

# Introduction to lymphoma

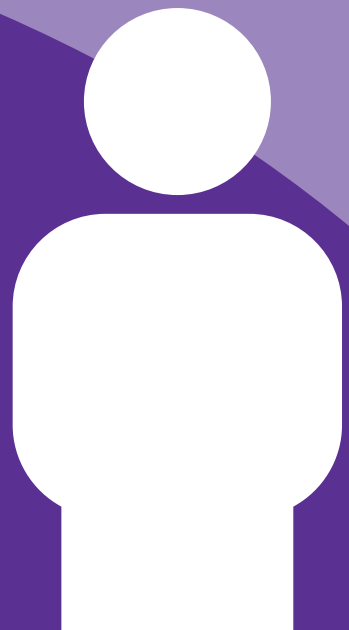
What is lymphoma?

Tests and scans

Treatment for lymphoma

After treatment

Further support





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

We could not continue to support you, your clinical team and the wider lymphoma community, without the generous donations of our incredible supporters. 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](https://lymphoma-action.org.uk/Donate)**



You might like to use the space below to note down key contacts so that you can find them easily.

Job title/contact	Name and contact details
General practitioner (GP)	
Consultant haematologist or oncologist	
Clinical nurse specialist (CNS) or nurse contact	
Treatment centre or clinic reception	
Hospital out-of-hours number	
Hospital ward	
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 treatment you might have. We've also included some questions you might like to ask your doctor 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.



Gives space for questions and notes.



Lists other useful resources.









Lists useful videos to watch.

This book uses some scientific words. Words that are shown in **bold purple** are explained in the glossary on pages 65 to 67.

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

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**I had no idea what lymphoma was when I was first diagnosed. I felt panicked and fearful. My brain was in shock and I couldn't take in the information from my doctors. My wife found out about lymphoma through Lymphoma Action. What really helped me was getting in touch with others who were affected by lymphoma.**

Malcolm, diagnosed with low-grade non-Hodgkin lymphoma

# What is lymphoma?

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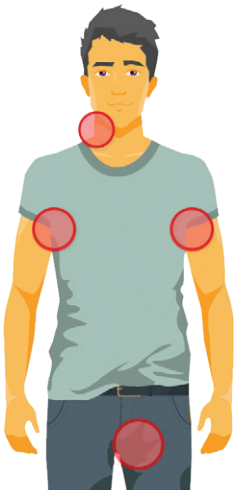
Lymphoma is a type of blood cancer. It's the fifth most common cancer in the UK. It can develop at any age. Lymphoma is nearly always treatable and people generally live well for many years after their diagnosis.

There are different types of lymphoma. Depending on which type you have and where it is in your body, it can cause different symptoms. Some people have no symptoms, however, and 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 is different to normal tiredness. It means feeling exhausted for no obvious reason or feeling washed out after doing very little.



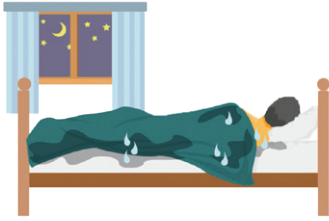
## Unexplained weight loss

Losing a lot of weight quite quickly without trying to can be a symptom of lymphoma.



## Infections

Getting infections more easily and having difficulty getting rid of them can be a symptom of lymphoma.



## Sweats

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



## Itching

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

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](https://lymphoma-action.org.uk/Symptoms)**

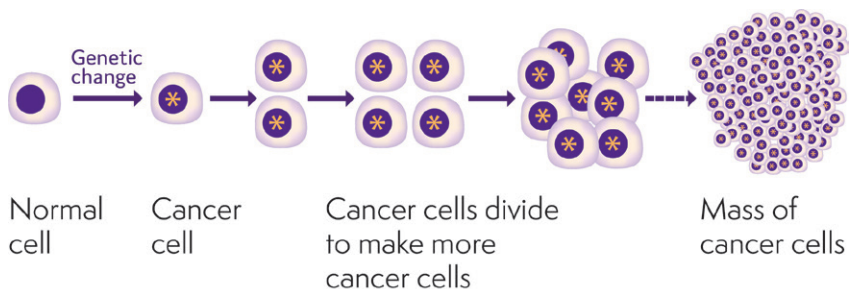
# How cancer develops

The human body is made up of many different cells, for example skin, bone and blood cells. As part of day-to-day life, 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. A genetic mutation can cause the cell to stop 'listening' to the chemical signals that control cell division. When this happens, cells can:

- 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 abnormal (unhealthy) cells, which can form a cancer.



