

Introduction to lymphoma



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If you would like to make a donation to Lymphoma Action to help us continue providing information and support to people affected by lymphoma, you can do so at lymphoma-action.org.uk/Donate



My lymphoma type:

Key worker contact

Name: _____

Role: _____

Contact details: _____

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

About this book

Whether you're having tests, you've been diagnosed, or you're supporting someone with lymphoma, we're here for you.

This book tells you what lymphoma is, and about possible tests and treatments. There's also information to help you live well, with and beyond lymphoma.

You might want to read only the sections that are relevant to you now and return to others as and when you need to. We've included some questions you might like to ask your medical team and space to add notes.

Words in **bold purple** are explained in the glossary on pages 76 to 78.

You can find our full range of resources on our website.

If you can't find the information you're looking for, or in the format you would like, please contact us (see page 79).

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“ After discovering the lump, I made an appointment with my GP and had tests that confirmed lymphoma. I felt conflicted emotionally: relieved to have a diagnosis and positive to know there was treatment available. But I also felt very daunted. I found Lymphoma Action’s information and support very helpful, as well as having psychological therapy during my treatment.

Tom, diagnosed with lymphoma

What is lymphoma?

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What is lymphoma?

Lymphoma is a type of blood cancer because it develops when white blood cells called **lymphocytes** grow out of control. However, some people think of it as a cancer of the **immune system** – this is because lymphocytes are part of your immune system (which fights infection).

A few key facts:

- Lymphoma can happen at any age.
- There are over 60 types of lymphoma.
- In most cases, there is no known cause.
- There is effective treatment and, generally, people live well for many years after diagnosis.

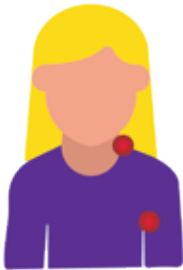
Your medical team will work with you to choose the best treatment plan for your situation.

There is information about how cancer develops on page 11.

Common lymphoma symptoms

Symptoms depend on the lymphoma type and where it is in your body. Some people don't have symptoms though, and the lymphoma is found during tests for something else.

The most common lymphoma symptoms are shown below, but all of these can have other causes.



Swollen lymph nodes

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



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 (over about 6 to 12 months).



Infections

Getting infections more easily than you usually would and having difficulty getting rid of them.



Sweats

These can happen at any time of the day, but most commonly at night. Some people describe them as 'drenching' as they make your nightclothes or bed sheets soaking wet.



Itching

Itching (pruritus), without a rash, which can be very uncomfortable, particularly when you are hot.



Fevers

Some people get fevers (temperatures above 38°C or 100.4°F). Usually, these come and go. Fevers often come together with night sweats and weight loss, but they can happen separately.



Search 'lymphoma symptoms' on our website to read more and to watch a short video about common symptoms.

B symptoms

Doctors use the term '**B symptoms**' to describe a set of symptoms:

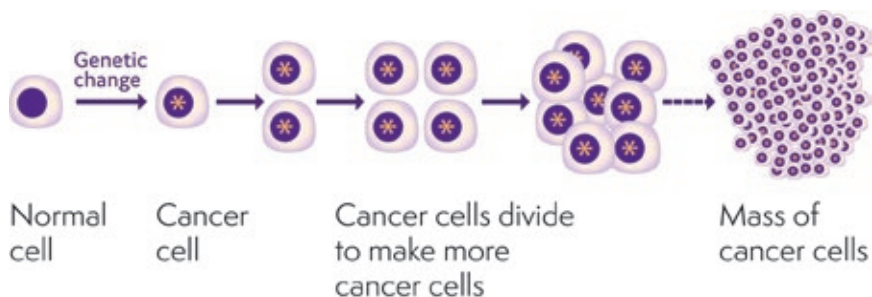
- unexplained weight loss
- night sweats
- fever.

B symptoms can give doctors information about your lymphoma and help them plan the best treatment for you.

How lymphoma develops

Our bodies are made up of lots of different types of cell. Cells grow and divide to make new cells every day. This replaces old cells that die off naturally. The process is carefully controlled by chemical signals. Some cells, such as skin cells and blood cells, are dividing all the time.

Cancer can happen when there is a mistake (genetic change or 'mutation') that happens as a cell divides. This changes the genetic code (DNA) inside a cell. Because of this, the cell can stop 'listening to' the chemical signals that control cell division. This can cause a build-up of abnormal, unhealthy cells and form a cancer.



How cancer develops

The cells that build up in lymphoma are lymphocytes, which 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 (page 13).

Lymphoma develops when lymphocytes grow out of control. Lymphocytes might then:

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

A group of unhealthy lymphocytes can then build up, causing lymphoma to develop.



Search 'What is lymphoma?' on our website for more information and to watch a short video about how lymphoma develops.

If you've been diagnosed with lymphoma, your medical team should help you to manage any needs you have. These could be physical, practical, social, emotional or spiritual. To help identify these areas, you have a holistic needs assessment (HNA), which is often completed as a questionnaire that you go through with a member of your medical team.

Around 3 to 12 weeks after diagnosis, you should also be offered a cancer care review (page 68).

