



**Lymphoma**  
association

# Introduction to lymphoma



# About this book

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

This booklet covers:

- what lymphoma is
- what tests you might have
- what treatments are available
- what questions you might like to ask your doctors.

You might want to read only the sections that are relevant to you at the moment, and return to other sections.

Throughout this booklet you'll find some symbols:



marks key information



lists practical tips



a space for questions and notes



signposts you to other resources you might find relevant.

Words that are in **teal** are explained in the glossary on pages 55-56.

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

Use this space to note key contacts so you can find them easily.

<b>Health professional</b>	<b>Name and contact details</b>
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist/ key nurse contact	
Treatment centre/ clinic reception	
Hospital out-of-hours number	
Hospital ward	
Key worker	
Support group coordinator	

# Acknowledgements

We would like to acknowledge the continued support of our Medical Advisory Panel, Nurse Forum and other expert advisers as well as our Reader Panel, whose ongoing contributions help us in the development of our publications. In particular we would like to thank the following people for their assistance with this booklet:

- Dr Pam McKay, Consultant Haematologist, Beatson West of Scotland Cancer Centre, Glasgow
- Charlotte Bloodworth, Lymphoma Clinical Nurse Specialist, University Hospital of Wales, Cardiff
- Jane Gibson, Lymphoma Association Clinical Nurse Specialist, The Christie NHS Foundation Trust, Manchester
- Lesley Wright, Macmillan Clinical Nurse Specialist Haematology, Harrogate and District NHS Foundation Trust, Harrogate.

Special thanks to Andy, Reem, Adam, Andrew, Emma, Gary, Sue, Carol, Ashley and Julian for sharing their experiences of lymphoma. Quotations from their stories are featured throughout the book.

# Contents

	<b>What is lymphoma?</b>	<b>7</b>
	<b>Tests for lymphoma</b>	<b>19</b>
	<b>Treatment for lymphoma</b>	<b>29</b>
	<b>After treatment</b>	<b>45</b>
	<b>Information and support</b>	<b>53</b>
	<b>Glossary</b>	<b>55</b>



I didn't feel scared or angry and I didn't think, 'Why me?' But I did find that the best way through diagnosis and treatment for me was adapting my life, being open with all those around me and keeping as fit as possible.

**Andy, diagnosed with Hodgkin lymphoma**

# What is lymphoma?

How cancer develops	10
What kind of cancer is lymphoma?	11
What causes lymphoma?	13
Types of lymphoma	13

Lymphoma is the 5th most common type of cancer in the UK. It can occur at any age, including in children. Lymphoma is nearly always treatable; most people live for many years after their diagnosis.

There are different types of lymphoma. Depending on its type and where it is in the body, lymphoma can cause many different symptoms. Some people have no symptoms at all, and their lymphoma is discovered when they have tests for another condition.

Here are the most common symptoms of lymphoma. **Note that each of these can have another cause.**



### Swollen lymph nodes

The most common symptom of lymphoma is a lump or several lumps. These are enlarged (swollen) lymph nodes and are usually painless. They are often noticed in the neck, armpit or groin.



### Fatigue

Fatigue means you are exhausted for no obvious reason or feel washed out after doing very little.



## Unexplained weight loss

Unexplained weight loss means losing a lot of weight quite quickly without dieting.



## Sweats and infections

Lymphoma can cause sweats that often happen at night and make your nightclothes and bed sheets soaking wet. Night sweats are often described as 'drenching'.

Some people get fevers (temperature above 37.5°C). Fevers often occur together with night sweats and weight loss, but they can occur separately. Repeated or persistent infections (that you can't shake off) can also be a symptom of lymphoma.



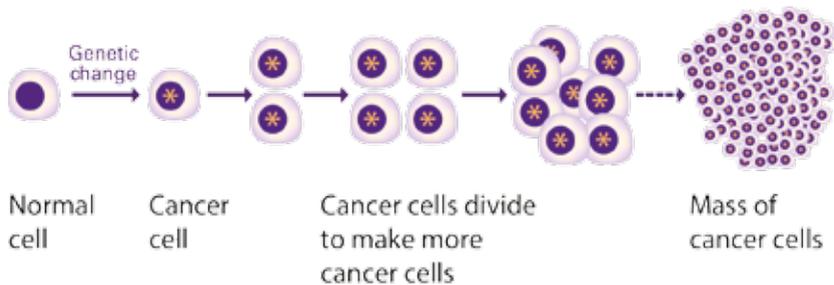
## Itching (pruritus)

Itching, with or without a rash, can be a symptom of lymphoma. It can be very troublesome, particularly in hot weather.

## How cancer develops

Your body is made up of many different types of cell, for example skin, bone and blood cells. As part of day-to-day life, cells grow and divide to form new cells. New cells replace cells that are older, as well as cells that have become damaged and die. Cell division is carefully controlled by chemical signals.

A cancer can develop when a genetic change happens within a cell. This might cause the cell to stop 'listening' to these chemical control signals. When this happens, cells can divide and multiply in an abnormal way, or old or damaged cells might not die as they should. This breakdown in control leads to the build-up of a large number of abnormal cells, which may form a cancer.