**Figure: How cancer develops**

## What type of cancer is lymphoma?

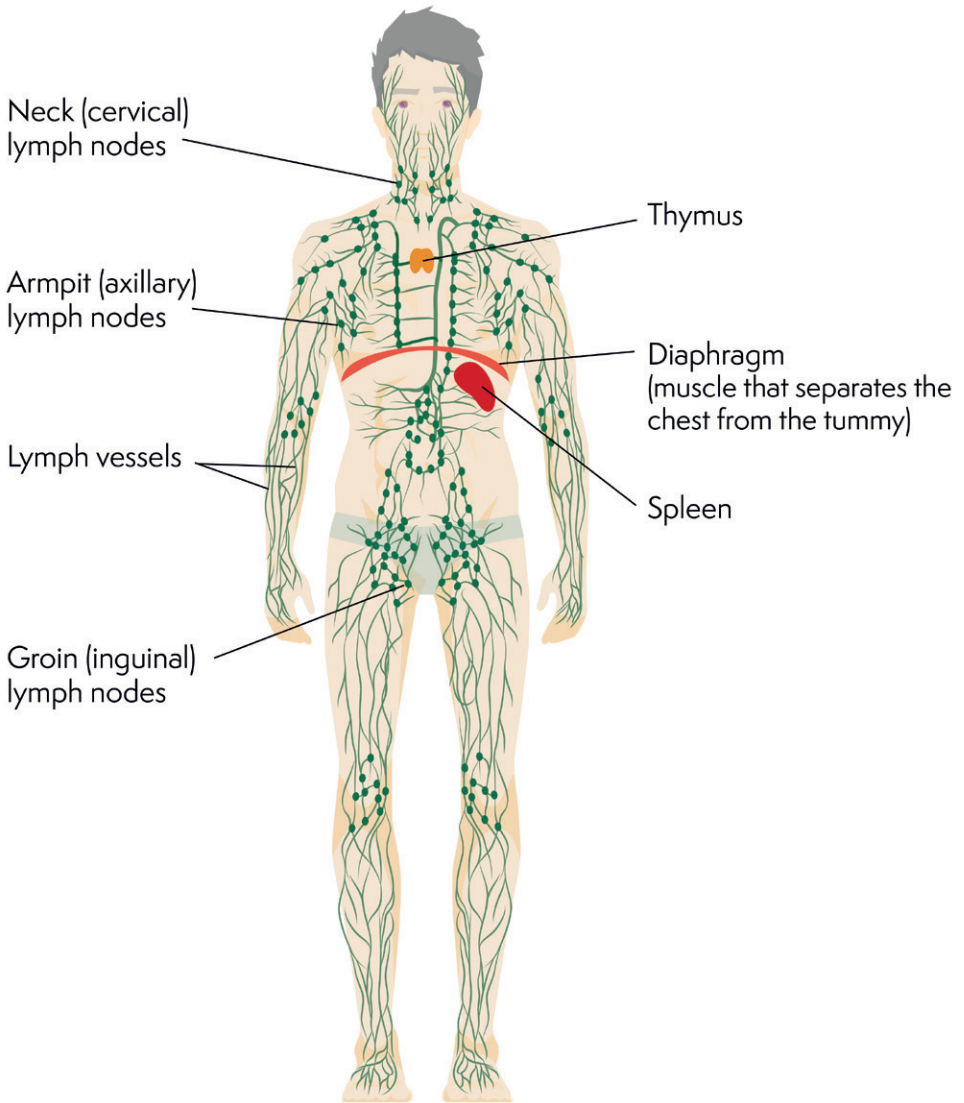
Lymphoma is a type of blood cancer. It develops in cells called **lymphocytes**. Lymphocytes are a type of white blood cell that fight infection. Healthy lymphocytes travel around your body in the **lymphatic system**, which is part of your **immune system**.

