

Classical Hodgkin lymphoma

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My lymphoma type, stage and date of diagnosis:

My treatment plan:

Key worker contact

Name: _____

Role: _____

Contact details: _____

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

About this book

Over 1,600 people are diagnosed with classical Hodgkin lymphoma each year in the UK. This book explains what classical Hodgkin lymphoma is, how it is diagnosed, and the treatment options available.

You might also be interested in our book *Living with and beyond lymphoma*, which gives tips on coping practically, physically and emotionally.

Words in **bold teal** are explained in the glossary on pages 96 to 100.

You can find our full range of resources on our website. If you can't find the information you're looking for, or in the format you would like, please contact us (see page 101).

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“ *I had never heard of Hodgkin lymphoma. I needed to find out what I was facing and was learning about a condition I had never thought of before. Now I know more about Hodgkin lymphoma, I can see that being a young man didn't by any means make me immune from having this type of cancer; in fact, I fitted the profile.*

Joel, diagnosed with classical Hodgkin lymphoma

What is classical Hodgkin lymphoma?

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What is lymphoma?

Lymphoma is a type of blood cancer. It develops when **white blood cells** called **lymphocytes** grow out of control.

Lymphocytes are part of your **immune system**, which helps to fight infection. Lymphocytes travel around your body in your **lymphatic system** in a fluid called lymph.

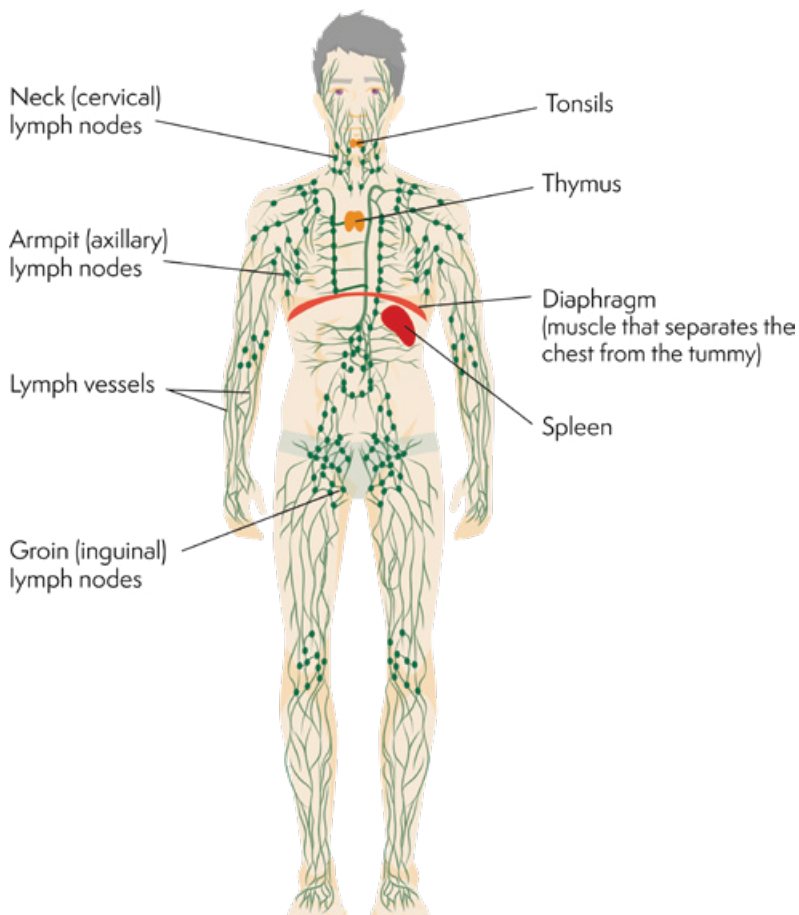
The lymphatic system, shown in the diagram opposite, is a network of lymph vessels and **lymph nodes** (sometimes known as lymph glands). It also includes organs, such as your **spleen**, tonsils and **thymus**.

If you have lymphoma, your lymphocytes divide in an abnormal way or do not die when they should.

The abnormal lymphocytes build up, usually in lymph nodes in your armpits, neck or groin. However, they can collect in almost any part of your body.