**Image 1** How cancer develops

---

## What kind of cancer is lymphoma?

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

Lymphoma develops when lymphocytes become out of control. They divide in an abnormal way or do not die when they should.

### What is the lymphatic system?

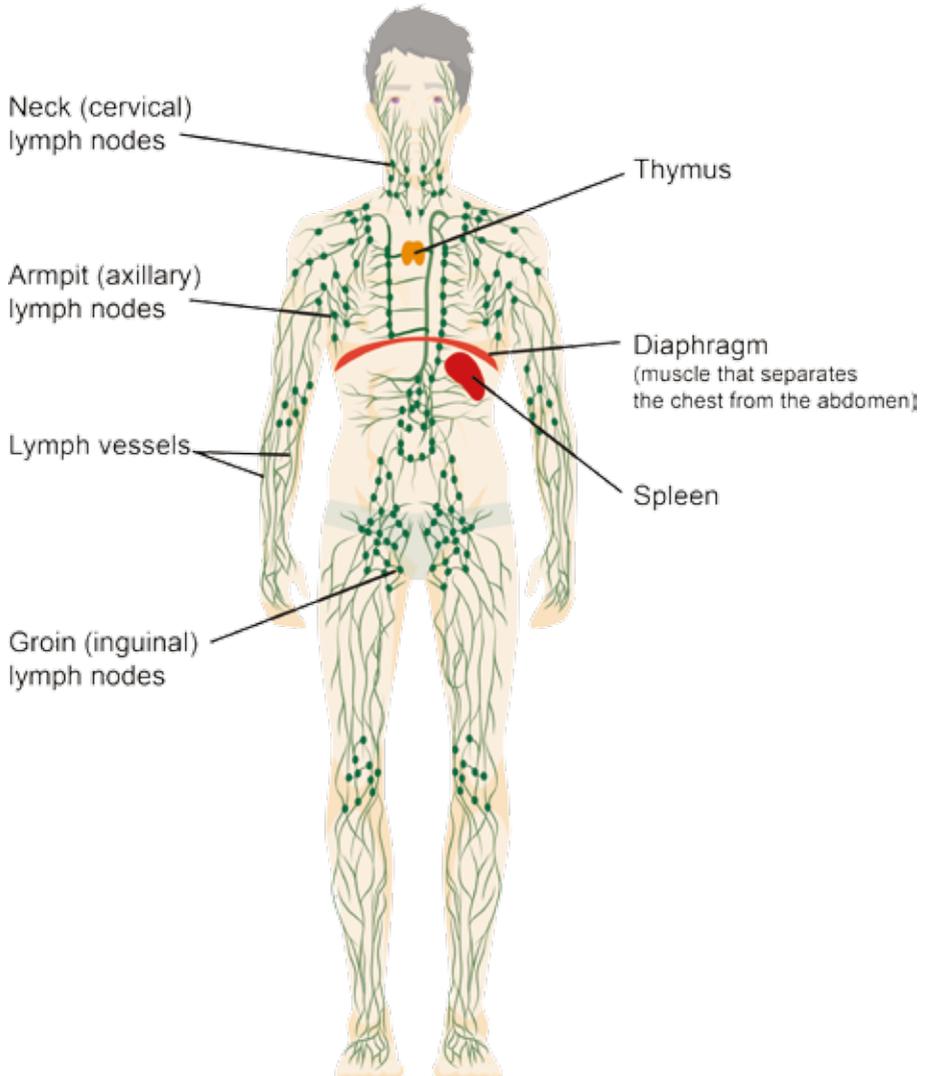
The lymphatic system runs throughout your body and includes lymph nodes (glands that contain lymphocytes) as well as organs of your immune system like your **thymus** and your **spleen**.

### Where does lymphoma develop?

When you have lymphoma, abnormal lymphocytes can collect almost anywhere in your body. They usually collect in **lymph nodes**, which are found throughout your body, often in groups.

Lymphoma commonly develops in the lymph nodes in the neck, armpit or groin. It can also develop in lymph nodes and tissues deeper inside your body. In some people, lymphoma develops in the **bone marrow**.

Less commonly, lymphoma starts in other areas of your body, such as the breast, stomach, bowel, skin, brain or liver.



**Image 2** The lymphatic system

---

## What causes lymphoma?

In most cases, the cause of lymphoma is not known. There is no evidence that anything you have or haven't done caused your illness.

Some people with conditions that affect their immune system have a higher risk of developing lymphoma. This includes, for example, people with HIV and those who have had an organ transplant.