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



**Figure: 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, it's not possible to know the cause of lymphoma. This is because scientists think the genetic changes 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.

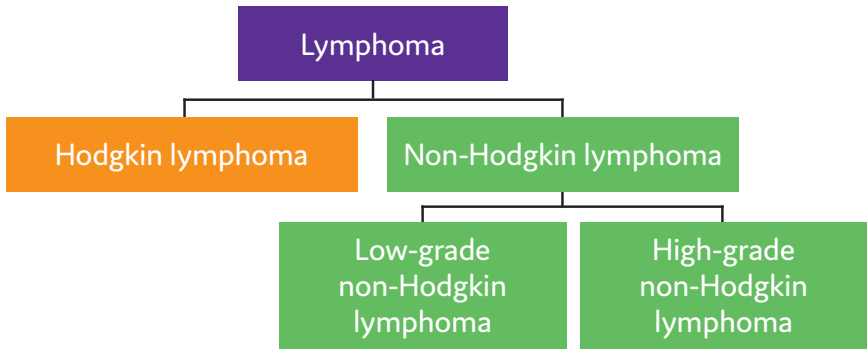
### **Can I pass on lymphoma?**

You can't catch lymphoma and you can't give it to other people. Most of the time, there isn't a 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 (see 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.



**Figure: The main types of 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 sometimes classified as a form 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.

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

<b>Low-grade NHL</b>	<b>High-grade NHL</b>
Most commonly affects people aged over 60.	Most commonly affects people aged over 50.
Most common types are CLL, follicular lymphoma and marginal zone lymphoma.	Most common type is diffuse large B-cell lymphoma (DLBCL).
Might not need treatment straightaway (known as 'active monitoring' – see page 37).	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 about your lymphoma

- What type of lymphoma do I have?
- Where in my body is the lymphoma?
- Is the lymphoma growing quickly?
- Are my symptoms caused by the lymphoma?
- Will my symptoms go away once I start treatment?
- 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? Is it curable?



## Notes



**I'd been tired for a long time, but explained it away. Then I found I couldn't run 50 metres without becoming out of breath. I'd run a marathon only a few months before. My doctor said my right lung wasn't filling properly and sent me to A&E. After about 10 days of tests, including CT scans, X-rays and a bone marrow biopsy, I was diagnosed with cancer. Roger, diagnosed with high-grade non-Hodgkin lymphoma**

# Tests for lymphoma

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Your GP is often the first person you speak to if you feel unwell. They can examine you and ask you about any symptoms you have, but they won't be able to confirm if you have lymphoma; if it's appropriate, you'll be referred to hospital for tests to find out what's wrong.



Note that you might not have **all** of the tests described in this section. The tests you have are suited to your individual situation and based on the symptoms you are experiencing.

## Biopsy

In general, lymphoma can't be confirmed without a small operation called a 'biopsy'.

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

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** as an outpatient. You're likely to be in the hospital for a few hours.

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 an **ultrasound**.

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 for further tests.

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' (see page 28).

## **Blood tests**

During a blood test, a sample of your blood is taken. It is then sent to be tested in a laboratory. 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.

# Bone marrow biopsy

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 so that the procedure isn't painful.

## 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 base their recommendation of the type of scan that is best for you 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 X-rays and a computer
- **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 have very low levels of radioactivity in your body. As a precaution, avoid close contact with pregnant women, babies and young children during this time.**

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



Photo credit: The Royal Marsden NHS Foundation Trust

**Figure: A person having a scan**

## Waiting for test results

It can take a couple of weeks for test results to come back. Although this can feel like a long wait, your doctors are finding out about your lymphoma 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 high-grade non-Hodgkin lymphoma



**We have more information about waiting for test results at [lymphoma-action.org.uk/Waiting](https://lymphoma-action.org.uk/Waiting)**

# Questions to ask about tests and scans

- What tests and scans are you recommending and why?
- What do the procedures involve?
- Where and when will I have them?
- Are they safe?
- Are they painful? If so, will I have an anaesthetic or **sedative**?
- Can I drive myself home after the tests?
- 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 to me?



