can cause glandular fever.

EBV is carried by around 9 in 10 adults, but it usually doesn't cause any symptoms. After you're infected with EBV, the virus stays in your body and your immune system keeps it under control.

EBV-positive DLBCL NOS is linked to the Epstein-Barr virus, but only a very small number of people who have had EBV go on to develop lymphoma. It typically develops in people over 50.

It is a rare type of DLBCL.

Symptoms of EBV-positive DLBCL

People with EBV-positive DLBCL might have:

- **extranodal** lymphoma, most commonly in the skin, lungs, tonsils or stomach, therefore symptoms depend on where in your body the lymphoma is growing
- lymphoma in lymph nodes.

Treatment for EBV-positive DLBCL

Treatment for EBV-positive DLBCL is similar to that for DLBCL (page 106).

Search 'EBV-positive DLBCL' at lymphoma-action.org.uk for more information.

Intravascular large B-cell lymphoma

The abnormal lymphocytes in this type of lymphoma are found within small blood vessels called 'capillaries'. It mainly affects older adults. It is a rare type of DLBCL.

Symptoms of intravascular large B-cell lymphoma

People with intravascular large B-cell lymphoma might have:

- nervous system symptoms (confusion, seizures, dizziness or weakness)
- reddened patches or lumps in the skin
- enlarged liver or spleen
- **B symptoms** (fever, night sweats, weight loss).

Treatment for intravascular large B-cell lymphoma

Treatment for intravascular DLBCL is often similar to that for DLBCL (page **106**).

Search 'Intravascular large B-cell lymphoma' at lymphoma-action.org.uk for more information.

Primary central nervous system (CNS) lymphoma

This type of high-grade non-Hodgkin lymphoma is most often a form of DLBCL. It usually develops in your brain, but can affect your eyes. It tends to affect people over 60 and is slightly more common in men than women.

Symptoms of primary CNS lymphoma

People with **CNS** lymphoma might have:

- confusion, problems with memory
- increased irritability
- problems with speech
- seizures, headaches or drowsiness
- nausea (feeling or being sick)
- blurred vision if the lymphoma involves your eye.

Treatment for primary CNS lymphoma

Treatment for primary CNS lymphoma usually involves ‘induction therapy’ and ‘consolidation therapy’.

Induction therapy is likely to be a chemo-immunotherapy regimen. The exact combination of drugs will depend on your individual circumstances. Consolidation therapy may involve an **autologous** stem cell transplant (page 83) or **radiotherapy** (page 79).

Search ‘CNS lymphoma’ at lymphoma-action.org.uk for more information.

Rare types of high-grade B-cell lymphomas that are difficult to classify

Double-hit and triple-hit lymphoma

These are types of high-grade B-cell lymphomas that have two (double-hit) or three (triple-hit) genetic mutations.

Double-hit and triple-hit lymphoma tend to develop in older people. Most people have advanced stage lymphoma when they are diagnosed.

Symptoms of double-hit and triple-hit lymphoma

People with double-hit or triple-hit lymphoma might have:

- swollen lymph nodes throughout their body
- **B symptoms** (fever, night sweats, weight loss)
- CNS symptoms (seizures, dizziness, difficulties with memory and concentration, weakness or tingling in an arm or leg)
- fatigue due to lymphoma in the bone marrow.

Treatment for double-hit and triple-hit lymphoma

There is no standard treatment for double-hit or triple-hit lymphoma. These lymphomas are difficult to treat and have a higher risk of **relapsing**.

Your medical team will discuss your treatment options with you. These might include having treatment as part of a clinical trial, or **chemo-immunotherapy**. You are also likely to have treatment to prevent the lymphoma spreading to your brain and spinal cord, this is called **CNS prophylaxis**.

Search 'Double-hit and triple-hit lymphoma' at lymphoma-action.org.uk for more information

Grey zone lymphoma

Grey zone lymphomas have features of more than one type of lymphoma. This is usually primary mediastinal B-cell lymphoma (PMBL; page 109), as well as classical Hodgkin lymphoma.

Grey zone lymphomas usually affect adults aged 20 to 40. It affects around twice as many men as women. Most people develop a large lymphoma mass in the centre of the chest. It is usually diagnosed at an early stage.

Symptoms of grey zone lymphoma

People with grey zone lymphoma might have:

- coughing or breathing problems
- swollen lymph nodes above the collar bone.

Treatment for grey zone lymphoma

While there is no standard treatment for grey zone lymphoma, your medical team will discuss your treatment options with you, depending on your particular biopsy results.

This might include:
- having treatment as part of a clinical trial
- **chemo-immunotherapy** similar to treatment for people with DLBCL (page 106)
- chemotherapy similar to treatment for people with classical Hodgkin lymphoma such as **ABVD**: doxorubicin (**A**driamycin®), **b**leomycin, **v**inblastine, **d**acarbazine, or **BEACOPDac**: **b**leomycin, **e**toposide, doxorubicin (**A**driamycin®), **c**yclophosphamide, vincristine (**O**ncovin®), **p**rednisolone, **dac**arbazine.