### Can I pass on lymphoma?

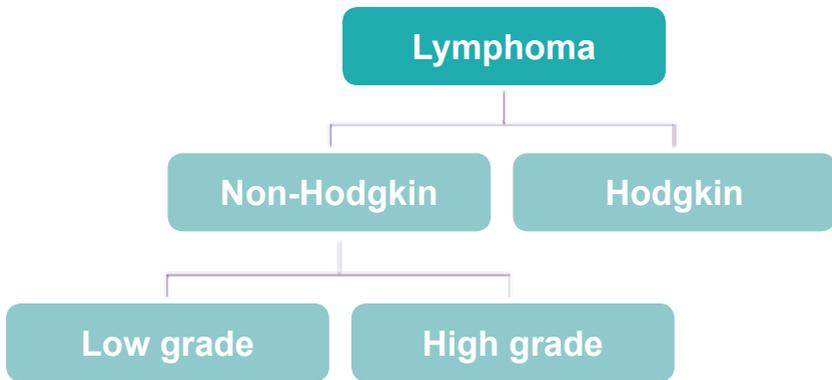
You can't catch lymphoma and you can't give it to someone else. Most people with lymphoma have no family history of the disease.

## Types of lymphoma

There are 2 main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). Within these types, there are many subtypes.

Your doctors might suspect which type of lymphoma you have based on your symptoms. However, they don't know your exact type until you have had tests.

The tests help doctors find out as much as possible about your specific type of lymphoma – different types can behave differently and need different treatment.



**Image 3** The main types of lymphoma

---

### **Hodgkin lymphoma**

Nearly 2,000 people are diagnosed with Hodgkin lymphoma each year in the UK. It affects slightly more males than it does females. Hodgkin lymphoma can occur at any age, although most people diagnosed are between the ages of 15 and 34, or over 60.

### **Non-Hodgkin lymphoma (NHL)**

More than 13,000 people are diagnosed with NHL each year in the UK. In addition, more than 3,000 people each year are diagnosed with chronic lymphocytic leukaemia (CLL), which is sometimes considered to be a form of NHL.

The risk of developing NHL increases with age. Most people who are diagnosed are over 55. It affects slightly more men than women.

NHLs are divided into 2 main types:

- **B-cell non-Hodgkin lymphomas**, which develop from B cell lymphocytes. B cell lymphocytes produce **antibodies** to fight infection.
- **T-cell non-Hodgkin lymphomas**, which develop from T cell lymphocytes. T cell lymphocytes protect you from viruses and cancers by attacking them directly.

B-cell lymphomas are more common than T-cell lymphomas.

NHLs are also classified according to how quickly they are growing:

- **'Low-grade' or 'indolent' lymphomas** are slow-growing.
- **'High-grade' or 'aggressive' lymphomas** grow more quickly.

Low-grade lymphomas are more common in older people. They are very rare in children and young adults. The most common types of low-grade NHL are follicular lymphoma and marginal zone lymphoma. Low-grade lymphomas tend to come back from time to time after they have been treated, so treatment is usually given with the aim of controlling, rather than curing them.

High-grade lymphomas are more common in people aged over 50, but they can occur at any age. The most common high-grade NHL is diffuse large B-cell lymphoma. Treatment for high-grade lymphomas usually aims to cure the lymphoma.

## Questions to ask your doctor about your lymphoma

- What type of lymphoma do you suspect I have?
- Is my type of lymphoma quite common or is it rare?
- Where in my body is the lymphoma?
- How fast is the lymphoma growing?
- Are my symptoms caused by the lymphoma? Will they go away once treatment starts?
- Is there anything you can give me to relieve the symptoms, or anything I can do to help lessen them?
- What is the outlook for my lymphoma? Is it curable?



### Notes



## Notes



I delayed going to my doctor until I felt really weak. Once at a surgery, I got a referral that led to many tests. I had to wait 10 days between tests and diagnosis, which gave me time to adjust to the idea of cancer.

**Reem, diagnosed with Hodgkin lymphoma**

# Tests for lymphoma

<b>Biopsy</b>	<b>20</b>
<b>Blood tests</b>	<b>21</b>
<b>Bone marrow tests</b>	<b>21</b>
<b>Scans and X-rays</b>	<b>22</b>
<b>Waiting for test results</b>	<b>23</b>
<b>Staging of lymphoma</b>	<b>25</b>
<b>Your medical team</b>	<b>27</b>

Usually, a general practitioner (GP) cannot confirm whether or not you have lymphoma. He or she will refer you to your local hospital, so that you can have tests to find out what is wrong.

We outline typical tests for lymphoma in this chapter. You may not have all of these tests – just the ones that are most suited to your individual situation.



**Don't worry if other people you meet in the clinic are having different tests from you – it's not a 'one-size-fits-all' approach.**

---

## Biopsy

A biopsy is a sample of tissue taken from your body and looked at under a microscope to check for abnormal cells. In most cases, a biopsy is the only way to confirm a diagnosis of lymphoma.

Sometimes a whole lymph node is removed. You might hear this called an 'excision' biopsy. An excision biopsy is a minor operation. It usually involves having a general **anaesthetic**. You go to hospital as an outpatient and the visit takes a few hours. Sometimes a smaller sample of the lymph node is taken under a local anaesthetic. This is called a 'core' biopsy.

It can take a number of weeks for a biopsy to be arranged and for the results to come back.

If the biopsy shows that you have lymphoma, you are then referred to a lymphoma specialist – either a haematologist (a doctor who treats blood cancers and other blood diseases), or an oncologist (a doctor who treats cancer).