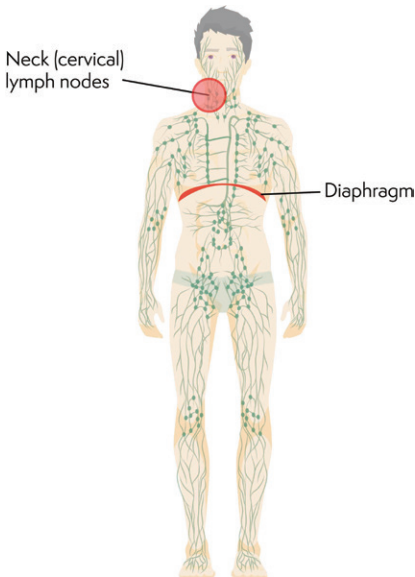
## Notes

# Staging of lymphoma

'Staging' is the process of working out where in your body the lymphoma is, or how 'advanced' it is. Tests and scans help to tell the stage of your lymphoma. Staging helps doctors plan your treatment.

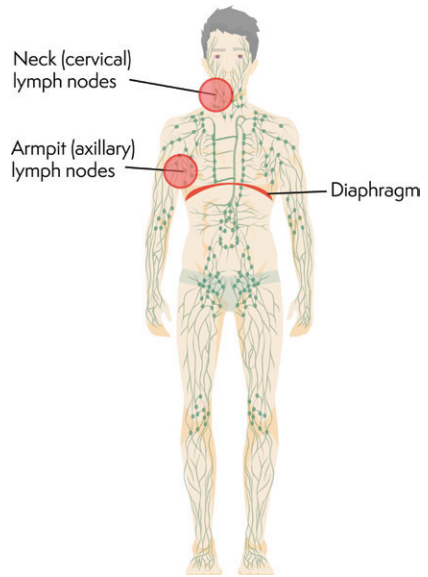
## Stage 1

One set of lymph nodes is affected



## Stage 2

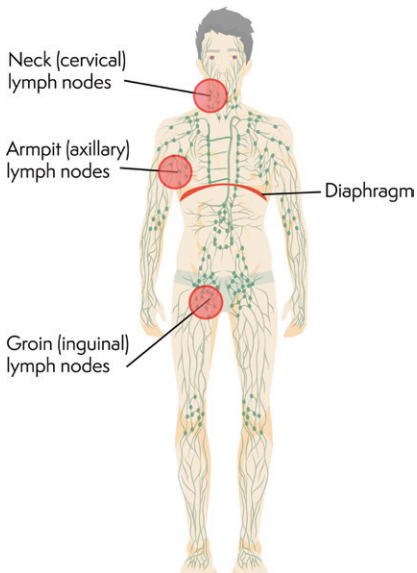
Two sets of lymph nodes on the same side of the **diaphragm** are affected



Most lymphomas are given a stage: 1, 2, 3 or 4. Sometimes, these are written in Roman numerals (I, II, III or IV). A different staging system is used for skin lymphomas and for NHL in children.

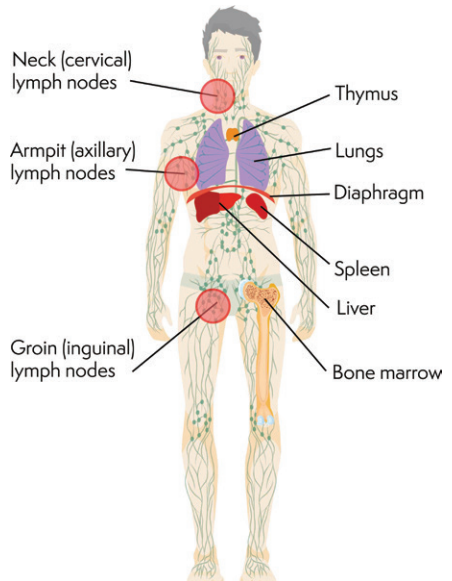
### Stage 3

Lymph nodes on both sides of the diaphragm affected



### Stage 4

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



You might hear stages 1 and 2 called 'early stage' lymphoma. 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. A higher stage does not mean it's not treatable.

