

Introduction to lymphoma

What is lymphoma?

Tests and scans

Treatment for lymphoma

Living well

Further support





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

Key contact

Name: _____

Role: _____

Contact details: _____

Job title/role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist or key worker	

About this book

You might be having tests for lymphoma, or you might know someone who's been diagnosed. Whoever you are, however you're feeling, we're here to support you.

This book tells you what lymphoma is, and about the tests and treatments you might have. We've also included some questions you might like to ask your medical team and space to add your notes.

You might want to read only the sections that are relevant to you now and return to others if you need to.

Important and summary points are written in the chapter colour.



Gives practical tips.



Allows space for questions and notes.



Lists other useful online resources.

You might see some words in this book that your medical team use. These words are in **bold purple** and are explained in the glossary on pages 68 to 70.

If you'd like this information in large print, please contact us - see back cover for details.

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My consultant explained that I had a rare form of lymphoma and that although it was fast-growing, it was also treatable. Joining the closed Lymphoma Action Facebook group allowed me to feel part of a community, which has made me feel far less isolated.

Jean, diagnosed with a type of high-grade non-Hodgkin lymphoma

What is lymphoma?

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What is lymphoma?

Lymphoma is the fifth most common type of cancer in the UK. It can develop at any age.

Lymphoma is a type of blood cancer. It develops when a type of white blood cell (**lymphocyte**) grows out of control. Lymphocytes are part of your immune system, which fights infection. Lymphoma is therefore a type of blood cancer, but it can also be referred to as a cancer of the immune system.

There is effective treatment for lymphoma. Generally, people live well for many years after their diagnosis.

There are different types of lymphoma (page 16). Depending on which type you have and where it is in your body, it can cause different symptoms. Some people have no symptoms – their lymphoma is found during tests for another condition.

Common symptoms of lymphoma

The symptoms of lymphoma can have other causes.

Having one or more of these doesn't necessarily mean that you have lymphoma.



Swollen lymph nodes

The most common sign of lymphoma is a lump or lumps, usually in the neck, armpit or groin. These lumps are swollen **lymph nodes**, sometimes known as 'glands'. Usually, they're painless.



Fatigue

Fatigue means feeling exhausted for no obvious reason or feeling washed out after doing very little. It is different to normal tiredness.



Unexplained weight loss

Losing a lot of weight quite quickly without trying to.



Infections

Getting infections more easily and having difficulty getting rid of them.



Sweats

Sweats can happen at any time of the day with lymphoma. If they happen at night, they can make your nightclothes and bed sheets soaking wet and are often described as 'drenching'.



Itching

Itching (pruritus) without a rash can be a symptom of lymphoma. It can be very uncomfortable, particularly when you get hot.



Fevers

Some people get fevers (temperatures above 38°C or 100.4°F). Fevers often come together with night sweats and weight loss, but they can happen separately. They can also be a sign of infection.



Watch a short video about the common symptoms of lymphoma at lymphoma-action.org.uk/Symptoms

B symptoms

You might hear the term 'B symptoms'. This means that you have:

- unexplained weight loss
- night sweats
- fever.

Doctors will take account of whether you have any B symptoms when they plan your treatment.

How cancer develops

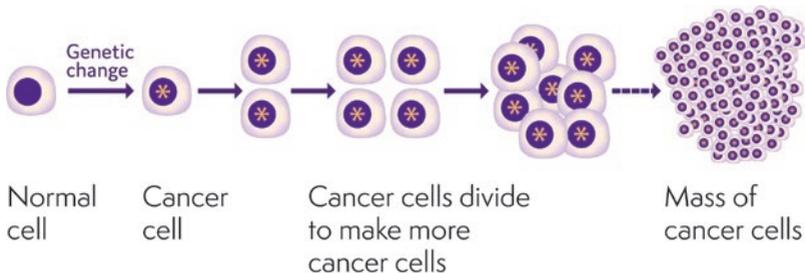
Our bodies are made up of many different cells, for example skin, bone and blood cells. Each day, cells grow and divide to make new cells, replacing old cells that die off naturally. This balance of cell division and cell loss is carefully controlled by chemical signals.

Cancer develops when a mistake (mutation) happens during cell division. This changes the genetic code (DNA) inside a cell. When this happens, it can cause the cell to stop 'listening' to the chemical signals that control cell division.

The cells can then:

- divide and multiply when they shouldn't
- keep dividing when they should stop
- stay alive when they should die.

This breakdown in control leads to the build-up of a large number of unhealthy, abnormal cells, which can form a cancer.



How cancer develops



Search 'what is lymphoma' on our website to find a short video that explains what lymphoma is, how it develops and treatments available.

What type of cancer is lymphoma?