Once your lymphoma is diagnosed, the next step is to find out which parts of your body it affects. This is called ‘staging’ (see page 25).

## **Blood tests**

In a blood test, a sample of your blood is taken and tested in a laboratory. Blood tests help doctors find out more about your general health and how well your organs are working. Your general health can affect what treatment you can have.

## **Bone marrow tests**

Bone marrow is the spongy tissue in the centre of some of your large bones. It is where blood cells are made.

You might have a bone marrow biopsy to check if there are lymphoma cells in your bone marrow.

A special needle is used to take a sample of the bone marrow from your hip bone. Before it is taken, the area is numbed using a local anaesthetic. Even with an anaesthetic, a bone marrow biopsy can be painful. Sedatives sometimes help. Painkillers are not usually needed afterwards; however, your doctor will advise you what to take should you have any pain.

## Scans and X-rays

Scans give more detailed pictures of the organs and lymph nodes in your body. There are several different kinds of scan that work in different ways.

- A **CT** or CAT scan uses X-rays
- A **PET** scan measures uptake of radioactive sugar
- An **MRI** scan uses magnetic waves
- An **ultrasound** uses sound waves.

The most common scans used in lymphoma are CT scans and PET scans – often combined into a PET/CT scan. Few people have an MRI scan.

An X-ray uses a form of radiation to take pictures of the inside of your body. You may have a chest X-ray to see if there are any enlarged lymph nodes in your chest. If you have had problems with your bowels, you might have an X-ray of your abdomen (tummy).

Each scan can take anywhere from 15 minutes to over an hour to do. An X-ray takes around 15 minutes. Scans and X-rays are painless and you can go home afterwards.



**You will not be radioactive after having an MRI scan, ultrasound or X-ray and you won't pose any risk to the people around you.**

**You may have very low levels of radioactivity in your body for around 6 hours after a PET or PET/CT scan. As a precaution, you should avoid close contact with pregnant women, babies and young children during this time.**

---

## Waiting for test results

It could take a couple of weeks for your test results to come back. This might seem a long time to wait and it is natural to feel anxious during this time. Rest assured that your doctor is collecting important information about your lymphoma to help plan the best treatment for you. The wait should not make your treatment any less successful.



**Image 4** A person having a scan.

---

Photo credit: The Royal Marsden NHS Foundation Trust

## Questions to ask about tests and scans

- What tests do I need and why?
- What do the tests involve?
- Could the tests do me any harm?
- Are the tests painful? Do I need an anaesthetic or sedation?
- Where and when will I have the tests?
- Can I drive myself home after the tests?
- Do I need to take time off from work or school after the test or scan?
- How long before I get the results?
- How will I get the test results? Who will explain them to me?



### Notes

## Staging of lymphoma

'Staging' is the process of working out which parts of your body contain lymphoma. Doctors use tests and scans to tell which stage your lymphoma is: 1, 2, 3 or 4. You might also see the stage written in Roman numerals (I, II, III or IV). Staging helps doctors to plan your treatment.

Most people with stage 1 or 2 lymphoma are said to have 'early-stage' lymphoma. People with stage 3 or 4 lymphoma are often said to have 'advanced-stage' lymphoma. The lymphatic system is spread throughout the body so it is not uncommon for lymphoma to be advanced when it is diagnosed. Lymphomas at any stage can be treated successfully.

As well as the numbers 1–4, the letters 'A' or 'B' are often used to describe the stage of lymphoma.

- 'B' means that you have unexplained weight loss, night sweats or fevers.
- 'A' means that you have not had any of these symptoms.

Sometimes, the letter 'E' (for 'extranodal') is also used. This means that the lymphoma started in an organ that is not part of the lymphatic system, for example, in the digestive system or salivary glands.

## 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 outlook for my type of lymphoma at this stage?



### Notes

## Your medical team

Your treatment is planned and managed by a multi-disciplinary team (MDT). The team is made up of various professionals, each with a different type of specialist knowledge.

You will be introduced to some of the members of your MDT. Ask them all the questions you have and find out how to get in touch with them if you have other questions or any concerns between appointments. They can also advise you on how to access practical or social support, including financial advisors or local support groups. Your clinical nurse specialist (CNS) is often a good first point of contact if you need information or have any worries about your lymphoma or your treatment.

Your GP can also help you by explaining the information they get from the hospital. They can make enquiries on your behalf and tell you about local support services that may be of interest to you.

I spoke to my GP about my difficulties and about my feelings. He suggested things that have really helped.

**Adam, diagnosed with Hodgkin lymphoma**





'Watch and wait' can be very difficult to deal with because it feels like nobody's doing anything, but it becomes easier over time. You realise that the medics are watching and waiting for your benefit.

**Andrew, diagnosed with follicular lymphoma**

# Treatment for lymphoma

Active monitoring ('watch and wait')	31
Chemotherapy	33
Steroids	33
Antibody therapy and other targeted therapies	34
Radiotherapy	35
Stem cell transplants	36
Side effects of treatments	38
Effects of treatment on other areas of your life	40
Clinical trials	42

Lymphoma can be treated with drugs (chemotherapy, steroids and targeted therapies), radiotherapy or a stem cell transplant. The type of treatment you need depends on the type and stage of your lymphoma.