Find out more and watch a short animation on our website lymphoma-action.org.uk/WhatIsLymphoma



The lymphatic system



Find out more about the lymphatic system on our website lymphoma-action.org.uk/LymphaticSystem

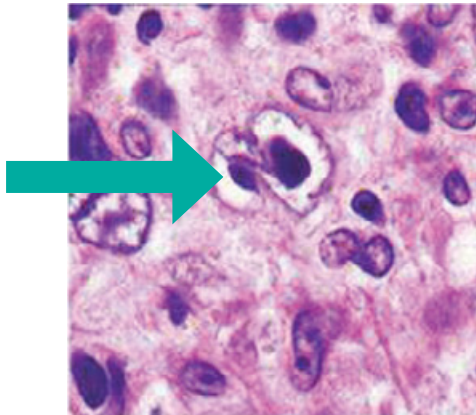
Types of lymphoma

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



Find out more about the different types of lymphoma on our website lymphoma-action.org.uk/Types

Classical Hodgkin lymphoma is a type of lymphoma that contains abnormal cells called Reed–Sternberg cells. Doctors can see these cells when they look at a sample of classical Hodgkin lymphoma under a microscope.



Reed–Sternberg cells under a microscope

There are four subtypes of classical Hodgkin lymphoma. They are named after the appearance of the lymphoma cells and the cells surrounding them.

- Nodular sclerosis classical Hodgkin lymphoma is the most common type in young adults.
- Mixed cellularity classical Hodgkin lymphoma is more common in older people.
- Lymphocyte-rich classical Hodgkin lymphoma is rare.
- Lymphocyte-depleted classical Hodgkin lymphoma is very rare.

All four subtypes of classical Hodgkin lymphoma are diagnosed and treated in the same way.



Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL) is often listed as a type of Hodgkin lymphoma. However, it is managed and treated differently to classical Hodgkin lymphoma. We have information on this type of lymphoma on our website at lymphoma-action.org.uk/NLPHL



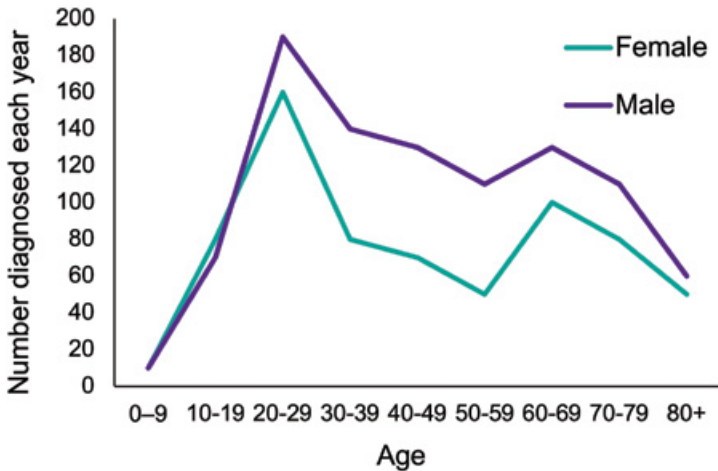
“ *I had never heard of lymphoma before I was diagnosed. I didn't even realise it was a blood cancer until further into my diagnosis.*

Georgia, diagnosed with classical Hodgkin lymphoma

Who gets classical Hodgkin lymphoma?

Over 1,600 people are diagnosed with classical Hodgkin lymphoma each year in the UK.

It can develop at any age, but most people diagnosed are between the ages of 15 and 34, or over 60.



New cases of classical Hodgkin lymphoma each year in the UK.

Data from Haematological Malignancy Research Network



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

Classical Hodgkin lymphoma affects slightly more males than females. It can affect people of any ethnic background.

In most cases, the cause of lymphoma is not known. Lots of different factors are likely to be involved.

Factors that might increase your chances of developing lymphoma include:

- **past infection with the Epstein-Barr virus (EBV).** EBV is a very common virus that can cause glandular fever. About 9 in 10 adults have been infected with EBV but many don't know they've had it because it might not cause any symptoms. However, most people who have had EBV do not get Hodgkin lymphoma.
- **a lowered immune system.** This could be due to a condition such as human immunodeficiency virus (HIV), or being on medicines that dampen the immune system (immunosuppressants).
- **a family history of lymphoma.** Lymphoma is not passed down from parents to children (inherited), but you have a very slightly higher risk of developing lymphoma if you have a close relative who has it due to similarities in your genetics.