Search 'Grey zone lymphoma' at lymphoma-action.org.uk for more information.

High-grade B-cell lymphoma, not otherwise specified (NOS)

If you have a high-grade B-cell lymphoma that doesn't fit any of the other categories, it is known as 'high-grade B-cell lymphoma, not otherwise specified (NOS)'. These types of lymphoma might have features of more than one type of lymphoma, such as DLBCL and Burkitt lymphoma. Lymphomas in this group can behave very differently to each other.

There is no standard treatment for high-grade B-cell lymphoma, NOS. Depending on your individual circumstances, you might be offered treatments usually used for other types of lymphoma, such as DLBCL or Burkitt lymphoma. Your doctor might ask you if you would like to take part in a clinical trial.

Burkitt lymphoma

Burkitt lymphoma is a type of high-grade non-Hodgkin lymphoma that can develop very quickly. It can affect people of any age, but it typically develops in children and young adults. It affects up to four times more men than women.

The most common subtype of Burkitt lymphoma is called sporadic Burkitt lymphoma. Other forms of Burkitt lymphoma are linked to infection with malaria and Epstein-Barr virus (Endemic Burkitt lymphoma) or develop in people who have **HIV** or have had an organ transplant (immunodeficiency-associated Burkitt lymphoma).

Symptoms of Burkitt lymphoma

People with Burkitt lymphoma might have:

- swollen lymph nodes, often in the tummy (abdomen) and bowel, which might cause tummy or back pain, feeling sick, diarrhoea
- **B symptoms** (fevers, night sweats, weight loss)
- lymphoma cells in the **bone marrow** potentially causing low blood counts.

Treatment for Burkitt lymphoma

Burkitt lymphoma is normally classed as 'low-risk' or 'high-risk' based on the results of your tests and scans, and how the lymphoma is affecting your day-to-day life.

Treatment for Burkitt lymphoma kills a large number of lymphoma cells very quickly and might cause a side effect known as tumour lysis syndrome (page 90).

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

Treatment for high risk Burkitt lymphoma

- Chemotherapy combined with **antibody therapy** (rituximab), for example:
  - **R-CODOX-M/R-IVAC**: **r**ituximab plus **c**yclophosphamide, vincristine (**O**ncovin®), **dox**orubicin, **m**ethotrexate/**r**ituximab plus **i**fosfamide, etoposide (**V**P-16), cytarabine (**A**ra-**C**)
  - **DA-EPOCH-R**: **d**ose-**a**djusted **e**toposide, **p**rednisolone, vincristine (**O**ncovin®), **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin) plus **r**ituximab (six cycles)
- **CNS prophylaxis** (this may involve chemotherapy done through a **lumbar puncture**).

Treatment for low risk Burkitt lymphoma, or if you are not fit enough for intensive chemotherapy

- A less intensive **chemotherapy** regimen combined with rituximab, such as:
  - **R-CODOX-M**: **r**ituximab plus **c**yclophosphamide, vincristine (**O**ncovin®), **dox**orubicin, **m**ethotrexate
  - **DA-EPOCH-R**: **d**ose-**a**djusted **e**toposide, **p**rednisolone, vincristine (**O**ncovin®), **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin) plus **r**ituximab (three cycles), with or without methotrexate
- A different regimen may be preferred if you are older, such as:
  - **R-CHOP**: **r**ituximab plus **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin), vincristine (**O**ncovin) and **p**rednisolone
  - **R-CHEOP**: **r**ituximab plus **c**yclophosphamide, doxorubicin (or **h**ydroxydaunorubicin), **e**toposide, vincristine (**O**ncovin) and **p**rednisolone.
- **CNS prophylaxis** (this may involve chemotherapy done through a **lumbar puncture**).

My treatment was CODOX-M/R-IVAC, which is an intense regime. I needed several tests to check that my heart, general health and fitness would mean I would be able to cope with the treatment. At the time I was a pretty fit 55-year-old, so was able to have this treatment. The nurse explained I would get worse before I got better. For the first couple of weeks I was so tired I could barely keep my eyes open. The first part of my treatment was CODOX, but for the last 3 days I was given methotrexate to prevent the lymphoma spreading to my central nervous system. This was particularly difficult.

Jean, diagnosed with Burkitt lymphoma

High-grade T-cell non-Hodgkin lymphomas

T-cell lymphomas are rare. There are many different types of T-cell lymphoma. This section includes the most common types of high-grade T-cell non-Hodgkin lymphoma.

Peripheral T-cell lymphoma not otherwise specified (PTCL-NOS)

PTCL-NOS includes all high-grade T-cell non-Hodgkin lymphomas that don't fit into another category. These can develop at any age, but they are more common in people in their 60s. They affect more men than women. Most people have advanced stage lymphoma when they are diagnosed.