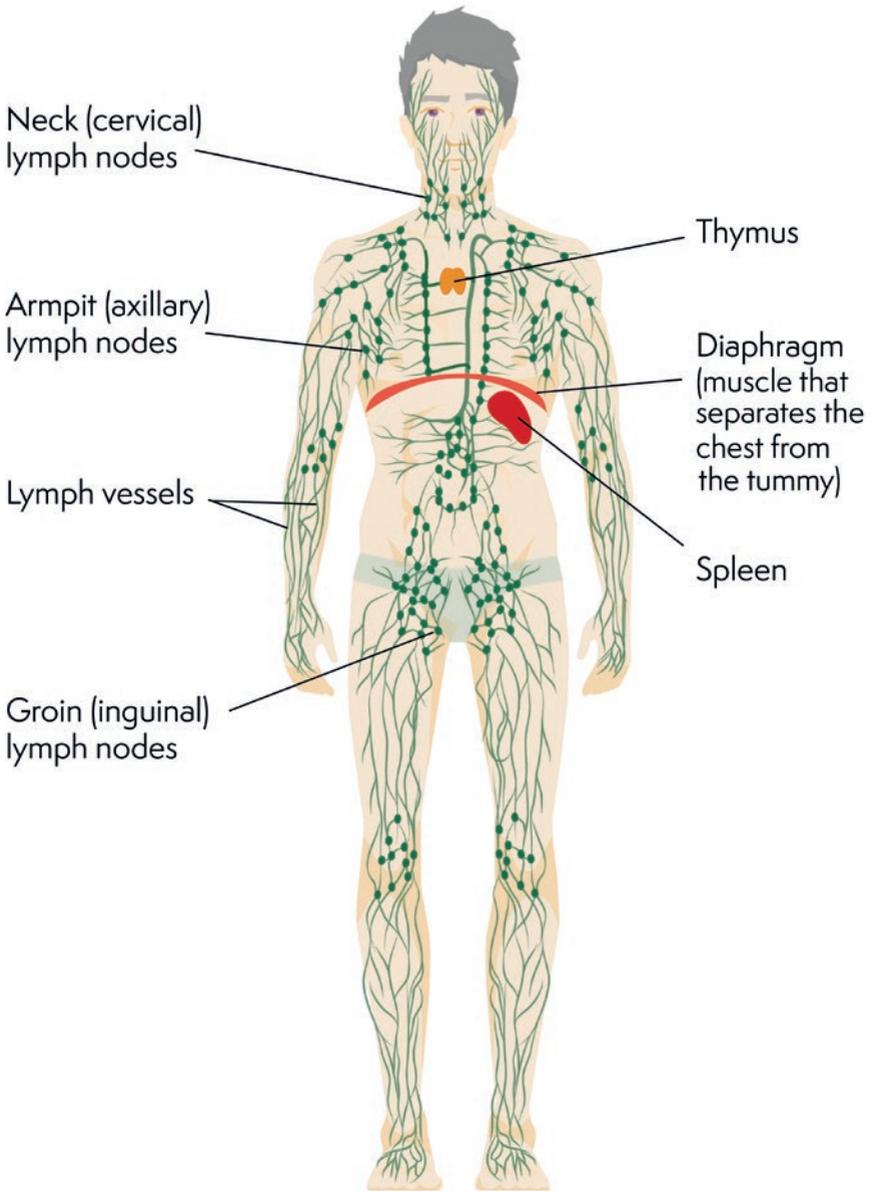
Lymphoma is a cancer of **lymphocytes**. Lymphocytes are a type of white blood cell that fights infection. Healthy lymphocytes travel around your body in the **lymphatic system**, which is part of your **immune system**.

Lymphoma develops when lymphocytes grow out of control. They divide in an abnormal way or don't die when they should, causing a group of lymphocytes to build up.

What is the lymphatic system?

The lymphatic system runs throughout your body. It includes:

- **Lymph nodes**, which contain lymphocytes. Lymph nodes are often found in groups.
- The organs of your immune system, such as the **thymus** and **spleen**.



The lymphatic system

Where does lymphoma develop?

Lymphoma can develop anywhere in the body.

- Usually, lymphoma cells collect in lymph nodes, often in the neck, armpit or groin.
- They can also develop in lymph nodes and tissues (groups of cells) that are deeper inside the body.
- In some people, lymphoma develops in the **bone marrow** (the spongy tissue in the centre of larger bones where blood cells are made).
- Although it's less common, lymphoma can start in other areas of your body, such as the breast, stomach, bowel, brain or liver.
- Rarely, lymphoma develops in the skin. This is known as skin (cutaneous) lymphoma.

What causes lymphoma?

Most of the time, the cause of lymphoma is not known. Scientists think the genetic changes (mutations) that stop cells from listening to their control signals happen by chance.

There is no evidence that anything you have or haven't done caused your lymphoma.

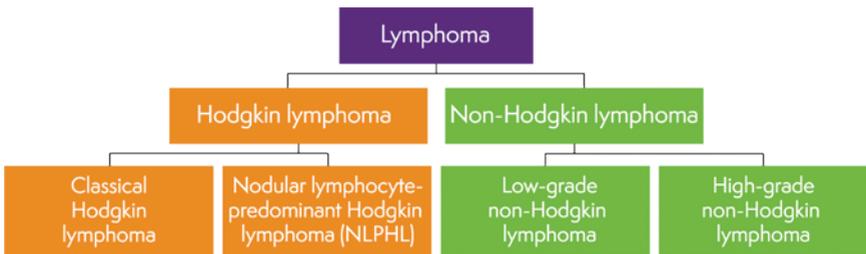
Some people with conditions that affect their **immune system** have a higher risk of developing lymphoma. This includes people with HIV (human immunodeficiency virus) and those who have had an organ transplant.

You can't catch lymphoma and you can't give it to other people. Most of the time, there is no family history of lymphoma.

Types of lymphoma

There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). Within these, there are lots of subtypes.

Based on your symptoms, your doctors might suspect that you have lymphoma. However, you'll need to have tests to be sure (page 21). Tests help doctors find out as much as possible about your specific type of lymphoma. This helps to plan the best treatment for you.



The main types of lymphoma

Below, we outline some of the differences between Hodgkin lymphoma and non-Hodgkin lymphoma.

Hodgkin lymphoma

Over 2,000 people are diagnosed with Hodgkin lymphoma each year in the UK. It affects slightly more males than females. Hodgkin lymphoma can develop at any age. Most people are diagnosed between the ages of 15 and 34, or over 60.

Non-Hodgkin lymphoma (NHL)

Nearly 14,000 people are diagnosed with NHL each year in the UK. In addition, almost 4,000 people each year are diagnosed with chronic lymphocytic leukaemia (CLL), which is often classified as a type of NHL.