For some people, an approach known as ‘watch and wait’ is recommended. This means that you do not have active treatment straightaway (see page 31).

In planning your treatment, your MDT is guided by your test results. You also have some say in how you’re going to be treated. Your consultant should meet with you to discuss:

- the aim of your treatment – whether it is to cure your lymphoma or to keep it under control for as long as possible
- the type of treatment you will have
- when you will begin treatment
- where you will be treated
- how long your treatment will take
- how you feel about the treatment.



### **Top tips**

- **Prepare your questions. Take them to your appointment and write down the answers you get.**
  - **Consider taking someone with you. They could take notes or remind you to ask specific questions.**
  - **Speak to your nurse specialist or another member of your medical team if you have questions or concerns about your treatment.**
-

## Active monitoring ('watch and wait')

Sometimes the best approach is to actively monitor the lymphoma rather than to treat it straightaway – this is often called 'watch and wait'.

If your doctor advises 'watch and wait', it means it is in your best interests to keep an eye on your lymphoma and to leave treatment for when it is really needed. There are several benefits to this approach, including preventing lymphoma cells becoming resistant to treatment and having no risk of side effects.

If you are on 'watch and wait', you have regular appointments at the clinic. You do not have treatment unless the lymphoma begins to grow or affect your general health. There is lots of evidence that people do just as well in the long-term on 'watch and wait', having active treatments only when they are really needed.



I'm on 'watch and wait', and regularly attend a clinic. The support group I go to is particularly helpful as it allows me to meet people in a similar position and talk with them.

**Emma, diagnosed with splenic marginal zone lymphoma**

## Questions to ask about active monitoring ('watch and wait')

- Why are you recommending 'watch and wait'?
- Could my lymphoma get worse if I don't have treatment straightaway?
- Will my life be 'on hold' while I'm on 'watch and wait'?
- 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 am worried about symptoms?
- If my lymphoma becomes active, do I need treatment straightaway? Which treatment?
- How long do you expect me to be on 'watch and wait'?



### Notes

## Chemotherapy

Chemotherapy means treatment with drugs. It works by stopping the lymphoma cells from dividing. Usually lymphoma is treated with a combination regimen made up of several different chemotherapy drugs. Each of the drugs kills lymphoma cells in a slightly different way.

Chemotherapy is usually given over a period of months, often in **cycles**. This means you have treatment some weeks, but not others. Chemotherapy can be given:

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

You often have chemotherapy as an outpatient, which means that you go into hospital for a few hours and then go home. Sometimes, however, you might need to stay in hospital overnight.

## Steroids

Steroids are a type of drug that can:

- treat the lymphoma itself
- increase the effectiveness of chemotherapy
- reduce some of the side effects of chemotherapy, eg nausea (feeling sick).

You might have steroids during or after treatment with chemotherapy. Sometimes you may have steroids for a few days before you start chemotherapy.

## **Antibody therapy and other targeted therapies**

Antibodies are proteins in your blood. When you have an infection, your body makes antibodies. The antibodies stick to proteins on the surface of bacteria or viruses that cause infection. They signal to your body to get rid of them.

Antibody therapy is a drug treatment. It uses antibodies that have been made in a laboratory. Just like bacteria and viruses, lymphoma cells have proteins on their surface. The antibodies target these proteins, stick to them and mark the lymphoma cells to be killed by your immune system.

Some antibody treatments are joined to another treatment, eg chemotherapy, to help target that treatment to the lymphoma cell.



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

---

There are many other new, targeted treatments that are now being used or are being tested for lymphoma.

New, targeted drugs work in different ways to stop cancer cells growing or dividing, to cause cancer cells to die, or to help the immune system to recognise and destroy the cancer cells. These drugs target the lymphoma cells more precisely than does chemotherapy. This helps to reduce the effect of treatment on healthy cells.

## Radiotherapy

Radiotherapy uses high-energy X-rays. It destroys cancer cells by stopping them from dividing. Radiotherapy uses radiation similar to that used by an X-ray machine, but in much higher doses. The X-rays are targeted directly at areas of your body where lymphoma is present.

Radiotherapy can be given:

- after chemotherapy, to make sure that the lymphoma cells are completely destroyed or to lower the chances of relapse (the lymphoma coming back)
- to control symptoms such as pain and breathlessness
- on its own in a small number of people with a low-grade lymphoma.

Radiotherapy is usually given daily, Monday to Friday. Each treatment lasts around 5–20 minutes. The treatments are painless and you can go home afterwards. A course of radiotherapy often lasts 2–4 weeks.

## Stem cell transplants

Lymphoma is sometimes treated using very high doses of chemotherapy. As well as killing lymphoma cells, high-dose chemotherapy can damage the bone marrow.

The bone marrow contains stem cells, which develop into different types of blood cell. A stem cell transplant allows you to have high-dose chemotherapy while also ensuring that your bone marrow continues to function as it should.