Symptoms of PTCL-NOS

People with PTCL-NOS might have:

- a swollen lymph node or nodes
- **anaemia** and **thrombocytopenia**, if the bone marrow is affected
- bloating or tummy pain if your liver or **spleen** is enlarged
- itchy red patches of skin
- shortness of breath, a cough if the lymphoma is in your chest
- **B symptoms** (fevers, night sweats, weight loss).

Treatment for PTCL-NOS

Your medical team will discuss recommended treatment options with you. These might include:

- CHOP chemotherapy, followed by **radiotherapy** to specific lymphoma sites if you respond to **chemotherapy**
- less intensive chemotherapy, such as gemcitabine or bendamustine
- an **autologous** or **allogeneic** stem cell transplant after high-dose chemotherapy
- **CNS prophylaxis**
- a new treatment as part of a clinical trial.

Search 'PTCL NOS' at lymphoma-action.org.uk for more information

Anaplastic large cell lymphoma (ALCL)

Anaplastic large cell lymphoma (ALCL) is rare. Each year, fewer than 200 people are diagnosed with ALCL in the UK. There are four main types of ALCL. Two of these types are high-grade T-cell non-Hodgkin lymphoma: ALK-positive ALCL and ALK-negative ALCL.

ALK-positive ALCL is the most common type of ALCL. It usually affects children and young adults, commonly in their 30s, and it affects three times more males than females. It is usually diagnosed at an advanced stage (stage 3 or 4).

ALK-negative ALCL tends to affect older adults, typically around 40 to 65, and is slightly more common in men than women. It is usually diagnosed at an advanced stage (stage 3 or 4).

Symptoms of ALK-positive and ALK-negative ALCL

People with ALK-positive and ALK-negative ALCL might have:

- swollen lymph nodes
- **B symptoms** (fever, night sweats, weight loss)
- symptoms from lymphoma affecting **extranodal** areas, such as the gut, which might cause pain, bloating diarrhoea, or the chest, which might cause coughing or shortness of breath
- anaemia and **thrombocytopenia**, if the bone marrow is affected.

Treatment for ALK-positive and ALK-negative ALCL

As ALCL is rare this makes it difficult to determine which treatment gives the best outcome. Your medical team will discuss treatment options with you.

This might include:

- **BV-CHP** (**b**rentuximab **v**edotin, combined with **c**yclophosphamide, doxorubicin (**h**ydroxydaunorubicin) and **p**rednisone)
- **radiotherapy** to the site of the lymphoma in selected cases if you have a response to BV-CHP
- **chemotherapy**, such as CHOP or CHEOP
- treatment as part of a clinical trial
- having an **autologous** stem cell transplant if you respond to chemotherapy (page 83).

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

Angioimmunoblastic T-cell lymphoma (AITL)/ follicular T-cell lymphoma (FTCL)

AITL and FTCL are sometimes grouped together under the name of 'nodal T-cell lymphomas with T-follicular helper (TFH) phenotype'.

AITL and FTCL are rare. Each year, only around 140 people are diagnosed with AITL or FTCL in the UK. These types of lymphomas usually affect older people, typically around the age of 70. Men and women are affected equally.

Symptoms of AITL and FTCL

People with AITL and FTCL might have:

- swollen lymph nodes, usually in several places
- **B symptoms** (fever, night sweats, weight loss)
- a swollen liver and spleen, which might cause bloating and tummy pain
- itching, skin rash
- anaemia and **thrombocytopenia**, if the bone marrow is affected.

Some people with AITL and FTCL might have abnormal **antibodies** that react against your healthy cells (**autoimmune reaction**). This can cause:

- a low red blood cell count, which might make you feel tired or short of breath
- a low platelet count, which might make you bleed or bruise more easily
- painful, swollen joints
- inflammation of your blood vessels
- thyroid problems.

Treatment for AITL and FTCL

Treatment of AITL or FCTL is usually treated in the same way as PTCL-NOS (page 124). Treatment might include:

- chemotherapy with CHOP or CHEOP
- a less intensive **chemotherapy regimen**, such as gemcitabine, bendamustine or cyclosporine
- **chemo-immunotherapy** (including **antibody therapy** with rituximab)
- a new **targeted treatment** or chemotherapy regimen as part of a clinical trial
- an **autologous** stem cell transplant if you respond well to chemotherapy.

Search 'AITL and FTCL' at lymphoma-action.org.uk for more information.

Adult T-cell leukaemia/lymphoma (ATL or ATLL)

Adult T-cell leukaemia/lymphoma (ATL or ATLL) is rare. It is a type of high-grade T-cell skin lymphoma. Only around 30 people are diagnosed with it in the UK each year.

ATL only affects people who have a virus called 'human T-lymphotropic virus type 1' (HTLV-1). Only about 1 in 20 people with HTLV-1 develop ATL.

ATL can be classified as a leukaemia if it affects the blood, or as a lymphoma if it affects the lymph nodes.

Here, we cover one type of ATL that is classed as a high-grade lymphoma: lymphoma-type ATL. In this type of ATL there are abnormal white blood cells in your **lymphatic system**, but not in your blood.