The lymphatic system

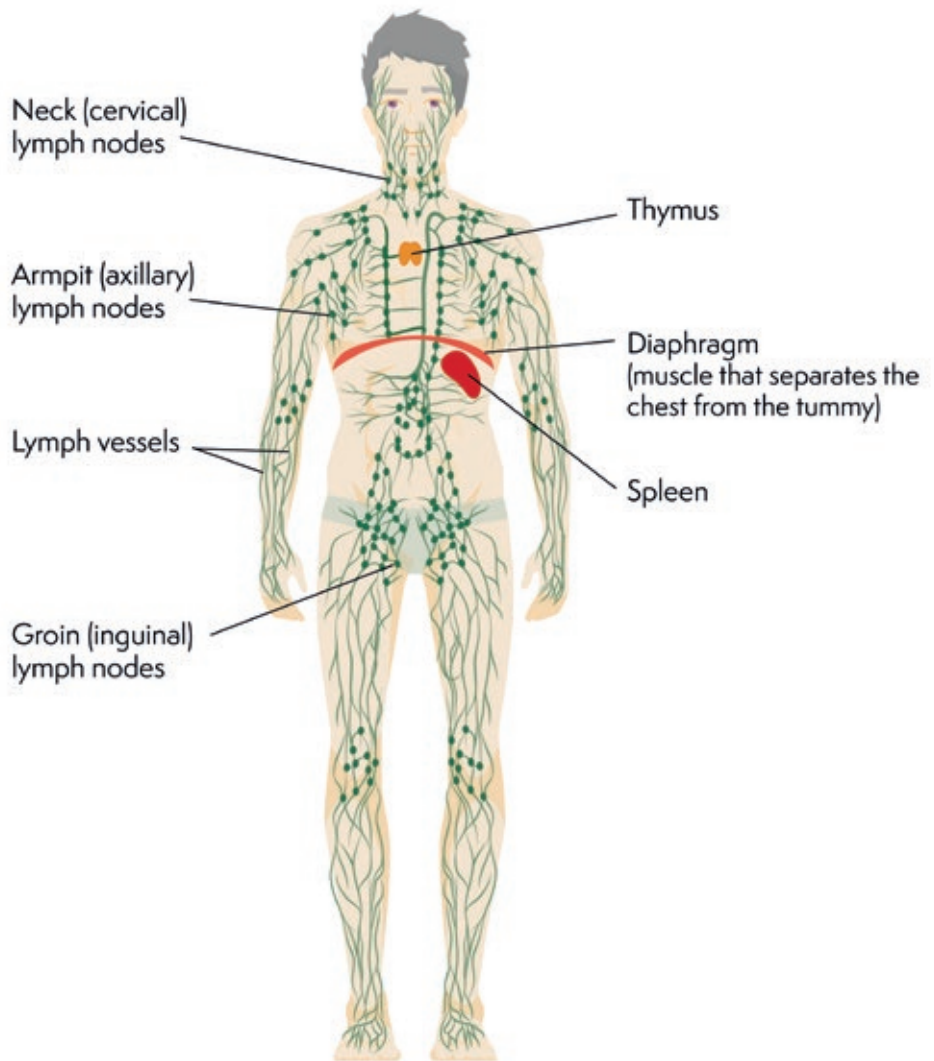
The lymphatic system runs throughout your body and includes:

- lymph nodes (containing lymphocytes), often found in groups
- the organs of your immune system (such as the **spleen** and **thymus**).

Where in the body can lymphoma develop?

Usually, lymphoma develops in lymph nodes – often in the neck, armpit or groin. However, it can develop anywhere, including:

- in lymph nodes and groups of cells deeper inside the body
- in the **bone marrow** – the spongy tissue in the centre of larger bones, where blood cells are made
- less commonly, in other areas of your body, such as the breast, stomach, bowel, brain or liver
- rarely, in the skin – known as skin (cutaneous) lymphoma.



The lymphatic system

What causes lymphoma?

Most of the time, the cause of lymphoma is not known.

Scientists think the mutations that stop cells from listening to their control signals happen by chance.

Some things increase your chance of developing lymphoma. These are known as risk factors.

Possible risk factors include having:

- had certain viral and bacterial infections
- a lowered immune system – for example, people who have HIV (human immunodeficiency virus) or have had an organ transplant
- certain autoimmune conditions (where your immune system mistakenly attacks your body)
- ongoing high exposure to certain chemicals.

Having one or all of these does **not** mean you will develop lymphoma. It means you are a bit more likely to develop lymphoma than someone without risk factors.



We have more information on our website about possible causes and risk factors.

Lymphoma types

Understanding a bit about which type of lymphoma you have can help you make sense of your diagnosis and treatment options.

The two main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). However, within these, there are lots of subtypes.

Below, we outline some key facts about Hodgkin and non-Hodgkin lymphoma.

Hodgkin lymphoma

Over 2,000 people are diagnosed with Hodgkin lymphoma each year in the UK – this is roughly six people each day.

Hodgkin lymphoma:

- can develop at any age, but most people diagnosed are between 15 and 34, or over 60
- affects slightly more males than females
- can develop in people of any ethnicity.

Non-Hodgkin lymphoma (NHL)

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

Non-Hodgkin lymphoma:

- can develop at any age, but most people are over 55 at diagnosis
- affects slightly more males than females
- can develop in people of any ethnicity.

Doctors classify NHL based on how quickly it's growing:

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

It can also be grouped into 2 main types:

- **B-cell non-Hodgkin lymphomas**, which develop from B lymphocytes (B cells). B cells make a type of **protein** called antibodies, which fight infection.
- **T-cell non-Hodgkin lymphomas**, which develop from T lymphocytes (T cells). T cells attack viruses and cancers.

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

The table below summarises the main differences between low-grade NHL and high-grade NHL.

	Low-grade NHL	High-grade NHL
Age group most commonly affected	Over 60.	Over 50.
Most common types	<ul style="list-style-type: none"> • Chronic lymphocytic leukaemia (CLL). • Follicular lymphoma. • Marginal zone lymphoma. 	<ul style="list-style-type: none"> • Diffuse large B-cell lymphoma (DLBCL). • Burkitt lymphoma.
Treatment approach	Might not need treatment straightaway (active monitoring – see page 44).	Treatment often starts soon after a diagnosis.
Treatment aim	Usually, to control growth as low-grade NHL can come back (relapse).	Usually, to get rid of the lymphoma.

Questions to ask your medical team about your lymphoma

- What type of lymphoma do I have?
- Is it growing quickly?
- Whereabouts in my body is the lymphoma?
- How might the lymphoma affect me – for example, in my day-to-day routine?
- What treatment approach do you advise?
- Is this the only treatment I'll need, or might I need more in the future?
- How can you help me manage any symptoms I have?
- What can I do to help myself?
- What is the outlook for my lymphoma?
- What emotional support is available to me?
- What **side effects** should I expect?
- Should I make any lifestyle changes, for example, to my day-to-day routine, diet and exercise).



Notes

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. Health professionals are used to being asked for things to be explained again, or in different ways.
- It can be difficult to remember lots of information given to you during appointments. You could note down key points to look at later.
- Think about taking someone to appointments with you. As well as offering moral support, they could help with noting down important points.



We have more tips, offered by our Facebook Support Group community. Search 'top tips for getting the best from your appointments' on our website.



Notes



“ *The GP referred me to an ENT specialist. I then had several tests, including a biopsy and CT scan. The lymphoma diagnosis was a huge shock, but once my treatment plan was set, I was strangely keen to get things started.*

Rachel, diagnosed with Hodgkin lymphoma

Tests and diagnosis

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Tests and scans help doctors diagnose lymphoma. They also help them find out more about it after a diagnosis is confirmed. They use this information to plan the best treatment for you. You might also have tests to see how well treatment is working.

Your doctors should explain why they are referring you for any tests or scans. You might not have all the tests outlined in this section – just the ones that are most suited to your situation.

Some people feel very anxious about having tests and scans – talk to your doctor before the day of your test or scan if you feel this way.