In general, NHL affects slightly more men than women.

The risk of developing NHL increases with age. Most people who are diagnosed are over 55. The highest rate of diagnosis is in people aged 80 to 84.

NHL can be classified according to how quickly it's growing:

- 'low-grade' or 'indolent' NHL grows slowly
- 'high-grade' or 'aggressive' NHL grows quickly.

NHL can also be divided into two main types:

- **B-cell non-Hodgkin lymphomas** develop from B lymphocytes (B cells). B cells make **antibodies** to fight infection.
- **T-cell non-Hodgkin lymphomas** develop from T lymphocytes (T cells). T cells attack viruses and cancers.

B-cell lymphomas are much more common than T-cell lymphomas. Both types can be high-grade or low-grade.

This table summarises differences between low-grade and high-grade non-Hodgkin lymphoma.

Low-grade NHL	High-grade NHL
Most commonly affects people aged over 60.	Most commonly affects people aged over 50.
Most common types are chronic lymphocytic leukaemia (CLL), follicular lymphoma and marginal zone lymphoma.	Most common type is diffuse large B-cell lymphoma (DLBCL).
Might not need treatment straightaway (this is called active monitoring – see page 39).	Treatment often starts soon after a diagnosis.
Can come back (relapse) after treatment, so treatment usually aims to control growth.	The aim of treatment is usually to get rid of the lymphoma.

Questions to ask your medical team about your lymphoma

- What type of lymphoma do I have?
- Where is the lymphoma in my body?
- Is the lymphoma growing quickly?
- Are my symptoms caused by the lymphoma?
- What treatment will I be given?
- Will my symptoms improve once I start treatment?
If so, will they go away completely?
- Is there anything I can do to help ease my symptoms?
- Can you prescribe anything to help with my symptoms?
- What is the outlook for my lymphoma?
- Am I likely to need treatment again in the future?



Notes



As the results of the needle biopsy weren't conclusive, I had two lymph nodes removed from my neck under general anaesthetic. I found it a difficult month waiting for the results before my diagnosis was confirmed. I then had further tests and scans before I started treatment.

Owen, diagnosed with a type of high-grade non-Hodgkin lymphoma

Tests for lymphoma

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About tests and scans

Your GP is often the first person you speak to about any health concerns. They can examine you and ask you about any symptoms you have. However, if they suspect that you might have lymphoma, you'll need further tests and scans to confirm the diagnosis.



In this section, we outline tests and scans you might have. However, you might not have all of these. The tests you have are suited to your individual situation and based on the symptoms you are experiencing.

Biopsy

A biopsy is a small procedure that is usually used to confirm whether or not you have lymphoma.

A biopsy takes a sample of tissue from your body. A type of doctor called a 'pathologist' looks at it under a microscope to check for abnormal cells.

Biopsy results take between a few days to a few weeks to come back. It might take longer if your sample needs to be sent to another laboratory (lab) for further tests. For example, not all labs can do all tests, and sometimes further ones are needed to confirm the type of lymphoma or give more information about it.

There are different types of biopsy. Common ones include excision biopsy and core biopsy.

Excision biopsy

You might have a whole lymph node removed during a biopsy, which is sometimes called an 'excision' biopsy. An excision biopsy is a minor operation, usually done under general **anaesthetic**. You're likely to be in the hospital for a few hours.

Core biopsy

Sometimes, a smaller sample of the lymph node is taken under a local anaesthetic. This is called a 'core biopsy'. The procedure is done as an outpatient procedure, guided by **ultrasound**.

What happens once the biopsy results are back?

If the biopsy shows that you have lymphoma, you'll be referred to a specialist lymphoma doctor – either a **haematologist** (who treats blood conditions including cancers of the blood) or an **oncologist** (who treats cancer).

If lymphoma is confirmed, the next step is to find out which parts of your body it affects. This is called 'staging' (page 29).

Bone marrow biopsy

The **bone marrow** is where blood cells are made, in the centre of some of your large bones. You might have a bone marrow biopsy to check if there are lymphoma cells in your bone marrow. This can affect which treatment you need.

Doctors use a small, thin needle to take a sample of bone marrow from your hip bone. The area is first numbed with local anaesthetic.

Blood tests

Blood tests help doctors find out more about your general health and how well your organs are working. This information helps to plan your treatment.

A sample of your blood is taken and sent to be tested in a laboratory.

Scans and X-rays

Scans give detailed pictures of the organs and **lymph nodes** in your body. Some types of scan are better than others at checking different parts of the body.

Doctors say which type of scan is best for you based on several factors. These include the type of lymphoma you have and where in your body it is.

Different scans work in different ways:

- **X-rays** use high-energy radiation
- **CT** or CAT scans use lots of X-rays
- **PET** scans use a radioactive sugar
- **MRI** scans use magnetic waves
- **Ultrasound** scans use sound waves.

CT scans and PET scans are the most frequently used types of scan for lymphomas. They can be combined as a PET/CT, or you might have both types of scan separately.

Scans are painless. They can take between 15 to 90 minutes, although you might be asked to arrive early for any preparation that's needed beforehand.

For around 6 hours after a PET or PET/CT scan, you might give off very low levels of radiation (be 'radioactive'). As a precaution, avoid close contact with pregnant women, babies and young children for around 6 hours.

After a CT scan, MRI scan, ultrasound or X-ray, you won't be radioactive so it's safe to be around other people.



An MRI scanner

Waiting for test results

It can take a couple of weeks for test results to come back. This can feel like a long wait, which can be difficult. During this time, doctors are finding out as much about your lymphoma as possible so that they can plan the best treatment for you.