Letters are sometimes added to the stage of lymphoma:

- A – you haven't had any B symptoms
- B – you have **B symptoms**: weight loss, night sweats or fevers (temperatures over 38°C)
- E – 'extranodal', meaning the lymphoma started in an organ outside of your lymphatic system, such as in the digestive system or salivary glands.

You might see the letter 'X' after your number. This means that the lymphoma measures above a certain size (depending on its type) and is classed as large or 'bulky'.

## Questions to ask about staging

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



**Notes**

## 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 either a **clinical oncologist** or **consultant haematologist**. 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.

“

**My clinical nurse specialist (CNS) gave me practical advice and emotional support that made a huge difference to me. Her expertise gave me the strength to believe I could get through my treatment and manage my illness, and take back control of my life.**

Carole, diagnosed with low-grade non-Hodgkin lymphoma







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
- telling you about 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.



**I was put on active monitoring (watch and wait). At first, it was difficult for me and my family to understand why I wasn't being treated straightaway, but I now call it 'watch and live'. I have appointments every 3 months and, despite still finding it hard to live with, talking to people and telling them how I feel really helps.**

Kate, diagnosed with low-grade non-Hodgkin lymphoma

# Treatment for lymphoma

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

Lymphoma can be treated with drugs, such as chemotherapy, steroids and targeted therapies. It can also be treated with radiotherapy or a stem cell transplant. For some people, active monitoring is recommended, which means you don't have treatment straightaway (see page 37).

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 you through:

- the aim of your treatment and whether it is to get rid of your lymphoma or to control its growth
- the type of treatment you'll have
- 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 your appointments

- Think about what you'd like to ask beforehand. It can be helpful to write questions down and to take them with you.
- If you don't understand the answer to your question, ask it again.
- As it can be difficult to remember lots of new information, 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 note-taking.

## Active monitoring (watch and wait)

In some cases, doctors advise actively monitoring your lymphoma rather than treating it straightaway. This is sometimes called 'watch and wait' or 'active surveillance'.



'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.

Although watch and wait can be difficult to understand, research shows that people do just as well in the long-term on watch and wait as people who have treatment straightaway. It can also lower the risk of lymphoma cells becoming resistant (unresponsive) to treatment and avoid side effects.

In addition, while you're not having treatment, you'll have fewer trips to hospital for treatment.



**We have more information about watch and wait on our website, including a video, at [lymphoma-action.org.uk/ActiveMonitoring](https://lymphoma-action.org.uk/ActiveMonitoring)**



**Active monitoring is good news for me. I don't need to have treatment for the time being as my cancer isn't affecting other aspects of my life. Though I get anxious when I detect a change in my body, I know my medical team will respond quickly should I need treatment.**

Scott, diagnosed with low-grade non-Hodgkin lymphoma

## Questions to ask about active monitoring

- Why are you recommending active monitoring?
- Could my lymphoma worsen 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 should I contact if I'm worried 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 is a type of treatment using drugs. It stops lymphoma cells from dividing.



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

Chemotherapy ('chemo') is usually given over a few months, often in **cycles** where you have treatment some weeks but not others.

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, 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. These might include fatigue (extreme tiredness), nausea (feeling or being sick) and hair loss.



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



**Find out more about how chemotherapy works in our short video at [lymphoma-action.org.uk/Chemotherapy](https://lymphoma-action.org.uk/Chemotherapy)**

## Steroids

Steroids are a type of drug. They're often used alongside other treatments for lymphoma. You might have steroids before, during or after chemotherapy. 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.

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 drugs

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

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

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.

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 radiation is similar to that used by an X-ray machine, but in much higher doses. 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 (relapse).

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

A course of radiotherapy usually lasts 2 to 4 weeks and you have treatment daily, Monday to Friday. Each treatment lasts around 5 to 20 minutes. Radiotherapy is painless and you can go home afterwards; however, you might experience side effects such as skin soreness and fatigue after treatment.