Tests and investigations at your GP surgery

You can talk to your GP about your symptoms. They might examine your body to check for swollen (enlarged) lymph nodes.

You might also have simple tests at your GP surgery, to find out more about your symptoms. Examples include blood tests (page 26) or an electrocardiogram (ECG), which records the electrical activity of your heart.

It is not possible, however, for your GP to know from these tests and investigations alone whether or not you have lymphoma. You need to be referred for a biopsy and any other further tests at a hospital before a diagnosis can be confirmed.

Biopsy

A biopsy is a small operation that is usually used to confirm a lymphoma diagnosis.

During a biopsy, doctors take cells from your body to look at under a microscope. In most cases, the cell sample is taken from a lymph node. Very occasionally, it is taken from an organ (such as your liver) or another area (such as part of your skin). Your doctor can explain where your biopsy will be taken from and why.

The most common types of biopsy are outlined on page 26.

Results can sometimes come back as quickly as within a few days. However, it often takes up to 2 weeks. If your biopsy sample needs to be sent for further laboratory tests, it could mean waiting up to about 4 weeks.

Ask your doctor how long you can expect to wait before you get your results.

There's more information about waiting for the results of tests and scans on page 30.

You can also listen to our podcast, which addresses some of the commonly asked questions about biopsies for lymphoma at [Lymphoma-action.org.uk/Podcast#BridgetWilkins](https://lymphoma-action.org.uk/Podcast#BridgetWilkins)



Needle core biopsy

A needle core biopsy uses a needle to take a small sample of a lymph node, guided by **ultrasound**. You have the procedure as an outpatient. It is done under local **anaesthetic**.

Excision biopsy

An excision biopsy takes a whole lymph node to be examined. If the lymph node is near the surface of your skin, it's usually done under local anaesthetic. If it is deeper inside your body, you might have a general anaesthetic. An excision biopsy is a minor operation. You go to hospital as an outpatient for a few hours.

If the biopsy results confirm a lymphoma diagnosis

If lymphoma is confirmed, you'll be referred to a specialist lymphoma doctor – either a haematologist (who treats blood conditions including cancers of the blood) or a **clinical oncologist** (who treats cancer).

The next step is to find out which parts of your body lymphoma affects. This is known as staging (page 32).

Blood tests

Blood tests can be used for several reasons, including to find out:

- more about your general health
- how well your organs are working
- how lymphoma is affecting your body.

This information can help to plan your treatment.

Bone marrow biopsy

The bone marrow is in the middle of your larger bones. It is where blood cells are made.

You might have a bone marrow biopsy to check if lymphoma cells are in your bone marrow. A sample of bone marrow is taken from your hip bone. The area is first numbed with local anaesthetic.

Scans

Scans give clear, detailed pictures of the organs and lymph nodes in your body.

Scans can take between 15 to 90 minutes, depending on the type of scan. However, you might be asked to arrive early for any preparation that's needed beforehand. You'll be given all the information you need about this in advance of the day.

Doctors will choose the type of scan that is best for you. Some are better than others at checking different parts of the body.

“ *I had blood tests and an ultrasound of my neck. The doctors suspected a blood condition, probably cancer. After a biopsy and PET scan, I was diagnosed with lymphoma.*

Jennie, diagnosed with high-grade non-Hodgkin lymphoma

Scans work in different ways to build up a picture of the inside of your body. For example:

- an X-ray uses high-energy waves, similar to radio waves
- a **computed tomography (CT or CAT)** scan uses lots of X-rays
- a **positron emission tomography (PET)** scan uses a harmless radioactive sugar
- a **magnetic resonance imaging (MRI)** scan uses magnetic waves
- an **ultrasound scan** uses sound waves.

CT scans and PET scans are the most commonly used types of scan for lymphoma. You might have a PET/CT scan, where you have both scans in one appointment.



CT scanner

You might give off very low levels of radiation (be 'radioactive') after a PET/CT scan until the radiotracer leaves your body. As a precaution, avoid close contact with pregnant women, babies and young children during this time – your medical team will tell you how long and can give you advice if this might be difficult.



Search 'tests, scans and staging' on our website for more information and to watch a video in which Consultant Radiologist Dr Subesinghe outlines the role of scans.

“ *I was referred for an ultrasound scan, blood tests, an X-ray and a biopsy over three weeks. Despite my professional experience as a cancer nurse working for Macmillan, nothing could prepare me for an actual diagnosis. My advice would be to take the help and support on offer, and tell people what they can do to help you.*



Emma, diagnosed with Hodgkin lymphoma

Waiting for the results of tests and scans

The health professional referring you for any tests and scans can tell you how long it'll be before you can expect the results. They should also tell you how, when and where you'll be given them.

Different professionals with different areas of specialist expertise look at the images from tests and scans. Together, they find out as much about your lymphoma as possible, to plan the best treatment for you.

Many people find the uncertainty of waiting for results of tests and scans very stressful and emotionally challenging. Contact your GP if you are concerned about how long you've been waiting. Our Helpline Team is also here to offer emotional support and practical information.



We have more information about waiting for test results, including tips to help manage the wait. You can also watch a video in which Lymphoma Nurse Specialist Lucy Whiteman explains why it can take a bit of time to get results. Visit lymphoma-action.org.uk/Waiting

Questions to ask about tests and scans

- What tests and scans are you referring me for and why?
- What happens during them?
- Where and when will I have them?
- Is there anything I need to do to prepare for my test or scan?
- Will I have an anaesthetic?
- How long will the tests and scans take?
- Do they come with any risks?
- Are there any precautions I need to take after having them?
- Can I drive home afterwards? If not and I don't have anyone to collect me, is there any hospital or community transport available?
- When can I expect the results and how will I get them?
- Who will explain the results to me?
- What happens next after I get the results?



Notes

Lymphoma staging

The stage of a lymphoma is a description of how much of your body is affected. Tests and scans help doctors work out the stage of your lymphoma. This helps them plan the best treatment for you.

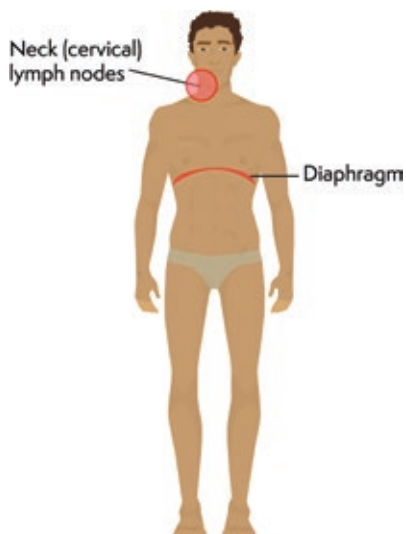
Most lymphomas are staged as 1, 2, 3 or 4. Sometimes, these are written in Roman numerals (I, II, III or IV). The diagrams on pages 33 and 34 explain more about these. You might also be given a letter after your stage (see page 35).