It felt like a long wait for results. It can be impossible to stop the mind from wandering into all kinds of thoughts. And I had them all. From the worst scenario to more happy outcomes. But then I made an important decision; to go with the flow and accept all thoughts, to neither deny them nor dismiss them.

Paul, diagnosed with a type of high-grade non-Hodgkin lymphoma

We have more information about waiting for test results at lymphoma-action.org.uk/Waiting including a video in which Lymphoma Nurse Specialist Lucy Whiteman explains why it can take a bit of time to get results.

Questions to ask about tests and scans

- What tests and scans are you recommending and why?
- What do these involve?
- Where and when will I have them?
- How safe are they?
- Are they painful? If so, will I have an anaesthetic or sedative?
- Can I drive straightaway after the tests? If not and I don't have anyone to collect me, is there any hospital or community transport available to help me get home?
- Do I need to take time out of work, training or studies after the tests and scans?
- How long will the results take to come back? How will I get them?
- Who will explain the results? Where will this happen?



Notes

Staging of lymphoma

'Staging' is the process of working out where in your body the lymphoma is. This is often referred to as how 'advanced' it is.

Tests and scans help to tell the stage of your lymphoma. Staging helps doctors plan your treatment.

Most lymphomas are given a stage: 1, 2, 3 or 4. Sometimes, these are written in Roman numerals (I, II, III or IV). On pages 30 and 31, you'll find diagrams that explain more about these.

Some lymphomas behave quite differently to most types of lymphoma. Doctors use different staging systems for these. These include non-Hodgkin lymphoma in children, skin (cutaneous) lymphoma, chronic lymphocytic leukaemia (CLL) and Waldenström's macroglobulinaemia.

If the lymphoma measures above a certain size, (depending on its type), it might be called 'large' or 'bulky'.



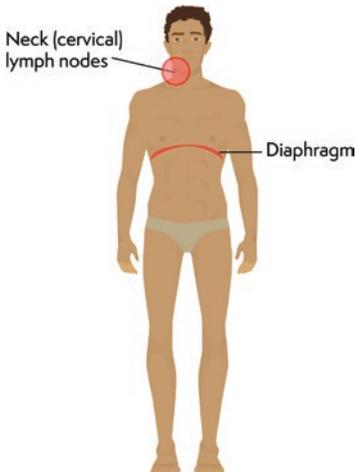
We have more information about these other types of lymphoma on our website, including how they are staged. Search for the type of lymphoma that affects you at lymphoma-action.org.uk

Stage 1 and 2 lymphomas

You might hear stages 1 and 2 called 'early stage' lymphoma.

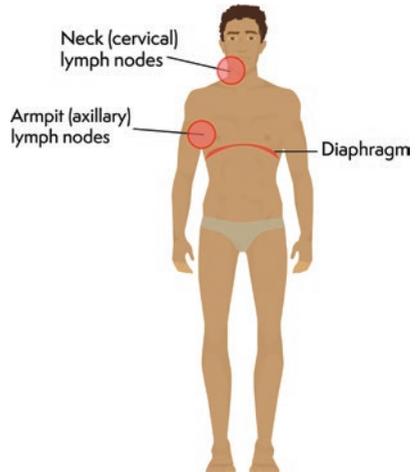
Stage 1

One set of lymph nodes is affected



Stage 2

Two sets of lymph nodes on the same side of the **diaphragm** are affected

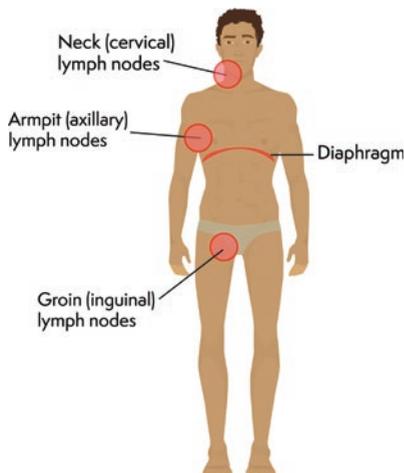


Stage 3 and 4 lymphomas

Stages 3 and 4 are often said to be at an 'advanced stage'. The lymphatic system spreads throughout your body so it's not uncommon for lymphoma to be advanced when it is diagnosed.

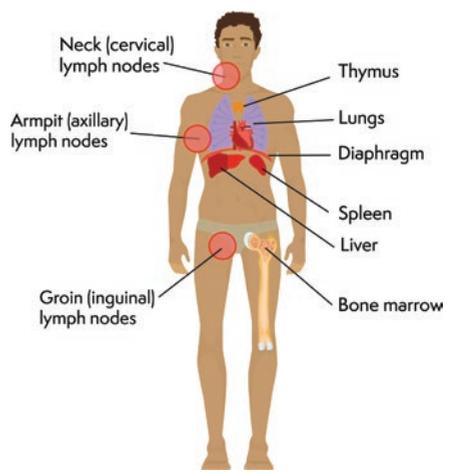
Stage 3

Lymph nodes on both sides of the diaphragm affected



Stage 4

Organs or **bone marrow** also affected (having started in nodes)



There is effective treatment for most types of lymphoma, including advanced stage lymphomas.

Letters in staging

You might also have a letter added to the stage of lymphoma, for example, stage 2B lymphoma.

A	You haven't had any B symptoms.
B	You have B symptoms : weight loss, night sweats or fevers (temperatures over 38°C/100.4°F).
E	'Extranodal' means that the lymphoma started in an organ outside of your lymphatic system, such as in the digestive system or salivary glands.
S	Lymphoma is in your spleen .



Questions to ask about staging

- What stage is my lymphoma? How does this affect treatment?
- Is it at an early or an advanced stage?
- What is the likely outlook?