Lymphoma-type ATL is the most common type of ATL that accounts for around 13 in every 20 cases of ATL in the UK. Most people with lymphoma-type ATL are advanced stage (grade 3 or 4) when they are diagnosed.

Symptoms of lymphoma-type ATL

People with lymphoma-type ATL might have:
- swollen lymph nodes
- a swollen liver and spleen, which might make you feel bloated or cause tummy pain
- a skin rash that can vary from itchy red patches to lumps
- sickness, diarrhoea, constipation, headaches, weeing more than usual, or feeling thirsty, weak, tired or confused (caused by high levels of calcium in your blood)
- **B symptoms** (fever, night sweats, weight loss)
- getting more infections than usual or having difficulty recovering from infections
- achy bones
- lymphoma that has spread to your **CNS**.

Treatment for lymphoma-type ATL

Your medical team will discuss treatment options with you as there is no standard treatment for lymphoma-type ATL. Treatment might include:

- a new treatment as part of a clinical trial
- **chemotherapy regimens**, such as CHOP, CHEOP, DA-EPOCH
- lower-dose chemotherapy regimens if you are not fit enough to have strong **chemotherapy**
- antiviral drugs, such as zidovudine and interferon-alfa to control the HTLV-1 infection
- **CNS prophylaxis** if you are at high risk of your lymphoma affecting your brain and spinal cord
- a donor (allogeneic) stem cell transplant if you respond well to chemotherapy.

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

Extranodal NK/T-cell lymphoma, nasal type

Extranodal NK/T-cell lymphoma, nasal type develops outside the lymph nodes (**extranodal**), usually in the nose.

Extranodal NK/T-cell lymphoma is extremely rare in the UK but is more common in the Far East. It is strongly linked to infection with the Epstein–Barr virus (EBV). EBV is a very common virus that can cause glandular fever. Most people who have EBV do **not** develop lymphoma.

Extranodal NK/T-cell lymphoma, nasal type is usually diagnosed when it is at an early stage (stage 1E or 2E).

Symptoms of extranodal NK/T-cell lymphoma, nasal type

People with extranodal NK/T-cell lymphoma, nasal type might have:

- a blocked nose, nosebleeds, or nasal crusting
- swelling or pain in your face
- weepy eyes (blocked tear ducts) or eye discomfort
- swollen lymph nodes
- **B symptoms** (fever, night sweats, weight loss)
- fatigue.

Treatment for extranodal NK/T-cell lymphoma, nasal type

For early stage extranodal NK/T-cell lymphoma, nasal type, treatment usually includes **chemotherapy** and **radiotherapy**. Chemotherapy can be given at the same time as radiotherapy, before and/or after your radiotherapy.

For advanced stage extranodal NK/T-cell lymphoma, nasal type, you are likely to have chemotherapy without radiotherapy, with regimens such as:

- **DDGP**: **d**examethasone, cisplatin, **g**emcitabine and **p**egasparaginase
- **SMILE**: dexamethasone (a **s**teroid), **m**ethotrexate, **i**fosfamide, **L**-asparaginase, **e**toposide
- a lower dose **chemotherapy regimen**, or radiotherapy on its own if you are not fit enough to have standard chemotherapy
- an **autologous** stem cell transplant if you respond well to chemotherapy.

Search 'extranodal T-cell' at lymphoma-action.org.uk for more information.

Sézary syndrome

Sézary syndrome is a rare high-grade T-cell skin lymphoma. It accounts for about 3 in every 100 cases of skin lymphoma.

Search Sézary syndrome at lymphoma-action.org.uk for more information

Symptoms of Sézary syndrome

People with Sézary syndrome might have:

- large areas of bright red, thickened, swollen and sore skin that sometimes peels
- thickening of the skin of the palms of the hands and soles of the feet
- severe itching
- swollen lymph nodes
- hair loss.

Treatment for Sézary syndrome

Sézary syndrome affects T-cells in your blood, not just the skin. Treatments might include:

- extracorporeal photopheresis (ECP) as a first choice treatment – this involves collecting your blood through a catheter, separating out the abnormal **white blood cells** and exposing them to ultraviolet irradiation, and then giving them back to you
- ECP might be combined with methotrexate, bexarotene or interfon-alpha
- **radiotherapy**, **chemotherapy** or **antibody therapy** (alemutuzumab, brentuximab vedotin or mogamulizumab), if Sézary syndrome has not responded to the first treatment or has spread to other organs
- a new treatment as part of a clinical trial
- an allogeneic stem cell transplant.

Lymphoblastic lymphoma

Lymphoblastic lymphoma is rare. It develops from immature lymphocytes (T cells or B cells). It typically affects younger people.