Doctors use different staging systems for some lymphomas that behave differently to most lymphoma types. These include:

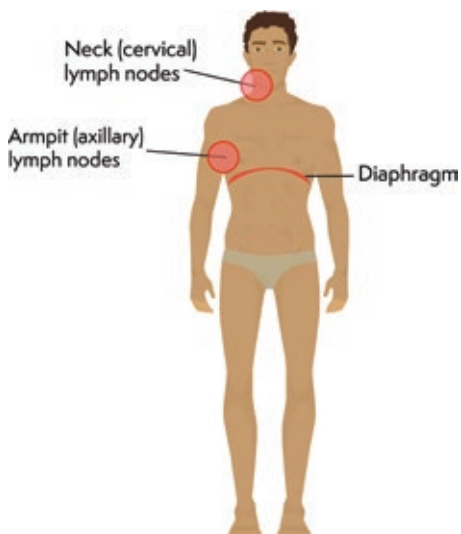
- chronic lymphocytic leukaemia (CLL)
- non-Hodgkin lymphoma in children
- skin (cutaneous) lymphoma
- Waldenström's macroglobulinaemia.

Most lymphomas can be treated effectively, whatever their stage.

Stage 1 lymphoma is in only **one** group of lymph nodes (glands). These can be anywhere in your body, either above or below the **diaphragm**.

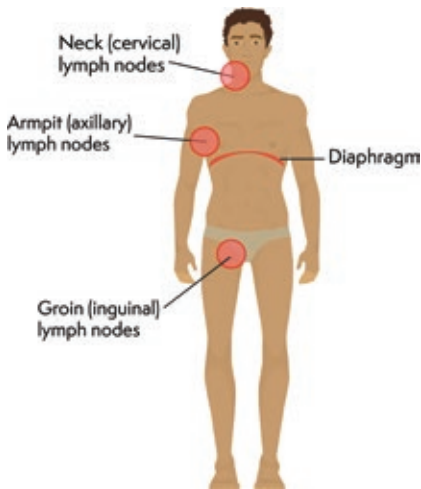


Stage 2 lymphoma is in **two or more** groups of lymph nodes. These can be anywhere in the body, but all will be on the same side of the diaphragm (either above or below).

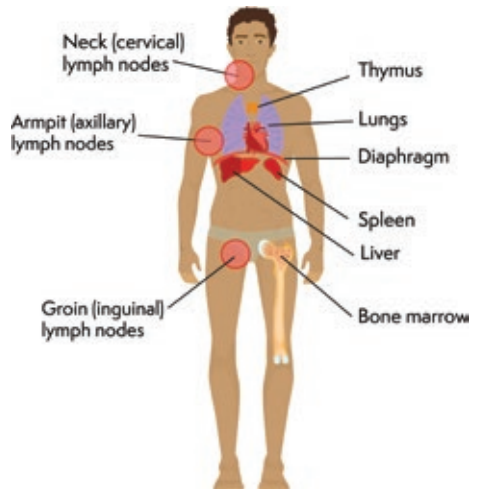


Sometimes, stages 1 and 2 are called 'early stage' lymphomas.

Stage 3 lymphoma is in lymph nodes on **both** sides of the diaphragm.



Stage 4 lymphoma has spread to one or more organs outside the lymphatic system (such as the lungs, liver, bone or bone marrow).



Stages 3 and 4 are often called 'advanced lymphomas'. It's not uncommon for lymphoma to be advanced when it is diagnosed because the lymphatic system spreads throughout your body. Unlike some other cancers, lymphoma is often treatable even at an advanced stage.

Letters in staging

Some hospitals include a letter in the stage of lymphoma, for example, stage 2B lymphoma. These give extra details, as outlined below:

- A You haven't had any **B symptoms**.
- B You have one or more B symptoms: unexplained weight loss, night sweats or fevers (temperatures over 38°C/100.4°F).
- E The lymphoma is 'extranodal' meaning that it started in an organ outside of your lymphatic system, such as in your digestive system or salivary glands.
- S Lymphoma is in your spleen (part of the immune system).
- X One or more of the lymph nodes that has lymphoma in is considered to be large or 'bulky'.

You can ask your medical team what stage your lymphoma is and what this means. They can also explain how the stage affects which treatment they recommend for you.

Your medical team

The team of professionals that plan and manage your care and lymphoma treatment are known as your multidisciplinary team (MDT). They have different areas of specialist knowledge and work together to plan the best treatment and care for you. You won't meet all the team - for example the laboratory staff who look at your biopsy sample - but you'll meet some members.

The person who has overall responsibility for your care is either a consultant oncologist (doctor specialising in cancer treatment) or consultant haematologist (doctor specialising in blood disorders).

Your key worker

Your key worker is part of your MDT. They are your main point of contact for any questions or concerns, including between appointments. Very often, this is a **clinical nurse specialist** (CNS) or lymphoma nurse specialist – an experienced nurse with specialist expertise in lymphoma.

An important part of your key worker's role is to help you live well, with and beyond lymphoma. You should have a holistic needs assessment (page 13), designed to help with any practical, physical, social or emotional needs you have.

Your key worker can help by:

- answering your questions about lymphoma, your treatment and side effects
- suggesting sources of social and emotional support, such as a local support group or a talking therapy, such as counselling
- directing you to help with practical things like work and finances.

You should be given the full name and contact details of your key worker. If you haven't, you can ask your consultant for it.

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



Notes



“ *My doctors recommended 6 cycles of intense chemotherapy. I remember walking out of the hospital after the last one, feeling that I had done it and wondering what the next stage would be. I now needed to start to recover a little, rest and regain strength. It was a life-changing experience and, a year on, I was just starting to come to terms with the new me.*

Mark, diagnosed with diffuse B-cell lymphoma

Lymphoma treatment

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Treatment

Your medical team plan the most suitable treatment for you. They base this on factors including the type and stage of your lymphoma, your general health, lifestyle and preferences.

Approaches could include one or more of the following:

- active monitoring – where you don't have active treatment straightaway (page 44)
- chemotherapy (page 47)
- radiotherapy (page 49)
- steroids (page 51)
- targeted treatments (page 52)
- CAR-T cell therapy (page 54)
- **stem cell** transplant (page 55).

You might also be offered treatments to help with symptoms of lymphoma, or **side effects** of treatment, so talk to your medical team about any that are troubling you. This gives them an opportunity to help you manage them.