Find out more about the causes and risk factors for lymphoma at lymphoma-action.org.uk/Causes

“ *At first I started questioning why I had lymphoma. Was it my fault? Have I done something to cause this? Have I not treated my body well? I now understand that there is no clear cause of Hodgkin lymphoma and it isn't because of anything I have or haven't done.*

Maddie, diagnosed with classical Hodgkin lymphoma



Outlook

Hodgkin lymphoma is very treatable. It usually responds very well to treatment. Most people go into complete **remission** and need no further treatment.

In some people, Hodgkin lymphoma comes back (**relapses**). There are effective treatments if this happens.

Your lymphoma specialist is the best person to talk to about the likely outcome of your treatment. In giving you this information, they will consider a range of factors, including:

- your age
- how much lymphoma you have in your body and where it is (the stage of your lymphoma – page 37)
- the results of your tests and scans (see page 34)
- your general health and fitness.

“ *On the one hand, I was relieved to have a diagnosis as I knew something was wrong for a long time. I was nervous waiting for the biopsy results but once I knew what type of lymphoma I had, I felt positive knowing that the condition was treatable.*



Tom, diagnosed with classical Hodgkin lymphoma

Summary

- Lymphoma is a type of blood cancer.
- It develops when white blood cells called lymphocytes grow out of control.
- There are two main types of lymphoma: Hodgkin and non-Hodgkin lymphoma.
- Classical Hodgkin lymphoma contains abnormal cells called Reed–Sternberg cells.
- Most people diagnosed with classical Hodgkin lymphoma are aged between 15 and 34 or over 60, but it can affect anyone.
- In most cases, the cause is unknown.
- The long-term outlook for people affected by classical Hodgkin lymphoma is generally very good.



“ *I had lots of symptoms of lymphoma before my diagnosis, but at the time I had no idea what the reason was behind them. I had extremely itchy lower legs, an egg-sized lump on the left side of my neck and I felt really fatigued. I went to the GP a few times before I was sent to the hospital, and that's when everything happened really fast.*

Ruby, diagnosed with classical Hodgkin lymphoma

Symptoms

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Symptoms of classical Hodgkin lymphoma

Classical Hodgkin lymphoma can cause a range of symptoms. The symptoms you have depend on which part of your body is affected. Usually, symptoms start to go away once you start treatment for lymphoma.

Speak to your medical team for advice to help you manage any symptoms you are experiencing.



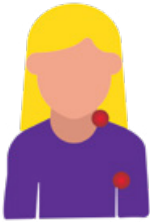
Find out more about symptoms, including an animation, on our website lymphoma-action.org.uk/Symptoms

“ *My symptoms included weight loss, fatigue like no other, intense itching, unexplained bruising, chest pain, breathlessness, non-healing sores, insomnia, night sweats, a cough, and paraesthesia (pins and needles type sensation). When I list my symptoms like this, I can't believe I didn't realise that something was wrong sooner! It's so easy to attribute these individual symptoms to something else. I didn't see my symptoms as being connected until after I was diagnosed. Then it seemed obvious.*

Lizzie, diagnosed with classical Hodgkin lymphoma



Swollen lymph nodes



The most common symptom of classical Hodgkin lymphoma is a lump or lumps that don't go down after a couple of weeks. These are swollen lymph nodes. They are usually painless and feel rubbery when you touch them.

They are most often found in the neck or just above the collar bones. They can also develop in other parts of your body, such as your armpits or groin.

Many people with classical Hodgkin lymphoma have swollen lymph nodes inside their chest. This might make you cough or feel breathless, or it might not cause any symptoms at all.

Occasionally, people with Hodgkin lymphoma have swollen lymph nodes that become painful a few minutes after drinking alcohol. This symptom is unusual – fewer than 1 in 20 people with Hodgkin lymphoma experience it – but it is a strong sign of Hodgkin lymphoma.

It is important to remember that lymph nodes can swell for lots of reasons. Most people with swollen lymph nodes do not have lymphoma.

B symptoms

Around 1 in 4 people with Hodgkin lymphoma have symptoms known as 'B symptoms'. These are:



Fever: a high temperature of above 38°C/100.4°F, that might come and go.



Unexplained drenching sweats: especially at night.

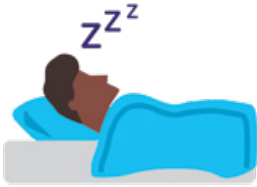


Unexplained weight loss: losing weight quickly without trying to.