Lymphoblastic lymphoma is very similar to acute lymphoblastic leukaemia. For more detail, visit leukaemiacare.org.uk/acute-lymphoblastic-leukaemia

> **There are many different types of lymphoma, which may behave or affect people individually. We're here to support anyone affected, no matter the type of lymphoma; helping to answer questions about lymphoma, offering a listening ear, and helping you to connect with others who are also affected.**
>
> Nicola, Lymphoma Action Information and Support Team

Notes

> **When I was first diagnosed I received R-CHOP chemotherapy followed by radiotherapy. We thought all was well, but 12 years later my lymphoma came back with a vengeance and I was given further chemotherapy. I had a biopsy to see whether this chemotherapy was working but unfortunately it wasn't and I had CAR T-cell therapy.**
>
> Fiona, diagnosed with DLBCL

If high-grade non-Hodgkin lymphoma doesn't respond to treatment or comes back

About relapsed or refractory lymphoma

For most people **high-grade** non-Hodgkin lymphoma responds well to treatment and needs no further treatment.

However, in some people, high-grade non-Hodgkin lymphoma does not respond to treatment (**refractory** lymphoma), gets worse during treatment (progressive lymphoma) or comes back after treatment (**relapsed** lymphoma).

High-grade non-Hodgkin lymphoma is most likely to come back within 2 years of original diagnosis. However, it can happen later. Some types of lymphoma, such as T-cell lymphomas, are more likely to relapse than others.

> **If I have aches, pains or unexplained lumps, I do not hesitate to see my doctor. No, I am not turning into a hypochondriac, but I am only too well aware that cancer generally needs to be identified quickly and I do not propose to take any chances.**
>
> Kathleen, diagnosed with Burkitt lymphoma

Treatment for relapsed or refractory high-grade non-Hodgkin lymphoma

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

- the type of lymphoma you have (a biopsy will determine if the lymphoma type is the same or different to your original diagnosis)
- 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. Treatment used to treat relapsed or refractory lymphoma is often called 'second-line', or 'salvage' therapy.

Treatment options include **chemo-immunotherapy**, **targeted therapies**, **stem cell transplant** and **CAR T-cell therapy**. Radiotherapy may be used if you have lymphoma that is causing local symptoms. You might also be asked if you would like to take part in a clinical trial.

Chemotherapy, chemo-immunotherapy and targeted therapies

Many people with high-grade non-Hodgkin lymphoma that has come back or has not responded to treatment have more **chemotherapy** or chemo-immunotherapy. Usually, this is a different type of treatment than your first treatment. Depending on your general health and fitness, it might also be stronger.

Targeted drugs (page 74) are available to treat some types of relapsed or refractory high-grade lymphoma.

You might have to stay in hospital to have some second-line regimens.

The most commonly used second-line regimens include:

- **R-IVAC**: **r**ituximab plus **i**fosfamide, etoposide (**V**P-16) and cytarabine (**A**ra-**C**)
- **R-GDP**: **r**ituximab, **g**emcitabine, **d**examethasone + cisplatin (**P**latinol®)
- **R-DHAP**: **r**ituximab, **d**examethasone, **h**igh-dose cytarabine (**A**ra-C) + cisplatin (**P**latinol®)
- **R-ICE**: **r**ituximab, **i**fosfamide, **c**arboplatin + **e**toposide (or ICE, without rituxiumab)
- **R-ESHAP**: **r**ituximab, **e**toposide, methylprednisolone (**S**olu-Medrone®), **h**igh-dose cytarabine (**A**ra-C) + cisplatin (**P**latinol®)

- **R-GEMOX**: **r**ituximab, **gem**citabine, **ox**aplatin
- **Brentuximab vedotin**: an antibody–drug conjugate (page 78), an option for relapsed or refractory anaplastic large cell lymphoma (ALCL)
- **Pola-BR**: **Pola**tuzumab vedotin, **b**endamustine, **r**ituximab. Polatuzumab vedotin is an antibody–drug conjugate (page 78), an option for relapsed or refractory DLBCL in people who are not able to have a stem cell transplant.

Stem cell transplant

If your lymphoma responds well to second-line 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; page 83). This is to help make your **remission** last as long as possible – which might be for the rest of your life.

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

CAR T-cell therapy

CAR T-cell therapy is a type of treatment that uses your own T cells or T **lymphocytes**. Your T cells are collected and genetically modified (changed) in the lab so they can recognise and kill lymphoma cells.

CAR T-cell therapy is used to treat some types of lymphoma that have come back (relapsed) or not responded (refractory) to treatment.

CAR T-cell therapy is a very intensive type of treatment and you have to be fit enough to have it.