Your medical team

Your care and treatment is managed by a team of professionals who have different areas of specialist knowledge. Together, they are known as a 'multidisciplinary team' (MDT).

The person with overall responsibility for your care is a consultant – either a **haematologist** or **clinical oncologist**. Your MDT meets to discuss and plan your treatment. You'll meet some of the team members but are unlikely to meet others, such as laboratory staff who look at your biopsy sample.



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



Your clinical nurse specialist (CNS) or key worker is often a good person to contact if you have questions or concerns. They can help you by:

- answering your questions or concerns, during and between appointments
- directing you to sources of practical support for help with things like work and finances
- suggesting where you can find social and emotional support, such as local support groups.

Your GP can also help to explain information they get from the hospital and tell you about local support services.



Notes



I had chemotherapy from November to May, which I generally tolerated well thanks to help from my mum, and also medicines to help manage side effects of treatment. My doctors adjusted my treatment to help me continue living life as normally as possible.

Maddie, diagnosed with Hodgkin lymphoma

Treatment for lymphoma

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Treatment for lymphoma

The treatment you have depends on the type and stage of your lymphoma, as well as on your general health and any other medical conditions you have.

Treatments could include chemotherapy, steroids, targeted therapies, radiotherapy or a stem cell transplant.

In some cases, active monitoring is recommended. This means you don't have treatment straightaway (page 39).

In addition to your lymphoma treatment, your medical team might offer treatments to help with symptoms of lymphoma, or with the side effects of its treatment.

Your multidisciplinary team (MDT) use your test results to guide them in planning your treatment. Your consultant should talk to you about:

- the type of treatment you'll have
- the aim of your treatment and whether it is to rid your lymphoma or to control its growth
- when and where you'll be treated.

You should also have opportunities to talk about your feelings and preferences, and to ask any questions.



Tips for asking questions at appointments

- Think about what you'd like to ask beforehand. It can be helpful to write questions down to take with you.
- If you don't understand information you're given, say so and ask for it to be explained again.
- It can be difficult to remember lots of new information. You could note down key points to come back to later.
- Consider taking someone into your appointments with you. As well as offering moral support, they could help with noting down important points.

Active monitoring (watch and wait)

In some cases, doctors advise active monitoring. This is sometimes called 'watch and wait' or 'active surveillance'. It means keeping checks on your lymphoma and how it is affecting you, rather than treating it straightaway.



'Watch' means you'll have regular check-ups at the clinic to monitor your lymphoma. 'Wait' means waiting until the lymphoma begins to grow or affects your general health before starting treatment.

Usually, this approach is only suitable for some types of slow-growing (low-grade) lymphomas.

Research shows that the long-term outlook for people on active monitoring is the same as for people who have treatment straightaway. There can be additional benefits, however. For example, while you are on active monitoring, you'll have fewer trips to the hospital for treatment, and you won't experience treatment side effects. Waiting until you really need treatment also lowers the risk of lymphoma cells becoming unresponsive (resistant) to treatment.



We have more information about active monitoring on our website, including a video, at lymphoma-action.org.uk/ActiveMonitoring



I am now on active monitoring, like thousands of other people with lymphoma, and love it when I see stories of people still on it 10 or 20 years later.

Kevin, diagnosed with a type of low-grade non-Hodgkin lymphoma

Questions to ask about active monitoring

- Why are you recommending active monitoring?
- Could my lymphoma get worse if I don't have treatment straightaway?
- How often do I need check-ups?
- What happens during a check-up?
- What symptoms should I look out for between check-ups?
- Who do I contact if I'm concerned about symptoms?
- If my lymphoma starts to grow, will I need treatment straightaway? If so, which treatment?
- How long do you expect me to be on active monitoring?
- How can I explain active monitoring to my family and friends?



Notes

Chemotherapy

Chemotherapy ('chemo') is a type of drug treatment. It stops lymphoma cells from dividing.



Usually, more than one drug is given at once. This is known as a 'chemotherapy regimen'. Each drug kills lymphoma cells in a slightly different way.

Chemotherapy is usually given over a few months. You often have the chemotherapy followed by a rest period to allow your body to recover. This is called a 'cycle'.

You can have chemotherapy:

- into a vein (intravenously), which is the most common way
- by mouth (orally), usually in tablet form
- by injection just under the skin (subcutaneously)
- into the cerebrospinal fluid (CSF), which surrounds the brain and spine (intrathecally).

Generally, chemotherapy is given as an outpatient, which means you go into hospital just for a few hours.

As with all treatments, chemotherapy can cause side effects (page 53). These can include fatigue (extreme tiredness), nausea (feeling or being sick) and hair loss. It can also increase your risk

of infection. Your medical team will give you advice on how to lower this risk, as well as telling you any important signs of infection to look out for and what to do if you notice them.

The side effects you experience depend on the specific chemotherapy drugs you're given; however, the same drugs can cause different side effects in different people. Your doctor should talk to you about the side effects you might expect before you start treatment.

Find out more about how chemotherapy works at lymphoma-action.org.uk/Chemotherapy



Steroids

Steroids are a type of drug. They're often used alongside other treatments for lymphoma. Steroids can:

- treat your lymphoma
- make chemotherapy more effective
- reduce some of the side effects of chemotherapy, such as feeling sick (nausea)
- increase your appetite, to boost your energy.

You might have steroids before, during or after chemotherapy. As with any treatment, steroids can cause side effects, such as mood swings, weight gain and difficulty sleeping.



Some people worry about the possible side effects of steroids. Usually, side effects are short-term and go away once you stop taking them. Doctors can often suggest effective ways of coping with them.