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

# Stem cell transplants

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. The stem cells might come from your own body ('autologous') or a donor ('allogenic').

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.



**It's tough, but 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



**Visit [lymphoma-action.org.uk/SCT](https://lymphoma-action.org.uk/SCT) to find out more about stem cell transplants. We also produce a book on autologous stem cell transplants, which is available to download or order at [lymphoma-action.org.uk/Books](https://lymphoma-action.org.uk/Books)**

# Questions to ask about treatment

- Which treatment are you recommending? Why?
- How does the treatment work?
- How is it given? Is it painful?
- Where will I have treatment? Will I stay in hospital overnight?
- 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, is there any support with transport available?
- 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?
- Are there any foods, supplements or medicines I should avoid?
- Is it safe to travel to another country during and soon after treatment?
- Is it OK for me to diet?
- Can I drink alcohol?
- Is it safe to have sexual contact during treatment? Should I use contraception? If so, what type?
- If my periods stop, could I still get pregnant?
- What happens if I choose not to have treatment?




# Notes

# 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 (called 'eligibility criteria'). These often 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.

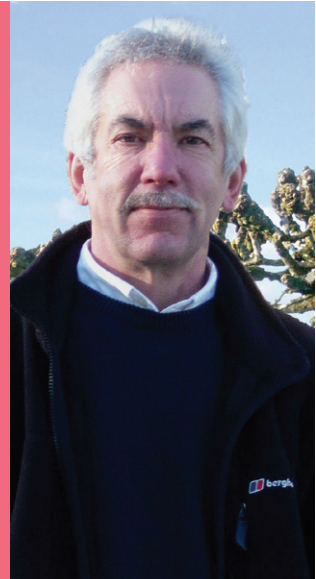
- 
- Our book *Clinical trials for lymphoma* tells you more about trials, including why and how they're done. It also features the personal experiences of people who have taken part in trials for lymphoma.
  - We also have an online clinical trials information service, [Lymphoma TrialsLink](#), where you can search for a trial that might be suitable for you.

Speak to your clinical nurse specialist or consultant to find out more about clinical trials and 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 high-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?
- What are the potential advantages and disadvantages of going on this trial?
- When will the results of the trial be available?
- How and when will I find out about the results of the trial?



## Notes

# 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 given. 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 permanent.

# 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?
- What help is available if I have particularly troubling side effects?
- Will my treatment affect my fertility? If so, how?
- Are there any late effects I should look out for?



## Notes



**Physically, going back to work was hard and I found it difficult even to walk up the stairs. But mentally, it did me so much good and helped me recover far more rapidly.**  
Carol, diagnosed with Hodgkin lymphoma