Before you start treatment, your consultant should talk you through:

- your treatment plan
- the aim of the treatment – to get rid of the lymphoma or to control the growth of it
- when and where you'll be treated
- any side effects of treatment you might have.

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

“ Ask your medical team for advice about what you can do to prepare yourself physically and mentally for treatment. Any time you put into this preparation will pay off – it can make such a difference to how you tolerate treatment and recover from it.

Charlotte Bloodworth, Lead
Haematology Clinical Nurse
Specialist



Search ‘prehab’ on our website for more information about getting ready for treatment (prehabilitation).

Side effects of treatment

The aim of treatment is to destroy the lymphoma cells. However, all treatments have other, unwanted effects (side effects).

Treatments have different side effects, and even the same treatment can affect individuals in varied ways.

Your medical team should talk to you about any side effects **you** might get. They can also tell you:

- when you could expect them to start
- how long they might go on for
- how to manage these
- who to contact if side effects are troubling you.

Most side effects are short-term, but some can last for a few weeks or months after finishing treatment. Rarely, side effects are permanent.

There is also a possibility of late effects – these are health problems that start months or years after you finish treatment. You should be given information about these too.

Questions to ask about your treatment plan

- Which treatment or treatments are you recommending and why?
- Do you expect treatment to get rid of the lymphoma completely, or to control its growth?
- How does the treatment work?
- How likely is it to be effective?
- How is it given?
- Where will I have the treatment? How often?
- Is it painful?
- What side effects might I get?
- How long is each treatment session?
- How soon after treatment can I go home? Can I drive myself?
- When do you expect me to finish treatment?
- How and when will we know if the treatment is working?
- What emotional support is available to me?

Notes



Active monitoring (watch and wait)

Lymphoma doesn't always need treatment straightaway, or even at all. Instead, your doctors might recommend active monitoring (sometimes called 'watch and wait' or 'active surveillance').

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

With active monitoring, you have appointments to check on your health and how the lymphoma is affecting you. You don't start treatment unless the lymphoma causes significant health problems.

Some people find the idea of active monitoring challenging at first. It can be difficult knowing that you're not receiving treatment straightaway. However, it can help to keep in mind that:

- there is no benefit in starting treatment before you need to – **treatment is just as effective if it's saved until you need it**
- treatment is still available, if and when, you need it – this might not be for months, years or ever
- while you are well, you can continue with your day-to-day life and avoid possible side effects of treatment for as long as possible, helping to protect your quality of life.



We have more information about active monitoring on our website at lymphoma-action.org.uk/ActiveMonitoring – you could show this to friends and family to help explain the approach. You can also download or order our book on active monitoring free of charge at lymphoma-action.org.uk/Books

“ *My medical team explained that as the lymphoma wasn't causing me problems, they would monitor me regularly until such time as I would need treatment. That turned out to be six years.*



John, diagnosed with low-grade non-Hodgkin lymphoma

Questions to ask about active monitoring

- Can you explain why you are recommending active monitoring for me?
- How often will I have check-ups and what do these involve?
- What symptoms or changes to my health should I look out for between check-ups?
- Who do I contact if I have concerns, and how?
- How long do you expect me to be on active monitoring?
- If I need active treatment, what might this be?



Notes

Chemotherapy

Chemotherapy (chemo) is a type of drug treatment that poisons cells and stops them from dividing. Most lymphoma cells are easily killed by chemotherapy.

The most common way of having chemotherapy is through a tube or injection into a vein (intravenously or 'by IV'). You can also take it by mouth (orally), usually as a tablet. Your medical team will tell you which type you need.

In a smaller number of cases, chemotherapy is given intrathecally. This means that it is injected into the cerebrospinal fluid, which surrounds the brain and spinal cord. Another possibility is by injection into the layer of fat that lies just under your skin (subcutaneous chemotherapy).

Your chemotherapy is planned specifically for you. Usually, chemotherapy is given:

- Over weeks or a few months. Often, it's given in cycles, where you have some of the treatment and then a rest period. This gives you time to recover before the next treatment.
- As an outpatient, which means you go into hospital just for a few hours at a time.
- As a 'chemotherapy regimen', where you have more than one drug at once, with each working in a slightly different way.

Often, a chemotherapy regimen is referred to as an acronym, much of the time using the first letter or two of the drugs that make them up. An example is **CHOP** for **c**yclophosphamide, **h**ydroxydaunorubicin (or doxorubicin), **v**incristine (**Oncovin**[®]) and **p**rednisolone.

Chemotherapy side effects

Some of the more common side effects of chemotherapy include fatigue (extreme tiredness), nausea (feeling or being sick) and hair loss.

Chemotherapy can also increase your risk of infection (page 62). Your medical team will give you advice on how to lower this risk. They will also tell you about any important signs of infection to look out for and what to do if you notice them. Ask them who to contact in the case of an emergency.



You can find out more about chemotherapy at lymphoma-action.org.uk/Chemotherapy

Radiotherapy

Radiotherapy destroys cancer cells with high-energy X-rays (a type of radiation). The X-rays are directed to areas of your body where there is lymphoma. Lymphoma cells are usually more sensitive to radiotherapy than many other types of cancer cell.

Often, radiotherapy is given in a treatment plan that includes other treatment types. For example, it might be given after chemotherapy to destroy any lymphoma cells that have 'escaped' chemotherapy. For a small number of people with low-grade lymphoma, radiotherapy is given on its own.

Radiotherapy might also be offered to help with lymphoma symptoms, by shrinking the lymphoma. Just one dose can be effective. However, sometimes, a longer course is recommended.

The total dose of radiotherapy is measured in Gray (Gy). You usually have it in separate treatments (fractions) over a few weeks – this increases the likelihood of the treatment reaching the lymphoma at a time in the cell cycle when they are most sensitive to radiotherapy. It also allows healthy cells time to recover between doses.

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

Radiotherapy side effects

Extreme tiredness (fatigue) is a common side effect of radiotherapy. It usually starts to get better within a couple of weeks of finishing treatment, but can go on longer.

The skin in the area treated might become dry or sore, or you might have a burning sensation in the area. While your skin is affected, sun safety is especially important – ask a member of your medical team for advice specific to your situation.

Hair loss can also happen in the areas of the body treated. This is usually temporary.

Other side effects depend on where the radiotherapy is targeted. For example, you might feel sick if radiotherapy is given to your brain, stomach or bowel. You might get diarrhoea or urinary changes (for example, frequent urination, pain or burning when urinating or a feeling of needing to urinate more urgently) if your tummy or pelvis area is treated.