The **stem cells** might be collected from you during or after chemotherapy, or they may come from a donor.

You are given a transfusion of stem cells via a drip into your vein. It can take a while for your bone marrow to start working again. You need to stay in hospital for a few weeks so that hospital staff can give you the care you need. You are likely to be in 'protective isolation' during this time. This means that you are in a room on your own to prevent you from picking up infections. You should still be able to have some visitors.



You can find more information about stem cell transplants on our website at [bit.ly/stem-cell-lymphoma](https://bit.ly/stem-cell-lymphoma). We also produce a booklet about autologous stem cell transplant. You can download or order a copy on our website at [bit.ly/Auto-stem-cell-book](https://bit.ly/Auto-stem-cell-book). If you prefer, call our helpline and ask for a copy.

---

## Questions to ask about treatment

- What treatment will I have? Why?
- How does the treatment work?
- How is the treatment given? Is it painful?
- Where will I have treatment?
- Will I need to stay in hospital overnight?
- How long does each treatment session last? How long does the whole course take?
- Can I drive myself home after my treatment?
- When and how will you know if the treatment is working?
- Does the treatment cause any side effects, straightaway or shortly afterwards? How long might these last?
- Are there any potential longer-term side effects?
- Will I be able to carry on my normal day-to-day routine during treatment?



### Notes

## Side effects of treatments

Treatments for lymphoma vary in what side effects they cause. For example, the side effects of chemotherapy depend on which drugs you have. The side effects of radiotherapy depend on the area of your body that is treated.



**The aim of treatment is to destroy all of the lymphoma cells. However, all treatments have other, unwanted effects called ‘side effects’.**

---

Different people are affected differently so it is not possible to say for certain how you’ll be affected. Your doctor should, however, give you an idea of what to expect. You should also be given information about how best to take care of yourself during treatment and who to contact if you have any concerns.

Most side effects are short-term, but some can last for a few weeks or months after you finish treatment (long-term side effects). Some side effects start long after the treatment has finished (**late effects**). Occasionally, side effects may be permanent.

## Questions to ask about side effects of treatment

- What are the potential side effects of the treatment I'm having? How long can they last?
- Is there anything I can do to lessen or prevent the side effects?
- Will the treatment affect my fertility? If so, how?
- Are there any treatments to help with side effects?



### Notes

## Effects of treatment on other areas of your life

Going through treatment for lymphoma can have a significant impact on other areas of your life – physically, emotionally and practically. Ask your medical team what to expect.

You should be given a holistic needs assessment (HNA) by a member of your MDT to identify and address any physical, practical, social, emotional or spiritual needs. Various health professionals (eg your consultant, CNS, physiotherapists) might be involved in the assessment and in making suggestions to address your needs.



An ability to understand the implications of my disease, to adjust to new situations and to deal positively with the challenges of living with lymphoma has been crucial to me.

**Gary, diagnosed with follicular lymphoma**

## Questions to ask about effects of treatment on other areas of your life

- Will I be able to carry on my day-to-day routine?
- Should I be on a special diet while I am having treatment?
- Are there any foods, supplements or medicines I should avoid while I'm having this treatment?
- Is it safe to travel abroad during treatment?
- Is it safe to eat out?
- Is it OK for me to diet?
- Can I drink alcohol?
- Can I have sex during treatment? Should I use contraception? If so, what type?
- If my periods stop, could I still get pregnant?
- What emotional support is available to me during my treatment?



### Notes

## Clinical trials

Your doctor may ask you if you would like to take part in a clinical trial. Clinical trials are scientific studies that test medical treatments. Many clinical trials for lymphoma investigate the best ways of using existing treatments. Other trials test new treatments to see if they are better than the current standard treatments.

Not all hospitals carry out clinical trials and there might not be one suitable for you. For each trial, you must meet certain 'eligibility criteria'. These often relate to the type of lymphoma you have, any previous treatment you've had, and your general health.



Talk to your doctor if you are interested in finding out more about clinical trials. You can look for a trial that might be suitable for you at [bit.ly/TrialsLink](https://bit.ly/TrialsLink).

You do not have to take part in a clinical trial if you do not wish to. If you do decide to take part and then change your mind, you can opt out at any point and have the standard treatment instead.



The information I was given about the trial was easy to understand, and I took it to my GP to discuss. She pointed out that my progress would be well-monitored, in terms of the number of check-ups, blood tests and opportunities to see the treating team.

**Sue, diagnosed with follicular lymphoma**

## Questions to ask about clinical trials

- Are there any clinical trials I should consider?
- Do I have to pay to take part in a trial?
- What happens if I change my mind about taking part once I have started the trial?
- When will the results of the trial be available?
- Will I be told the results of the trial? How and when?



### 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

# After treatment

Follow-up	49
Relapse (if the lymphoma comes back)	51

Lymphoma is often treated very successfully, but it takes time to recover, both mentally and physically. Be kind and patient with yourself during this time. Some side effects take weeks or months to go away. For example, you might feel low in energy or be more prone to infections for a while after treatment.