Targeted treatments

Targeted treatments work in different ways to affect cancer cells. You might hear them called 'targeted drugs', 'targeted therapies', 'biological therapies' or 'immunotherapies'.

These drugs target the lymphoma cells more precisely than chemotherapy. As well as making treatment more effective, this lowers the impact of treatment on healthy cells, which can reduce side effects.

Many targeted therapies are given in combination with, or after, chemotherapy. This is called 'chemoimmunotherapy'. Combining different types of treatment or using them in certain sequences can improve the overall effectiveness in certain types of lymphoma.

Targeted drugs can:

- stop cancer cells from growing or dividing
- cause cancer cells to die
- help your immune system get rid of cancer cells.



We have more information about how targeted drugs work on our website. Search 'targeted treatments' at lymphoma-action.org.uk

You might have a type of targeted treatment called 'antibody therapy'. Antibodies are proteins that recognise and stick to other proteins that don't belong in your body, such as viruses and bacteria. This signals to your body to get rid of them. When you have an infection, your body naturally makes antibodies.

Antibody therapy uses antibodies made in a laboratory. They target proteins on the surface of lymphoma cells, stick to them and mark them out to be killed by your immune system.



Rituximab is the antibody treatment most often given to treat lymphoma. It can be given on its own or with chemotherapy.

Radiotherapy

Radiotherapy uses high-energy X-rays (a type of radiation) to destroy cancer cells by stopping them from dividing. The X-rays are targeted directly at the areas of your body where there is lymphoma.

Your doctors might recommend radiotherapy after chemotherapy to:

- make sure the lymphoma cells are completely destroyed
- lower the chances of the lymphoma coming back (relapsing).

For a small number of people with low-grade lymphoma, radiotherapy is given on its own.

A course of radiotherapy usually lasts 3 weeks. You have it every day from Monday to Friday. Each treatment lasts around 5 to 20 minutes. Radiotherapy is painless and you can go home afterwards. Depending on where the radiotherapy is targeted, you might experience side effects such as dry or sore skin, or a burning sensation. Fatigue is also likely after treatment with radiotherapy.

Having radiotherapy does not cause you to be radioactive. It's therefore safe to be around others, including children, after treatment.

Stem cell transplants

In some cases, your doctor might recommend a very intense type of treatment called stem cell transplant.

Lymphoma is sometimes treated with very high doses of anti-cancer treatment. This can be very good at killing lymphoma cells, however, it can also damage your **bone marrow**.

A stem cell transplant replaces the damaged or destroyed **stem cells** in your bone marrow with healthy stem cells. You're given the stem cells through a drip into your vein. Usually, the stem cells come from your own body (autologous stem cell transplant). Sometimes, they come from a donor (allogenic stem cell transplant).

It can take a few weeks for your bone marrow to start working after a transplant. During this time, you'll need to stay in hospital and you'll probably be in 'protective isolation'. This means you have your own room to protect you against infections, but you should still be able to have visitors.



I had a stem cell transplant. I found it tough, but I'd say that one day you wake up and can eat breakfast more easily and go to the bathroom less frequently, and the next day it's slightly better.

Jason, diagnosed with Hodgkin lymphoma

CAR T-cell therapy

CAR T-cell therapy is used for some types of high-grade lymphoma that has come back (relapsed) or not responded to previous treatments. It uses cells from your own immune system (called 'T cells' or 'T lymphocytes') to fight lymphoma.

There are different types of CAR T-cell therapy. The one you are offered depends on the type of lymphoma you have.

CAR T-cell therapy can be effective. However, it is a very intense treatment with potentially serious side effects and you need to be physically fit enough to have it.



Questions to ask about treatment

- Which treatment are you recommending? Why?
- How does the treatment work?
- How is it given?
- Where will I have treatment? Will I stay in hospital overnight? If so, what facilities are available?
- How long does each treatment session last? How long does the whole course take?
- Can I drive myself home after treatment? If not, and I don't have someone to collect me, what support is available to help with transport?
- When and how will you know if the treatment is working?
- Will I need to make changes to my day-to-day routine during or after treatment? For example, if I feel well enough, can I continue to work?
- What steps can I take to help lower the risk of infection?
- Are there any foods, supplements or medicines I should choose or avoid?
- Is it OK for me to diet?
- Can I drink alcohol?
- Is it safe to travel to another country during and soon after treatment?
- Is it safe to have sexual contact during treatment? Should I use contraception?
- If my periods stop, could I still get pregnant?
- What happens if I choose not to have treatment?

Clinical trials

Clinical trials are medical research studies.

- Many lymphoma trials investigate the best ways of using current treatments, for example, to make them more effective or to lessen side effects.
- Other trials test new treatments to see if they're more effective than current standard treatments.
- Some trials focus on improving quality of life.

Whether you can take part in a trial depends on a number of factors, known as 'eligibility criteria'. These might include your type of lymphoma, any previous treatment you've had, and your general health. Your doctor might suggest a trial if there is a suitable one.



Clinical trials are voluntary – **it's your decision** whether you take part. If you start a trial but then change your mind, you can withdraw at any time.



We have an online clinical trials information service, Lymphoma TrialsLink, where you can search for a trial that might be suitable for you. Search 'TrialsLink' on our website.

Speak to your clinical nurse specialist or consultant to find out more about clinical trials. If you're interested in the possibility of entering one, ask whether there is one that's suitable for you.



My consultant asked if I'd be interested in a clinical trial. Initially I was worried about being a guinea pig, but he went through the strict protocol in detail. I wanted to help provide data for scientists to analyse. But I also realised that I would still get good treatment and a lot of care and follow-up.