You can find out more about radiotherapy on our website at lymphoma-action.org.uk/Radiotherapy

Steroids

You might have corticosteroids (a type of steroid drug), either alone, or together with other treatment types.

Steroids are poisonous to lymphoma cells. Doctors recommend steroids for lots of reasons. For example, steroids could:

- treat the lymphoma
- make chemotherapy more effective
- lower some of the side effects of chemotherapy, such as feeling sick (nausea)
- boost your appetite, to help you eat more and build your energy.

You might be given steroids as a tablet or liquid, by injection or intravenously (by IV). If you have skin lymphoma, you might be given it to put directly onto your skin (topically), as a cream or ointment.

Steroid side effects

Any side effects of steroids are usually short-term and gradually improve once you stop taking them.

Some of the more common side effects include an increased risk of infection (page 62), water retention, changes in how your body breaks down and uses food (your metabolism), changes in mood and difficulties sleeping.

Topical steroids can cause side effects in the areas they are applied to. Examples include a change in skin colour and thinning of the skin, making it bruise more easily.

Talk to your medical team if you struggle with side effects of steroids.



Our website has more information about steroids at lymphoma-action.org.uk/Steroids

Targeted treatments

Targeted treatments (including antibody therapies) are made to target cancer cells. You might also hear them called ‘targeted drugs’, ‘targeted therapies’, ‘biological therapies’ or ‘immunotherapies’.

These treatments work by attacking certain proteins on lymphoma cells. Proteins are important in helping a cell to work – they’re often what help a cancer cell grow and survive.

Many targeted treatments are given together with, or after chemotherapy (chemoimmunotherapy). They can also be given as a combination of different targeted treatments. Having more than one drug can increase the overall effectiveness of treatment in certain lymphoma types.

Antibody treatments

Antibody treatment is a type of targeted treatment.

Antibodies are proteins your body makes to fight an infection. They stick to proteins on cells that don't belong in your body, such as viruses and bacteria. They then either kill them or signal to your immune system to destroy them.

Antibody treatments use antibodies made in a laboratory. These stick to the proteins on lymphoma cells and mark them out to your immune system to be destroyed.

Antibody treatment is also known as 'immunotherapy' because it works through your own immune system. Antibody treatment is often given in combination with chemotherapy as 'chemoimmunotherapy'.

One of the most common types of antibody treatment for lymphoma is rituximab. It can be given alone, or with chemotherapy.



We have more information about how targeted drugs work on our website. at [Lymphoma-action.org.uk/TargetedTreatments](https://lymphoma-action.org.uk/TargetedTreatments)

Side effects of targeted treatments

These treatments can target lymphoma cells with high precision, which lowers the effect on healthy cells. This can mean fewer side effects.

CAR T-cell therapy

CAR-T cell therapy is used to treat some types of lymphoma that have come back (relapsed) or have not responded to treatment (refractory). It is a type of immunotherapy as it uses your own immune system cells to fight lymphoma. These cells are T cells, (T lymphocytes) – a type of white blood cell that can kill cancerous cells.

With CAR-T cell therapy, some of your T cells are collected and sent to a laboratory. Here they are changed (genetically modified) to be able to recognise lymphoma cells. The changed cells are called 'CAR-T cells'. CAR-T cells stick to a particular protein on the lymphoma cells, marking them out for your immune system to destroy.

CAR-T cell therapy can be an effective treatment option but it is only available for some types of lymphoma. Doctors also need to check that you are fit enough for it because it is very intensive and can have serious, and occasionally life-threatening, side effects.



Find out more about CAR-T cell therapy on our website at lymphoma-action.org.uk/CARTcells or download or order a free copy of our CAR-T therapy for lymphoma book at lymphoma-action.org.uk/Books

Stem cell transplants

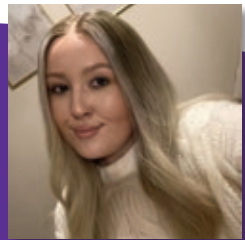
Stem cells are undeveloped cells that can divide and grow into all the different types of blood cell your body needs. A stem cell transplant is an intensive type of treatment. It replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells.

Usually, the stem cells come from your own body (autologous stem cell transplant). Sometimes, they come from a donor (allogeneic 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. Usually, you are in protective isolation, which means you have a room to yourself, to help protect you against infections – you should be able to still have visitors though.

“ *I had chemotherapy followed by an autologous stem cell transplant. I was dreading the transplant and potential side effects. However, it went well and I avoided infections, meaning I could leave the hospital 10 days after receiving the stem cells. I read the Lymphoma Action Facebook Support Group posts each day in hospital, clinging to the fact that people reiterated how it was tough, but does get better – at 6 months post-transplant, I can say it really does.*

Faye, diagnosed with Hodgkin lymphoma



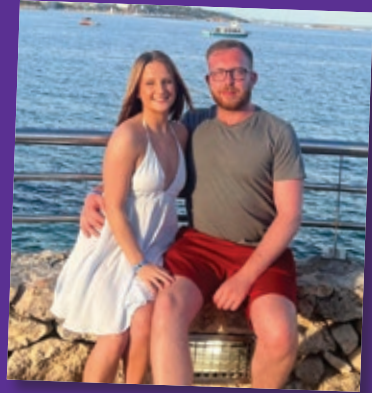
Questions to ask about treatment

- What treatment plan do you recommend for me and why?
- How is the treatment/how are the treatments given?
- How long does each treatment session last?
- How long do you expect the whole treatment plan to take?
- Where will I have treatment?
- Will I stay in hospital overnight?
- 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?
- What side effects might I get?
- When and how will we know if the treatment is working?
- What happens if I choose not to have treatment?
- What changes might I need to make to my day-to-day routine during, or after, treatment?
- What can I do to help lower my risk of infection?
- Can I continue to use regular products, such as my usual toiletries, hair and skin products?
- Is it safe to have sexual contact during treatment? Should I use contraception?
- Are there any late effects I should look out for?

Notes



“ *The first of six rounds of intensive chemotherapy were physically and mentally testing. On good days, I still went for days out. On others, I just needed to rest. I just took each day as it came.*



Bradley, diagnosed with a rare type of high-grade B-cell lymphoma.

Clinical trials

Clinical trials are carefully controlled research studies. Many trials for lymphoma look at the best ways of using current treatments. Other trials are to see if a new treatment could be better in some way than the current standard one. For example, more effective or less likely to cause side effects. Some trials focus on improving quality of life.

Your doctor might suggest a trial if there is a suitable one for you. Whether you can take part depends on eligibility criteria – a list of rules about who can enter. These might include, for example, people with a particular lymphoma type and stage, and being within a certain age range.