At the end of your treatment, your hospital provides a treatment summary, which is a record of:

- your diagnosis and ongoing care
- the treatment you've had (including any side effects and possible late effects of treatment)
- any signs of recurrence.

You and your GP should receive a copy of the summary.

There may be changes to your life after your diagnosis. They are not uncommon but they can be difficult to adjust to. Some of your relationships may change. You might have to make changes in your daily life too, for example, to the work you did before you had lymphoma.

See page 53 to find out how we can support you.



***Live your Life, living with and beyond lymphoma*** is an education and support programme for people affected by lymphoma. It has been developed to help you live well with and beyond lymphoma. Find out more at [bit.ly/LA-Live-your-Life](https://bit.ly/LA-Live-your-Life).

---



## Top tips

- Let a member of your medical team know if you have side effects or other problems.
- Ask about possible late effects and when they might occur.
- Lead a healthy lifestyle in terms of diet, exercise and not smoking.
- Go for any tests you are offered, such as checks for high blood pressure and cancer screening.

Ask for counselling if you feel it would be beneficial.

**Ashley, diagnosed with skin 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 follicular lymphoma**

## Questions to ask about ending treatment

- How can I stay healthy during and after my treatment?
- Is there anything I can do to reduce the risk of the lymphoma coming back?
- How soon after treatment finishes can I have dental treatment?
- Is it OK to have vaccinations? Should I have the winter flu jab?
- Can I return to using my usual hair products when my hair grows back? When can I dye my hair again?
- Can I travel?
- If I want to start a family, how long should I wait after finishing treatment?
- Do I need to declare my lymphoma diagnosis on a job application?
- How can I cope with anxiety or other challenging feelings?



### Notes

## Follow-up

You will see your medical team for regular check-ups after your treatment has finished.

During follow-up appointments, you are asked how you are feeling. You might also have a physical examination, blood tests and scans. The aim of follow-up appointments is to:

- monitor your recovery from treatment
- 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 raise concerns.

The timeframe for follow-up depends on several factors, such as the type of lymphoma you've had. As a general guide, you may be seen regularly during treatment and then once every 2–4 months. Gradually, your appointments become less frequent, spreading out to every 3–6 months and eventually down to once a year.

Some hospitals offer a new approach called 'patient-triggered follow-up' (PTFU), where you schedule your own appointments. This approach was introduced following research findings that recurrences are usually picked up by the person who has had lymphoma.

You would attend a workshop or information session about self-management before you start PTFU. The approach is only suitable for people who have been in remission for a long time and are at low risk of relapse.

## Questions to ask about follow-up

- What does follow-up involve?
- How often will I be seen in the clinic after my treatment has finished?
- What happens at the follow-up appointments?
- Are there any symptoms I should look out for that might suggest the lymphoma has relapsed (come back)?
- What should I do if I am worried about anything between appointments? Who do I contact?
- How will I know if the lymphoma relapses?
- Where can I go for help, support and advice between appointments?



### Notes

## Relapse (if the lymphoma comes back)

Lymphoma can sometimes come back after a course of treatment. This is called 'relapse'. It's natural to worry about the possibility of relapse and, of course, if it happens, relapse can be very distressing. It's important to remember, though, that many people are successfully treated again.

I found that if I just took things a day at a time. I could leave all the worrying to the specialist.

**Carol, diagnosed with Hodgkin lymphoma**



My consultation was very encouraging. The lump had decreased in size. Because I had no symptoms, I worry that I might not recognise the lymphoma if it comes back, but the regular review is reassuring.

**Julian, diagnosed with low-grade nodal marginal zone lymphoma**

## Questions to ask about relapse

- Am I likely to relapse?
- How will you know if the lymphoma relapses? Are there any symptoms I should look out for?
- Is there anything I can do to reduce the risk of relapse?
- How will I be treated if the lymphoma relapses?
- What are the chances of going back into remission with further treatment?



### Notes

# Information and support

A diagnosis of lymphoma can take a great deal of adjustment. Going through tests, scans and treatment can have an impact, physically, practically, socially and emotionally. For more information about any of the topics covered in this booklet, visit **[bit.ly/about-lymphoma](http://bit.ly/about-lymphoma)**.



Call our Freephone helpline on 0808 808 5555, Monday to Friday, 9am to 5pm. You can also use Live Chat on our website or text message on 07786 202030 or contact us on WhatsApp on 07494 181130



Come to one of our support groups. Find your nearest one at [bit.do/support-groups](http://bit.do/support-groups)



If you're over 16, join our online forum to chat with others who are affected by lymphoma



Why not talk to one of our buddies, volunteers who have personal experience of lymphoma



Join us on Facebook



Follow us on Twitter



Follow us on Instagram



Check out our YouTube to watch videos that contain expert opinions, medical information, and the personal experiences of people affected by lymphoma.

## Other useful organisations

On our website at [bit.ly/useful-orgs](https://bit.ly/useful-orgs), you can find a short list of other organisations you may find helpful. These organisations provide information, support and practical advice for people affected by cancer. There are many other organisations offering specialised help; you can find details of some of them on our topic-specific pages.