You might be eligible for CAR T-cell therapy if you have:

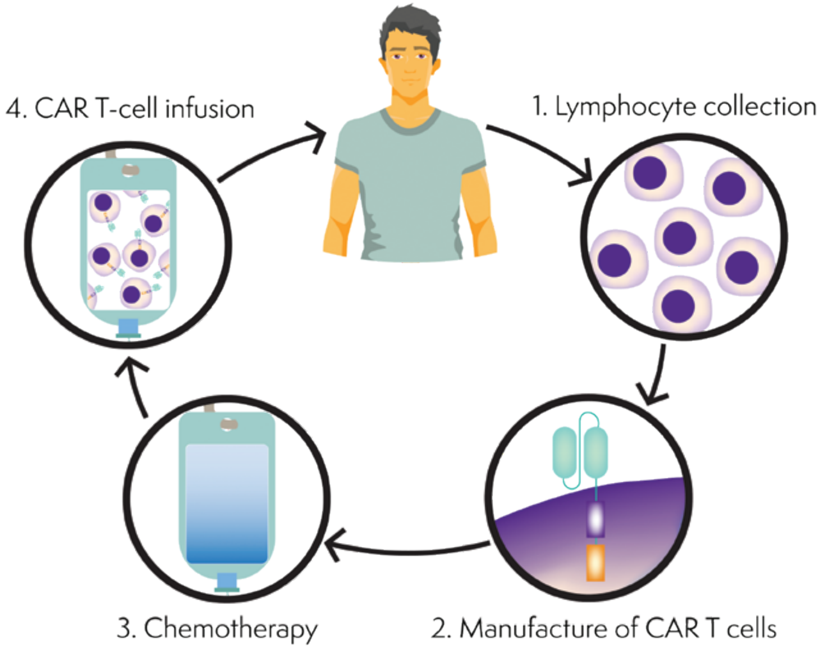
- relapsed or refractory diffuse large B-cell lymphoma (DLBCL)
- relapsed or refractory primary mediastinal large B-cell lymphoma (PMBL)

CAR T-cell treatments have to be made individually for each person. This can take several weeks. You are likely to have other treatments to keep your lymphoma under control while the CAR T-cells are being made. This is called ‘bridging therapy’.

Having CAR T-cell therapy

CAR T-cell therapy involves a number of different steps:

- collecting your T-cells from your blood
- making your CAR T-cells in a lab
- chemotherapy (known as ‘lympho-depletion’)
- having your CAR T-cells through a drip into a vein, or through a central line if you have one
- close monitoring and treatment of side-effects.



CAR T-cell treatment process

CAR T-cell therapy can cause serious side effects. It is only given in hospitals with the facilities and staff to treat side effects effectively. You have to stay in hospital to have the treatment, and you need to stay close to the hospital for another 2 weeks so you can be treated quickly if you develop any side effects.

> **I had a lot of side effects, including rigor attacks, confusion and a high temperature (fever). Everyday my medical team assessed my cognitive abilities. To me, having side effects showed that the CAR T-cell therapy was working.**
> Fiona, who had CAR T-cell therapy for DLBCL

Search CAR T on our website for more information.

Clinical trials

Many new treatments are being tested to see if they can help people with relapsed and refractory high-grade B-cell non-Hodgkin lymphomas. Some of these might be available to you through a clinical trial. They include:

- bispecific antibodies
- antibody-drug conjugates
- checkpoint inhibitors
- BTK inhibitors.

Many new treatments are being tested to see if they can help people with relapsed and refractory high-grade T-cell non-Hodgkin lymphomas. Some of these might be available to you through a clinical trial. They include:

- checkpoint inhibitors
- proteasome inhibitors
- HDAC inhibitors
- chemotherapy drugs
- **antibody therapies**.

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

For information about clinical trials, or to search for a trial that might be suitable for you, visit lymphoma-action.org.uk/TrialsLink

Summary

- Refractory lymphoma is lymphoma that does not respond to treatment.
- Relapsed lymphoma is lymphoma that comes back after responding to treatment.
- If you have relapsed or refractory high-grade non-Hodgkin lymphoma, you are likely to have treatment with a more intensive chemo-immunotherapy regimen.
- If you respond to second-line therapy and you are fit enough, you might have a stem cell transplant.
- Some people might have treatment with targeted drugs or CAR T-cell therapy.
- Your doctor might ask you if you'd like to take part in a clinical trial of an unlicensed or experimental drug.

Notes

I'm not the same person I was when my lymphoma experience began. There's nothing desirable about cancer but for me, I don't want to look back and see it as a negative period in my life. I worry less; I do get more frustrated when I witness behaviour that is unkind or unjust and I try not to waste opportunities. Every moment in life is that much more precious.

Paul, who was diagnosed with high-grade non-Hodgkin lymphoma

After treatment

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, Information and Support Team

Some people feel anxious and low once their treatment finishes. You might start to 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.

> **It's much more scary once treatment's finished. Until then you're caught up in frequent hospital appointments and treatments. Suddenly it feels like you're cut loose. That said, the haematology nurses are still at the end of a phone if needed.**
> Miriam, diagnosed with DLBCL

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.

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 Services team might be able to link you with a peer-support buddy who has personal experience of lymphoma (page 178).