You do not have to agree to take part in a clinical trial. If you start one and then change your mind, you can stop it at any time – you'll still be offered the standard treatment.

If you're interested in the possibility of entering a clinical trial, speak to your consultant or clinical nurse specialist to see if there is one that's suitable for you.



We have more information about clinical trials on our website at lymphoma-action.org.uk/about-clinical-trials. You can also search our database to search for a trial that might be suitable for you at lymphoma-action.org.uk/Trialslink

“ I spoke to my consultant about clinical trials. They were very supportive and organised a meeting at the nearest hospital that had a suitable one. The whole treatment is so closely monitored with examinations, tests and scans, and I see the research nurse at each appointment. One disadvantage is having to travel for appointments. However, I'm delighted overall. My care before the clinical trial was outstanding, but this feels like another level.

Andy, diagnosed with follicular lymphoma



Questions to ask about clinical trials

- Is there a suitable clinical trial for me?
- What is the aim of the trial?
- What are the possible advantages and disadvantages of taking part?
- If I don't want to take part, what treatment will I be offered instead?
- What appointments will I have during the trial?
- Where will these be, and what will they involve?
- Are travel expenses covered?
- Who do I contact if I have questions during the trial?
- What is the follow-up plan for this trial?



You can find further suggested questions by searching 'about clinical trials' on our website. We also have more tips for things to think about before taking part in a trial, including some of the possible advantages and disadvantages.



Notes



“ After treatment, I had so much to process. I am no longer the Jacqueline I was before cancer. I am working to rebuild a new version of myself of which I can be proud of all I have overcome. I am learning how to filter the emotions I can control and those I can't, while being gentle with myself.

Jacqueline, diagnosed with non-Hodgkin lymphoma

Living well

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Infection – risk and prevention

Lymphoma and its treatments can affect your immune system and increase your risk of getting infections. It can also be harder to fight them off.

If you think you might have an infection, it's important to seek medical attention early – some infections can become serious if they are not treated early.

Ask your medical team about any signs or symptoms of infection you should be aware of. Find out what to do if you have any of these, including who to contact and how. Always keep these details with you.

Common signs and symptoms of infection

Common symptoms and signs of infection are on page 63. However, this is not a list of every possibility – check with your medical team about anything else to be aware of.

Keep a thermometer so that you can easily check your temperature. **Seek medical advice promptly if you have a high temperature (above 38°C/100.4°F), especially if you have other symptoms of infection as well.**

Common signs and symptoms include:

- temperature above 38°C/100.4°F (fever)
- temperature below 35°C/95°F (hypothermia)
- pain, redness, discharge, swelling or heat at the site of a wound or intravenous (IV) line, such as a chemotherapy line
- chills and sweating
- shivering (even without fever, which is more likely if you are taking steroid medication)
- feeling generally unwell, confused or disoriented
- blocked nose, earache, sore throat or mouth, earache
- cough, yellow or green phlegm or snot (mucus), difficulty breathing
- diarrhoea
- being sick (vomiting)
- a feeling of burning or stinging when you wee, or needing to wee more often than usual
- vaginal discharge or itching
- headaches or unusual and new stiffness of the neck, with discomfort around bright lights
- new and increasing pain anywhere in your body.

Lowering your risk of infection

You can't protect yourself completely from infection, but you can help lower your risk.

- Keep good personal hygiene – which includes dental hygiene.
- Avoid places where infection can spread easily – for example, avoid using public transport during peak times, busy shops and public swimming pools.

- Protect your skin – for example, take care to avoid cuts and grazes. If you cut, scratch or graze yourself, wash your hands and clean the wound with tap water. Use a clean towel to pat the wound dry and place a sterile dressing on it.



You can find out more about infection risk and prevention at lymphoma-action.org.uk/Infection

“

My doctors warned me I would pick up infection extremely easily while I was having chemotherapy. Each time I did, I was given a strong dose of antibiotics. When I became ill around Christmas time, I really did not want to go into hospital but thankfully my wife persuaded me to. The consultant told me that if I had delayed coming to hospital for another few hours, I might not be alive! I am now in my 60s and in reasonable health, although my immune system is low and I have to be careful about infections, particularly in the winter.

Richard, diagnosed with high-grade B-cell non-Hodgkin lymphoma



Questions to ask about infections

- How does lymphoma affect my risk of infection?
- What signs or symptoms should I look out for?
- What should I do if I notice these?
- Are there any activities I should avoid while my risk of infection is higher?
- How can I lower my risk of infection?



Notes

Physical and emotional wellbeing

Lymphoma can affect you physically, emotionally and practically.

A key aspect of overall wellbeing is to follow a healthy lifestyle. This includes eating well, staying hydrated and keeping your alcohol intake to within the recommended guidelines. It's also important to build physical activity into your day-to-day life, to get enough rest and to manage stress.

“ *Exercise helped me both physically and mentally and really kept me going. Having a small garden was also a great motivator to stay active.*

Jana, diagnosed with diffuse large B-cell lymphoma



You can also help yourself by going for any health tests you're offered, for example, blood pressure checks and cancer screenings. Check with your medical team about which vaccinations you should and shouldn't have, and when to have them.



Search 'living with and beyond' on our website for more information to help you live well.

Personalised care and support

The NHS says everyone living with and beyond cancer should be offered personalised care and support.

“ *Personalised care means people have choice and control over the way their care is planned and delivered. It is based on 'what matters' to them and their individual strengths and needs.*

NHS England

In addition to having holistic needs assessments (page 13), personalised care and support can include the following parts, as outlined below.

Treatment summary

This summary is given at the end of treatment. It outlines your diagnosis, treatment, possible side effects and late effects of treatment. It should include your follow-up plan, and any lifestyle recommendations, for example about diet and exercise.

The summary should also tell you what symptoms to look out for. It should say who to contact if you notice them, including an out-of-hours number you can call at any time of the day or night if you need to.

Cancer care review

A cancer care review is an opportunity to talk about your health and wellbeing needs, including:

- how you're feeling, physically and emotionally
- your social support network
- any local or national support services available to you
- lifestyle advice to help you live well.

You have this review as a conversation with your GP or a GP surgery practice nurse. It is done between 3 to 12 months after your diagnosis.

Depending on your needs, you could ask about any practical and financial support available to you. For example, about prescription charge exemptions.

Life after treatment

Finishing treatment for lymphoma can bring a range of emotions. You might feel positive some, or a lot of the time. There might also be times when life feels more challenging – for example, if you have ongoing side effects, or if you're coping with feelings of uncertainty and changes in relationships.