If you can't find what you need, please contact our Freephone helpline for further information and support on **0808 808 5555** (9am-5pm Monday-Friday) or email us at [information@lymphomas.org.uk](mailto:information@lymphomas.org.uk). Our online forums may also provide suggestions of useful organisations.

There is a lot of information online. A simple way of checking that health and social care information is trustworthy is to look for the Information Standard quality mark (pictured below) which indicates that information is clear, accurate, evidence-based, up-to-date and easy to use. For more information about how we produce our information, please go to [bit.ly/LA-information](https://bit.ly/LA-information).



# Glossary

**Anaesthetic** a drug that stops feeling, especially of pain: in a general anaesthetic the drugs make you unconscious; in a local anaesthetic the drug just numbs part of the body

**Antibody** a protein that kills off disease-causing cells or microbes such as bacteria

**Bone marrow** spongy material in the middle of some of our bones that produces the body's blood cells

**CT scan** short for 'computed tomography', a test that uses X-rays to give a picture of the inside of the body in 'slices'

**Cycle** a block of chemotherapy that is followed by a rest period to allow your healthy cells to recover

**Immune system** the parts of the body that fight off and prevent infection

**Late effects** long-term side effects that can start many years after the treatment has finished

**Lymph node** a gland that contains cells that fight infection

**Lymphatic system** a network of lymph vessels, lymph nodes and other organs such as the spleen that is part of the immune system

**Lymphocyte** a type of white blood cell that normally helps to fight infections; the cell that becomes cancerous in lymphoma

**MRI scan** short for 'magnetic resonance imaging', a test using radio waves and magnetic fields to give a picture of the body

**PET scan** short for 'positron-emission tomography', a scan that uses radioactive sugar to look at how active cells are; it may show which parts of the body are affected by lymphoma

**Spleen** an organ found behind the stomach that is part of the immune system

**Stem cell** an immature cell that can mature into different kinds of specialised blood cells

**Thymus** a small flat gland at the top of the chest, immediately behind the breast bone. The thymus is the organ where T cells develop

**Ultrasound** a scan that uses sound waves that bounce off organs and tissues to build up a picture of the inside of your body

## Tell us what you think

We continually strive to improve our resources for people affected by lymphoma and are interested in your feedback. Share your comments at [bit.ly/LA-feedback](https://bit.ly/LA-feedback) or email us at [publications@lymphomas.org.uk](mailto:publications@lymphomas.org.uk). You can also call our Freephone helpline on **0808 808 5555**.

## Copyright

© Lymphoma Association 2017

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without the prior permission in writing of the Lymphoma Association, or as expressly permitted by law, by licence or under terms agreed with the appropriate reprographics rights organisation.

However, permission is granted to individuals to reproduce the content of the publication for personal and educational use only, provided explicit reference continues to be made to the Lymphoma Association as the publisher and copyright holder of the publication. Commercial or organisational reproduction, copying, hiring, lending is prohibited without prior permission in writing of the Lymphoma Association.

Enquiries regarding reproduction, copying, hiring and lending outside the scope of the above should be sent to the Publishing Department at [publications@lymphomas.org.uk](mailto:publications@lymphomas.org.uk).

## British Library Cataloguing-in-Publication Data

A catalogue record for this book is available from the British Library. ISBN 978-0-9957186-0-9

## Disclaimer

The Lymphoma Association shall hold responsibility for the accuracy of the information it publishes under The Information Standard and neither the Scheme Operator nor the Scheme Owner shall have any responsibility whatsoever for costs, losses or direct or indirect damages or costs arising from inaccuracy of information or omissions in information published on behalf of the Lymphoma Association.

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

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



**Tom (pictured with his wife, Soonita) was a London Marathon 2017 finisher. Tom ran to support his brother, and others affected by lymphoma.**

You don't have to run a marathon to support other people coping with lymphoma. Just text LAUK00 and the amount you'd like to donate to 70070.

As the UK's leading lymphoma charity, we can only offer our patient information free of charge thanks to the generosity of our fantastic supporters. Every donation, no matter how small, helps us to be there for someone else.

Thank you.

**[www.lymphomas.org.uk/donate-book](http://www.lymphomas.org.uk/donate-book)**



This booklet explains what lymphoma is, the tests you might have and what treatment is available.

The Lymphoma Association provides specialist information and emotional support to anyone affected by lymphatic cancer. Get in touch today to see how we can help you.

Lymphoma Association

3 Cromwell Court, New Street, Aylesbury, Bucks HP20 2PB

General enquiries 01296 619400

**Freephone helpline 0808 808 5555**

**information@lymphomas.org.uk**

**www.lymphomas.org.uk**

© Lymphoma Association 2017

Registered company in England and Wales (company number 03518755)

Registered charity in England and Wales (charity number 1068395)

Charity registered in Scotland (charity number SCO45850)

The Lymphoma Association logo and periwinkle is a UK registered trade mark (number UK2439521) of the Lymphoma Association.

LYM0225Introduction2017v1

1st edition produced: May 2017

Next planned review: May 2020

ISBN 978-0-9957186-0-9