> **Lymphoma – especially a rarer type – feels like a very isolating disease and I had not come across anyone with the same type as mine. I was so ill with the treatment. My Lymphoma Action Buddy saved my life. She told me that it would not always be like this. She said that at some point I would look back and say 'I don't know how I got through this, but I did'. And she knew, because she'd got through it.**
> Tracey, diagnosed with primary mediastinal
> B-cell lymphoma

You could also speak to a member of our Helpline Services 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

> **I had a lot of psychological counselling. Before cancer, I would have been quite dismissive of this type of support, but I found it enormously helpful.**
> Ian, diagnosed with Burkitt lymphoma

- **Search 'health and wellbeing' on our website to find a range of resources to help with your wellbeing.**
- **We have information about recovery from treatment, including about adjusting to life after treatment. Search 'recovery' at lymphoma-action.org.uk**
- **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 (page 178).

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, to help keep any radiation to a minimum.

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.

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.

Our *Introduction to lymphoma* book includes suggested questions you might like to ask your medical team, including about follow-up, and recovery after treatment, and a personalised care plan.

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.

Local health and wellbeing events have been marvellous in finding out about services available – from therapies to support groups.

Ros, diagnosed with diffuse large B-cell lymphoma

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 162).

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 follow-up appointments every few months at first. After this, appointments usually become less frequent.

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

Your medical team can also tell you about any **late effects** to be aware of (page 162) and give you advice about other aspects of your life, such as safety precautions to take if you travel to another country.

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

- **feelings and emotions**
- **coping with symptoms and side effects**
- **relationships, family and friends**
- **self-esteem**
- **managing stress and anxiety**
- **day-to-day living**
- **life after treatment.**

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.

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.*

If you drive and you are diagnosed with **CNS** lymphoma or **peripheral neuropathy** (page 89), 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 'day-to-day' on our website for more information about where to find support with practicalities.

When someone close to you has lymphoma

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.

My husband visited every single morning once he'd taken our little girl to school, so it felt like a little bit of the real me was coming in to see me every day. I don't know how he did it but he put on his cheeky chappy act and brought light to the whole ward, every single day.

Nicola, diagnosed with diffuse large B-cell lymphoma

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

One important message I have is the need to care for carers. Family and friends have to master their own fears. Cancer impacts upon whole families, friends and communities.

Kathleen, diagnosed with Burkitt lymphoma

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.

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 but noticing problems early gives you a better chance of treating or managing them effectively.

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

> **Understanding late effects is such an important part of rehabilitation after treatment. Knowing what organs might have been affected allows people to focus in on what areas are most important when planning life after treatment.**
> Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology

Depending on your lymphoma treatment, if you need to have a blood transfusion in the future, you may need to 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.

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with **radiotherapy** to the chest or very occasionally may be caused by drug treatment. 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. 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 CHOP.

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 high-grade non-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 developing depends on the treatment and 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.

Following a healthy lifestyle (page 158) can help to reduce your risk of health problems in general, including other cancers.

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:

- underactive thyroid (hypothyroidism)
- reduced fertility
- early menopause.

Talk to your medical team or GP if you have any concerns as specialist help may be available.

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: 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**.

We have separate information about reduced fertility on our website. This includes about fertility preservation options for men and women. Search 'fertility' at lymphoma-action.org.uk

Early menopause

Cancer treatments work by killing cells that are dividing quickly. As well as cancer cells, they can also affect some healthy cells, including those in the ovaries that are involved in the development of eggs. When the ovaries stop releasing eggs, levels of the hormones oestrogen and progesterone drop. This causes periods to stop and can cause an early menopause.

We have separate information about early menopause on our website, including symptoms, tips on coping and frequently asked questions. Search 'menopause' at lymphoma-action.org.uk

Less common late effects

There are some other, less common late effects of lymphoma treatment. These might include eye problems such as dryness and cataracts. **Radiotherapy** can increase your risk of tooth decay, diabetes or brittle bones depending on the area of the body treated.

Ask your medical team about any specific late effects you should be aware of.

There is support available to help you live well, with and beyond lymphoma. This includes 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 178 to find out how.

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.

Glossary

Allogeneic	tissues or cells that come from a donor, rather than from you
Anaemia	shortage of red blood cells, which means you don't have enough haemoglobin (the protein that carries oxygen around your body)
Anaesthetic	a drug given to numb part of your body (local anaesthetic) or to put your whole body to sleep (general anaesthetic)
Antibody	a protein made by white blood cells that recognises and sticks to things that don't belong in your body, such as viruses or bacteria and some cancer cells
Antibody–drug conjugate	a monoclonal antibody joined to a chemotherapy drug that can deliver the chemotherapy directly to the target lymphoma cell
Antibody therapy	treatment that uses antibodies made in a laboratory to target cancer cells

Antiemetic	anti-sickness medicine that can help to reduce nausea (feeling sick) and vomiting (being sick)
Autoimmune reaction	if you make abnormal antibodies that react against healthy cells
Autologous	the use of your own tissues or cells, rather than a donor's
B symptoms	fever (temperature above 38°C), night sweats and unexplained weight loss
Biopsy	a procedure that takes a sample of cells that a doctor looks at under a microscope
Bone marrow	the spongy material at the centre of larger bones where blood cells are produced
Bulky disease	swollen lymph nodes that can form large lumps
Central nervous system (CNS)	your brain and spinal cord
Chemotherapy	treatment that uses drugs to kill cancer cells; 'chemo' for short