Photo credit: Magi Haroun

# Living well with and beyond lymphoma

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# Recovery after treatment

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

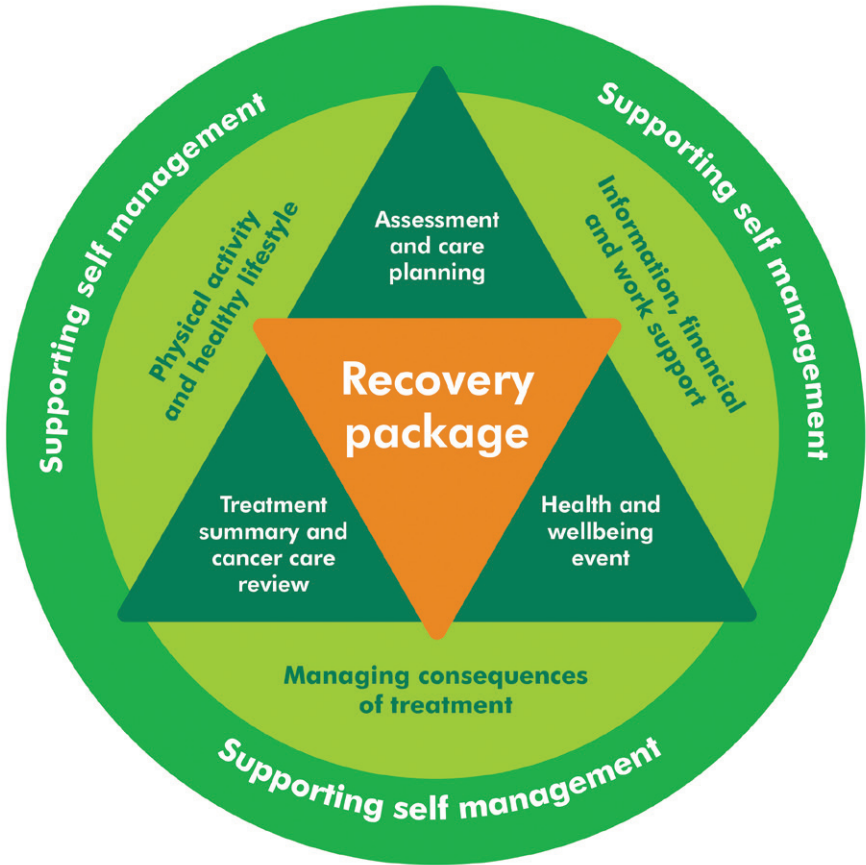


From the point of diagnosis onwards, your medical team should work with you to identify and address your needs, including those that are physical, practical, social, emotional or spiritual. This is sometimes called a 'holistic needs assessment (HNA)'.

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


## The recovery package

It takes time to adjust to life after treatment. The National Cancer Survivorship Initiative (NCSI) developed the recovery package to help people identify their individual needs and to prepare for the future.



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**Figure: The recovery package**



**Learn more about the recovery package at [lymphoma-action.org.uk/Recovery](https://lymphoma-action.org.uk/Recovery) and find tips to help you live well with and beyond lymphoma at [lymphoma-action.org.uk/LWL](https://lymphoma-action.org.uk/LWL)**

## Questions to ask about recovery from treatment

- Will I need to make changes to my day-to-day routine? If so, for how long?
- If my earnings are affected, 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?



### Notes





- **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 68.**
- **We also run free one-day interactive 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](http://lymphoma-action.org.uk/LYL)**



**I found the Live your Life workshop provided a 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 non-Hodgkin lymphoma





## Tips to help you live well after lymphoma

- Tell a member of your MDT 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.
- Lead a healthy lifestyle. This means eating healthily, building physical activity into your day-to-day life, and not smoking.
- Go for any health tests you're offered, such as checks for high blood pressure and cancer screenings.



**One of the best decisions I made was to see a counsellor to help with my anxiety. She helped me to come to terms with the changes I'd been through and helped me to feel a lot better.**

Georgia, diagnosed with Hodgkin lymphoma

**At first, I had some cognitive therapy and tablets to help with the anxiety. Now, I do what I can. I travel, I sing, but when I can't do it, I just stop.**

Andrew, diagnosed with low-grade non-Hodgkin lymphoma



**Over a year on and eight rounds of chemotherapy later, I am still in shock that I have cancer but I am pleased to say we have just taken our first trip abroad and I intend to get back into exercising.**

Julia, diagnosed with low-grade non-Hodgkin lymphoma



# Follow-up

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

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

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

The schedule for follow-up depends on a number of factors, including the type of lymphoma you've had, your hospital's protocols, and your preferences. 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 present) 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'. This allows you to book appointments as-and-when you need to, for example, if your symptoms worsen.



Although the idea of self-monitoring might seem daunting, many people find it helps to give them a greater sense of control over their health. Your medical team fully support you throughout and give you clear guidance about when and how to contact them, and how to book appointments.

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

## Questions to ask about follow-up

- How often will I have follow-up appointments?
- What happens at follow-up appointments?
- 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)

Lymphoma sometimes relapses after treatment. It's natural to worry about this possibility and it can be very distressing if it happens. Keep in mind that many people are successfully treated again.