Stephen, diagnosed with a type of low-grade non-Hodgkin lymphoma





Questions to ask about clinical trials

- Is there a suitable clinical trial for me? What's involved?
- What happens if I choose not to take part?
- Can I leave the trial if I change my mind once I've started it?
- How can you support me with any side effects?
- When will the results of the trial be available?
- How and when will I find out about the results of the trial?



**We have more suggestions on our website.
Search 'questions about clinical trials' at
lymphoma-action.org.uk**

Side effects of treatment

Although the aim of treatment is to destroy all of the lymphoma cells, all treatments have other, unwanted effects, known as 'side effects'.

Different treatments have different side effects. For example, the side effects of chemotherapy depend on the specific drugs you have. The side effects of radiotherapy depend on which area of your body is treated. However, the same treatment can affect different people differently.



It's impossible to say for certain which side effects you'll have, but your doctor should tell you what you might expect and give you advice to help you take care of yourself during treatment. You should be given information about who to contact if you have concerns. Ask for this information if you're not given it.

Most side effects are short-term, but some can last for a few weeks or months after you finish treatment. Some side effects start months or even years after you finish treatment. These are called **late effects**. Rarely, side effects are long-lasting or even permanent.



We have information on our website about side effects, including tips to help you cope with them.

Questions to ask about side effects

- What are the most likely side effects of my treatment?
- What other side effects might I get?
- How long are any side effects likely to last?
- Is there anything I can do to lessen these side effects?
- How can you support me with any side effects?
- Will my treatment affect my fertility? If so, what can I do to help preserve it?
- Are there any late effects I should look out for?



Notes



Notes



I finished my treatment in June 2019 and was back at work the following month. For my mental wellbeing I really needed to get back to some sort of normality.

Surinder, diagnosed with nodular lymphocyte-predominant Hodgkin lymphoma

Living well

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Recovery after treatment

Treatment for lymphoma can affect you physically, emotionally and practically.



From the point of diagnosis onwards, your medical team should work with you to identify and address your needs, including those that are physical, practical, social, emotional or spiritual. This is sometimes called a 'holistic needs assessment (HNA)'.

Different health professionals are involved in finding out about your needs and in making suggestions to help. These might include your consultant, CNS, dietitians and physiotherapists.

Personalised care and support

The NHS is committed to offering tailored care and support to everyone living with and beyond cancer. This is known as a personalised care and support plan.

Personalised care might include:

- **Holistic needs assessment (HNA)**, which is a questionnaire to help you and your medical team work together to identify and address any practical, financial, physical, emotional and social needs you might have.
- **Treatment summary**, that outlines your diagnosis and treatment, as well as its possible side effects and late effects. It should also tell you what symptoms you should look out for and who to contact if you notice them, including an out-of-hours number. The summary should outline your follow-up plan and any lifestyle recommendations, for example about diet and exercise.
- **Cancer care review**, which is a conversation you have with your GP or a GP surgery practice nurse. It's an opportunity to check in about any medical needs you might have and to talk about any points raised in your HNA. You could also find out about any financial support available to you, including prescription charge exemptions.
- **Health and wellbeing events**, which aim to help people affected by cancer and their families live well. An example is our Live your Life programme (page 61).

Learn more about the support available after treatment for lymphoma on our website. Search 'recovery after treatment' at [lymphoma-action.org.uk](https://www.lymphoma-action.org.uk)





Questions to ask about recovery from treatment

- Will I need to make changes to my day-to-day routine? If so, for how long?
- When can I go back to work?
- How long is it likely to be before my energy levels return to pre-treatment levels?
- Where can I get financial advice and support?
- What emotional support is available to help with my recovery?
- How soon after treatment can I have dental treatment?
- Is it OK to have vaccinations? Should I have the winter flu jab?
- When can I start using my usual hair products again?
- If I want to start a family, how long should I wait after finishing treatment?
- Do I need to declare my lymphoma diagnosis on applications for paid employment or voluntary positions?



- **Our Helpline Services offer support if you'd like to talk about any aspect of your lymphoma, including how it affects your life and how you're feeling. Find out how to get in touch on page 71.**
- **We also offer free workshops to give you practical advice and support to help you live with and beyond lymphoma. These Live your Life workshops are for people who have finished lymphoma treatment or are on active monitoring. Find out more at lymphoma-action.org.uk/LYL**



I found the Live your Life workshop provided a safe space for me to recognise and accept my feelings in a safe environment and to discuss with others the different ways in which I could move on and find a new norm.

Dorothy, diagnosed with a type of low-grade non-Hodgkin lymphoma



Tips to help you live well after lymphoma

- Lead a healthy lifestyle. This means eating well, building physical activity into your day-to-day life, and not smoking.
- Tell a member of your medical team or your GP if you have concerns or struggle with side effects. They can suggest ways of helping and signpost you to other organisations that could help.
- Ask about possible late effects and any signs or symptoms to look out for.
- Go for any health tests you're offered, such as checks for high blood pressure and cancer screening.

“



I take more care of my body now. In fact, I feel healthier than I did before my treatment. I have joined a gym and am doing exercise 5 or 6 times a week now. This isn't something I did before, but I'm really enjoying it.

Lyle, diagnosed with Hodgkin lymphoma



I had a meeting with a very helpful nurse specialist who said I could contact her if I ever needed to between appointments, which were roughly every three months.

Pat, diagnosed with a type of low-grade non-Hodgkin lymphoma

Follow-up

Once your treatment finishes, you'll be offered regular check-ups. The aim of follow-up is to:

- give you a chance to ask questions and talk about any concerns you have
- check your recovery
- help you to manage any side effects and late effects of treatment
- check for signs of relapse.

During follow-up, your doctors will ask you how you're feeling. You might also have physical examinations, blood tests and scans. You'll be given information about whether these appointments will be at the hospital where you were treated, or at your local GP surgery.