Chemo-immunotherapy	chemotherapy given with antibody therapy
Chemotherapy regimen	a combination of chemotherapy drugs given at a particular dose and schedule
CNS prophylaxis	treatment that aims to stop lymphoma spreading to your CNS
Contrast agent	a type of dye that helps to show internal structures (blood vessels, organs and tissues) clearly
Cycle	a round of treatment followed by a rest period to allow your body to recover before the next round of treatment
Extranodal	outside the lymph nodes
High-grade	a type of lymphoma that can progress quickly; also called ‘fast-growing’ or ‘aggressive’
HIV	human immunodeficiency virus: the virus that causes AIDS
Immune system	a complex system in your body that prevents and fights off infection

Immunotherapy	treatment that helps your immune system recognise and destroy cancer cells
Intrathecal	injection given into the fluid around your spinal cord
Late effects	side effects that develop months or years after treatment
Low-grade	a type of lymphoma that progresses slowly; also called ‘slow-growing’ or ‘indolent’
Lumbar puncture	a test that involves looking at a sample of the fluid around your spinal cord under a microscope
Lymph	a fluid containing white blood cells that flows in the lymphatic system
Lymphatic system	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
Lymph nodes	small, bean-shaped structures spread throughout your lymphatic system that filter lymph

Lymphocytes	specialised white blood cells (including T lymphocytes and B lymphocytes) that are part of your immune system; the cell that becomes cancerous in lymphoma
MRI scan	magnetic resonance imaging; a scan that uses magnetic waves to produce a picture of the body
Multidisciplinary team (MDT)	a team made up of different professionals, sometimes from more than one hospital, that plans your treatment
Neutropenia	shortage of neutrophils in the blood
Neutrophils	a type of white blood cell that is important in fighting infections
Peripheral neuropathy	damage to the nerves of your peripheral nervous system, which carries signals between different parts of your body
Platelets	tiny fragments of cells in your blood that help your blood clot
Proteins	found in all living things, proteins have many roles including helping to control how your cells work and to fight infection

Radiotherapy	treatment that uses radiation to kill cancer cells
Red blood cell	the type of blood cell that carries oxygen around your body
Refractory	lymphoma that doesn’t respond to treatment
Relapse	lymphoma that comes back after responding to treatment
Remission	no evidence of disease on tests or scans; ‘partial’ remission means the disease has reduced but not gone completely
Spleen	a pear-sized organ behind your ribcage on the left-hand side; it filters blood
Stage	a measure of how much of your body is affected by lymphoma
Stem cells	undeveloped cells that can mature into many different cell types; ‘haematopoietic’ stem cells mature into different types of blood cell

Stem cell transplant	a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells
Steroid	a medicine with anti-cancer effects that also affects your body's response to infection and injuries
Targeted treatments	drugs that interfere with particular proteins or biological processes in cancer cells to stop them growing or dividing
Thrombocytopenia	a shortage of platelets in your blood
Thymus	a small, butterfly-shaped gland behind your breastbone where T lymphocytes develop
Transfusion	having blood or blood products given to you through a drip into a vein
Tumour lysis syndrome	rapid breakdown of tumour cells that releases chemicals that can damage your kidneys and heart
White blood cell	a cell that helps your body fight infections; several different types exist including lymphocytes and neutrophils

Useful organisations

Blood Cancer UK provides information about blood cancers, including stem cell transplants.
0808 2080 888 bloodcancer.org.uk

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

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

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.
0808 808 0000 macmillan.org.uk

Maggie's Centres provides free practical, emotional and social support to people with cancer and their family and friends.
0300 123 1801 maggiescentres.org

Young Lives vs Cancer provides emotional and practical support for young people with cancer and their families.
0300 330 0803 younglivesvscancer.org.uk

Visit lymphoma-action.org.uk/UsefulOrgs 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 or email information@lymphoma-action.org.uk

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

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

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

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

See our website for full details of our services. For our latest news and updates, follow us on social media:

@ lymphomaaction lymphoma_action

If you're interested in finding out more about any of the topics in this book, we have lots more information available on our website.

We also produce a number of books, which are available free of charge. In particular, you might find the following books helpful:

- ***Introduction to lymphoma***
- ***Autologous stem cell transplant***
- ***Living with and beyond lymphoma***

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

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

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

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

References

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

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Notes

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This book is about high-grade non-Hodgkin lymphoma. It describes how high-grade non-Hodgkin lymphoma typically affects people, how it is treated and what to expect during and after treatment.

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

☎ Helpline (freephone) **0808 808 5555** (Mon to Fri, 10am to 3pm)

✉ Email **information@lymphoma-action.org.uk**

Visit **www.lymphoma-action.org.uk**

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

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