It can take time to adapt once you finish treatment. There is support available to help you adjust – speak to a member of your medical team or your GP for advice. We're also here to support you. Over time, many people describe finding a 'new normal'.



If you've recently finished treatment or you're on active monitoring (watch and wait), you might be interested in our peer-led *Live your Life* course, designed to help you connect with others and adapt well. Search 'live your life' on our website to find out more.

Follow-up after treatment

After your treatment finishes, you'll have a schedule of check-ups to support your physical and emotional recovery. These appointments might be at the hospital you were treated at, or at your local GP surgery. Some appointments might be suitable to have over the phone or by video call.

During follow-up, your doctors will ask how you're feeling. You might have physical examinations, blood tests and scans.

Follow-up gives you a chance to:

- ask any questions you might have
- talk about how you're feeling and any concerns you have
- get help with managing any side effects and late effects of treatment
- find out about any further support available to you.

The schedule for follow-up depends on factors such as the type of lymphoma you were diagnosed with, the usual practice at the hospital you were treated at and your preferences. Follow-up might differ if you were treated as part of a clinical trial.

As a rough guide, you'll have an appointment with one or more of your medical team professionals every few months when your treatment first ends.

Over time, appointments usually become less frequent. After a number of years in remission, you might be discharged from follow-up. However, this depends on the practices of your hospital. You can still get support from your GP whenever you need it. If necessary, they can refer you back to the hospital.

Supported self-management (patient-led follow-up)

Some hospitals offer supported self-management, also known as patient-led follow-up. This might be suitable for you if you are in remission (no evidence of lymphoma from tests and scans) and your risk of relapse is low.

With supported self-management, your medical team tell you how to book appointments. They give clear guidance about when and how to contact them.

The idea of self-monitoring might seem daunting at first. In time, however, many people say it helps to give them a greater sense of control over their health.

Questions to ask about life beyond lymphoma

- Will I need to make changes to my day-to-day routine and activities? If so, for how long?
- When can I go back to work?
- How long do you think it will be before my energy levels return to pre-treatment levels?
- Where can I get money advice and support?
- Do I need to state my lymphoma diagnosis on applications for paid employment or voluntary positions?
- What emotional support can I access to support my recovery?
- How soon after treatment can I have dental treatment?
- Which vaccinations should I have, and when?
- Are there any vaccinations I shouldn't have?
- If I want to have a baby, how long should I wait after finishing treatment?

Notes



Tell a member of your medical team or your GP if you have concerns. They can also help you to manage side effects. This could include by suggesting tips, prescribing any medicines, and signposting you to other organisations.



We have more information on our website about day-to-day life, including diet and nutrition, work, finances and relationships. Search 'living with and beyond' on our website.

You can also download or order a copy of our book *Living with and beyond lymphoma*, free of charge at lymphoma-action.org.uk/Books

If the lymphoma comes back (relapses)

Many people have further successful treatment after relapse. It's natural to worry about the possibility of relapse. The risk depends on the lymphoma type and the treatment you've had. However, your medical team are best placed to advise you based on your individual circumstances.

Your medical team will tell you about any possible signs of relapse to look out for, what to do if you notice them, and show you how to check for swollen lymph nodes.

“ *My lymphoma relapsed and I had radiotherapy. I have carried on with my life, albeit at a slower pace. I do some dog training, swimming and walk as much as I can. Exercise is a vital part of feeling well.*

Linda, treated for relapsed
follicular lymphoma

It can be very difficult to adapt to the possibility of relapse. Hard as it can be, it is often beneficial to focus on leading a healthy lifestyle and finding ways of managing stress and anxiety. Talk to your key worker, another member of your medical team or your GP if you would like emotional support.

“ *It can be challenging to live with the possibility of lymphoma coming back. I've found that it can be helpful for people to keep in mind that their medical team will have a back-up plan, in case it's needed. Speak to them if you're worried.*

Charlotte Bloodworth, Lead Haematology Clinical
Nurse Specialist



Remember that our Helpline Team is here for you. We also have online support groups specifically for people in remission. Find information about these at lymphoma-action.org.uk/Online-Support-Meetings

Questions to ask about relapse

- How likely is it that my lymphoma will relapse?
- How will you know if it does?
- What symptoms or signs of relapse should I look out for?
- 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 the uncertainty that comes with the possibility of relapse?

Notes



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 nurse specialist	an experienced nurse with specialist expertise in a specific area such as lymphoma
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)

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
Lymphatic system	a network of tubes, tissues and organs that runs throughout your body; it is part of the immune system
Lymph nodes	small, bean-shaped structures, up to 2cm in length, grouped together in certain areas of the body – for example, the neck, armpits or groin
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
Side effects	unwanted effects of treatment that can happen when healthy cells are damaged
Spleen	a pear-sized organ behind your ribcage on the left-hand side; it filters blood
Stem cells	undeveloped cells that can divide and mature into all the different types of blood cell
Thymus	a small butterfly-shaped gland in your chest; the organ where T cells (a type of lymphocyte) develop into active immune cells
Ultrasound	a type of sound energy; an ultrasound scan uses soundwaves to take pictures inside your body

Information and support

If you or someone you love is affected by lymphoma, we're here to support you. We have a range of support services that are free to access. Find out more at lymphoma-action.org.uk



Helpline: a freephone helpline available Monday to Friday, 10am to 3pm on 0808 808 5555, or use Live Chat on our website



Online Support Meetings: a safe place to connect with others affected by lymphoma



Facebook Support Group: our UK-wide group is for anyone affected by lymphoma



Buddy Service: peer support from someone with similar lived-experience of lymphoma



Preparing for Treatment Service: online support and information to help you prepare for treatment.

For our latest news and updates, follow us on social media:

 @lymphomaaction   lymphoma_action

[More information](#)

If you're interested in finding out more about lymphoma, we have lots more information on our website, including videos and podcasts.

We also produce a number of books, which are available free of charge, including:

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

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

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



How you can help us

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 strive to improve our resources and are interested in any feedback you might have. Can you spare five minutes to give feedback on this book? It will help us plan future versions. Please scan the QR code to complete our short survey. Alternatively, 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.



References

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This book has been researched and written by Lymphoma Action, the UK's leading 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

This book tells you what lymphoma is and about some of the tests and treatments you might have. It also covers follow-up and aspects of living well, with and beyond lymphoma.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma since 1986.

We're here for you.



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



information@lymphoma-action.org.uk



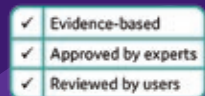
www.lymphoma-action.org.uk



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

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