**Because I had no symptoms before I was diagnosed, I worry that I might not recognise the lymphoma if it comes back, but the regular review is reassuring.**

Julian, diagnosed with low-grade non-Hodgkin lymphoma

**Initially, I had chemotherapy. My lymphoma relapsed 2 years later and I've since had a variety of other treatments. It has felt fairly non-stop, but on each occasion, a suitable treatment was found.**

Ron, diagnosed with high-grade non-Hodgkin lymphoma

# Questions to ask about relapse

- Is my lymphoma likely to relapse?
- What symptoms should I look out for?
- How will you know if the lymphoma relapses?
- 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 numb part of the body (local anaesthetic) or to put the whole body into a sleep-like state (general anaesthetic)

**Antibody** a protein made by white blood cells; antibodies recognise and stick to proteins that don't belong in your body, such as viruses or bacteria

**B symptoms** fever (temperature above 38°C), drenching night sweats and unexplained weight loss

**Bone marrow** the spongy material at the centre of larger bones where blood cells are produced

**Clinical oncologist** a doctor who specialises in treating people who have cancer

**Consultant haematologist** a doctor who specialises in diseases of the blood, including lymphoma

**CT scan** short for computed tomography: a scan that uses X-rays to take pictures of 'slices' through your body

**Cycle** a round of treatment followed by a rest period to allow your body to recover before the next round of treatment

**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** side effects that develop months or years after treatment

**Lymph nodes** small, bean-shaped structures spread throughout your lymphatic system that filter the fluid that surrounds all your tissues and cells (lymph)

**Lymphatic system** a network of tubes (vessels), nodes and organs that filters out germs and toxins, helps destroy cells that are old or damaged and drains waste fluids from your tissues

**Lymphocytes** specialised white blood cells that are part of your immune system; the cell that becomes cancerous in lymphoma

**MRI scan** short for magnetic resonance imaging: a scan that uses magnetic waves to produce a picture of the body

**PET scan** short for positron-emission tomography: a scan that uses a 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

**Remission** no evidence of disease on tests or scans (complete remission); partial remission is when the amount of lymphoma in your body has reduced by at least half, but is not completely gone

**Sedative** a drug to help you relax

**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, such as T lymphocytes

**Ultrasound scan** a scan that uses soundwaves to take pictures inside your body

**X-ray** a scan that uses high-energy radiation to take pictures of the inside of the body

# Information and support

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



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)



Come to one of our **Support Groups**. Find one near you at [lymphoma-action.org.uk/SupportGroups](http://lymphoma-action.org.uk/SupportGroups)



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



Visit [lymphoma-action.org.uk/TrialsLink](http://lymphoma-action.org.uk/TrialsLink) to search for clinical trials that might be suitable for you



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

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



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**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 (CLL) and small lymphocytic lymphoma (SLL)**
- **Active monitoring (watch and wait)**
- **Living with and beyond lymphoma: coping practically, physically and emotionally**

**Find our full range of books and information at [lymphoma-action.org.uk/Books](https://lymphoma-action.org.uk/Books) or call us on 0808 808 5555.**

Our information is evidence-based, approved by experts and reviewed by users. 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](https://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](http://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](http://lymphoma-action.org.uk/BookFeedback) or email us at [publications@lymphoma-action.org.uk](mailto: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](http://lymphoma-action.org.uk/GetInvolved)

## References

The full list of references is available on request. Please email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or call 01296 619409 if you would like a copy.

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# Notes





# Notes



# Notes

# Acknowledgements

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

- Charlotte Bloodworth, Lymphoma Clinical Nurse Specialist, University Hospital of Wales, Cardiff
- Dr Pam McKay, Consultant Haematologist, Beatson West of Scotland Cancer Centre, Glasgow.

Special thanks to Andrew, Carol, Carole, Dorothy, Georgia, Jason, Julia, Julian, Kate, Malcolm, Paul, Roger, Ron, Scott and Stephen for sharing their experiences. Quotations from their stories are featured throughout the book.

This book has been part-funded by a donation in memory of Julie Bostock. As per our policy, they have no influence over our content.

This book outlines what lymphoma is, what tests you might have and what treatment is available. It gives details of where to find further information and support.

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



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



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



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

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© Lymphoma Action 2020  
2nd edition produced June 2020  
Next revision due June 2023  
ISBN 978-1-9160205-5-9

Registered company in England and Wales  
(03518755). Registered charity in England and  
Wales (1068395) and Scotland (SC045850).  
LYM0225Introduction2020ed2

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