The schedule for follow-up depends on a number of factors, including the type of lymphoma you've had, the usual practice (protocol) at the hospital you've been treated at, and your preferences. Clinical trials have their own follow-up protocol, so you'll have check-ups according to this.

As a general guide, you might have check-ups every 2 to 4 months once treatment finishes. Gradually, follow-up appointments become less frequent, spreading out to around once every 3 to 6 months. In time, they'll probably drop down to once a year.

If you're in full or partial **remission** (no evidence of lymphoma from tests and scans) and you're at a low risk of relapse, you might be offered a self-management scheme known as 'patient-triggered follow-up' (PTFU) or 'remote monitoring'.

Your medical team fully support you throughout PTFU. They offer clear guidance about when and how to contact them, and how to book appointments, for example if your symptoms worsen.

A lot of people find the idea of self-monitoring a bit daunting at first; however, they then find it helps to give them a greater sense of control over their health.

If you've been in remission for a number of years, you might be discharged from hospital follow-up; however, this depends on the protocols at your hospital.

Questions to ask about follow-up

- What happens at follow-up appointments?
- How often will I have follow-up appointments?
- Why am I being offered follow-up appointments?
- Can I have follow-up appointments by phone or video call?
- Are there any symptoms I should look out for that could mean the lymphoma has relapsed?
- Who should I get in touch with if I'm worried between appointments?
- Where can I go for help, support and advice?



Notes

If the lymphoma comes back (relapses)

The risk of relapse depends on the type of lymphoma you have and the type of treatment you've had.

Lymphoma sometimes relapses after treatment. It's natural to worry about this possibility. Keep in mind that many people go on to have further successful treatment, and that nothing you have done or haven't done has caused the relapse.



I was first diagnosed with lymphoma 23 years ago and it has relapsed several times. Each time, I've been offered further treatment plans. The healthcare professionals looking after me are always very sympathetic, give me lots of time to absorb the information, and answer any questions that I or my family want to ask. Despite my distress, they reassure me that I can be helped. I've been living with lymphoma for a long time now – I'm still here and I'm still fit enough to look after my grandchildren and now also a new puppy!

Nuala, whose lymphoma transformed (changed) from a low-grade to a high-grade type

Questions to ask about relapse

- Is my lymphoma likely to relapse?
- How will you know if the lymphoma relapses?
- What symptoms should I look out for?
- Is there anything I can do to reduce the risk of relapse?
- What treatment might I have if I relapse?
- How likely is it that the lymphoma will go into remission with more treatment?
- How can I cope with anxiety related to the possibility of relapse?



Notes

Glossary

Anaesthetic	a drug given to make a part of your body numb (local anaesthetic) or to put your whole body into a sleep-like state (general anaesthetic)
Antibody	a protein made by white blood cells that sticks to proteins on things that don't belong in your body, such as viruses, bacteria and some cancer cells
B symptoms	three significant symptoms of lymphoma: fever, drenching night sweats and unexplained weight loss
Bone marrow	the spongy material at the centre of larger bones where blood cells are made
Clinical oncologist	a doctor who specialises in treating people who have cancer
CT scan	short for 'computed tomography', a scan that uses X-rays to take pictures through your body
Diaphragm	the sheet of muscle that separates your chest from your tummy (abdomen)

Haematologist	a doctor who specialises in diseases of the blood, including lymphoma
Immune system	the system in your body that fights off and prevents infection
Late effects	health problems that develop months or years after treatment has ended
Lymph nodes	small structures spread throughout your lymphatic system, they filter the liquid that flows through your lymphatic system (lymph)
Lymphatic system	a network of tubes, nodes and organs that runs throughout your body; it is part of the immune system
Lymphocytes	specialised white blood cells that are part of your immune system; the cells that become cancerous in lymphoma
MRI scan	short for 'magnetic resonance imaging', a scan that uses magnetic waves to make cross-sectional images of your body
PET scan	short for 'positron-emission tomography', a scan that uses a harmless radioactive form of sugar to look at how active cells are

Protein	found in all living things, proteins have many roles, including helping to control how your cells work and to fight infections
Relapse	lymphoma that has come back after treatment
Remission	disappearance or significant shrinkage of lymphoma
Sedative	a drug to relax you given through a vein to enable a procedure to be done more comfortably and easily
Spleen	a pear-sized organ behind your ribcage on the left-hand side; it filters blood
Stem cells	undeveloped cells that can mature into many different cell types; 'haematopoietic' stem cells can mature into different types of blood cell
Thymus	a small, butterfly-shaped gland behind your breastbone where some immune cells develop; where T lymphocytes develop
Ultrasound scan	a scan that uses soundwaves to take pictures inside your body

Further information and support

Contact us for information and support.



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



Come to one of our **Online Support Meetings**. Find one for 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 find 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 covered in this book, we have lots more information on our website. We also produce a number of books, which are available free of charge, including:

- *Hodgkin lymphoma*
- *High-grade non-Hodgkin lymphoma*
- *Low-grade non-Hodgkin lymphoma*
- *Chronic lymphocytic leukaemia and small lymphocytic lymphoma*
- *Young person's guide to lymphoma*
- *Living with and beyond lymphoma*
- *When someone close to you has lymphoma*

Find our full range of books and information at lymphoma-action.org.uk/Books

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

How you can help us

Volunteering is at the heart of what we do. 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 strive to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.

Lymphoma Action is a charity and relies on the generosity of its supporters. If you or your family would like to get involved with some of our fundraising activities, visit lymphoma-action.org.uk/GetInvolved

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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This book outlines what lymphoma is, what tests you might have and what treatment is available. It also covers follow-up and life after lymphoma.

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



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



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



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



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