Whether or not you have B symptoms can affect which treatment options are most appropriate for you.

Other symptoms

Other symptoms of classical Hodgkin lymphoma can include:



Unexplained fatigue. This is exhaustion that can be physical, emotional or mental. It means feeling exhausted for no obvious reason or feeling tired after doing very little.

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



Itching. This affects around 1 in 3 people with Hodgkin lymphoma. It can be worse at night and in hot weather. Scientists think that itching is caused by cytokines - proteins that are released by your immune system when your body is fighting an infection or illness.



Infections. Getting infections more easily than you usually would and having difficulty getting rid of them can be a symptom of lymphoma. Usually, white blood cells fight infections. However, if you have lymphoma, you have some cancerous white blood cells, which can make it harder to fight infections.

Extranodal symptoms. Rarely classical Hodgkin lymphoma starts in an organ in your body rather than a lymph node. For example, in the liver, lung or bone marrow. The symptoms you get depend on where the lymphoma is.



You can find tips to help you cope with symptoms of lymphoma on our website (search 'coping with symptoms') and in our book *Living with and beyond lymphoma* available from lymphoma-action.org.uk/Books

Summary

- Classical Hodgkin lymphoma can cause a variety of symptoms.
- The most common symptom is a swollen lymph node or nodes.
- Usually, symptoms start to go away once you start treatment for lymphoma.
- Speak to your medical team for advice about how to cope with any symptoms you experience.



Notes



“ My doctor did a raft of blood tests and referred me to ear, nose and throat (ENT). After examining the lumps in my neck, I was immediately sent for a biopsy. Ten days later, I was diagnosed with Hodgkin lymphoma. I then needed a scan to stage the lymphoma, which came back as stage 4 with lymphoma across my tonsils, collarbone, sternum, armpits, lungs, L1 spinal disk, and hip.

Craig, diagnosed with classical Hodgkin lymphoma

Tests, diagnosis and staging

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Diagnosis

Your GP is likely to have been the first person you spoke to about any symptoms or health concerns.

You'll be referred to a hospital specialist and seen quickly if your GP thinks there is a possibility that you have lymphoma.

Once you have been referred to a hospital specialist, you're likely to need further tests and scans. You have most of these tests as an outpatient, which means that you don't have to stay in hospital overnight.

It's important that your medical team get all the information they need about your lymphoma so that they can plan the most suitable treatment for you.

We outline some of the most common tests and scans for lymphoma in this chapter. You might not need all of them, but you will need a **biopsy** (page 28) to confirm a diagnosis of lymphoma.



For more information about tests and scans, visit lymphoma-action.org.uk/Tests

Blood tests

Most people have blood tests as part of their diagnosis for lymphoma, and then throughout treatment.

Blood tests can help doctors see how the lymphoma is affecting your body, and to plan the best treatment for you.

Blood tests can check:

- your general health.
- your blood cell counts. Lymphoma and its treatment can lower your levels of red blood cells, white blood cells and platelets. This can cause problems that might need treatment. You might also need to take some extra health and safety precautions. If your blood counts are low, your doctors might advise waiting until they are higher before it is safe for you to have treatment.
- for past and current infections. These can be treated to prevent recurrence during lymphoma treatment.
- how well your kidneys, liver and thyroid gland are working. Sometimes, lymphoma and its treatment can affect the functioning of these organs.

Biopsies

Lymph node biopsy

Most people need a procedure called a lymph node biopsy to confirm whether or not they have lymphoma.

This involves removing a swollen lymph node, or a sample from it. This is usually done under local **anaesthetic** and guided by a scan. An expert pathologist examines the sample under a microscope and does specialised tests on it to find out what type of lymphoma it is.

Speak to a member of your medical team in advance of the day of having your biopsy if you feel worried about it. Tell your medical team if you have been on blood thinners.

After your biopsy, your wound is covered with a plaster or protective dressing. You should be given clear guidance about how to care for it.

You can usually go home on the same day as having a biopsy, but check with your doctor in advance. The general advice is for someone to collect you and drive you home after a biopsy. If you have had a sedative or a general anaesthetic you shouldn't drive yourself home. Speak to your medical team if you need help organising transport.

It is important to contact your medical team straightaway if you notice any signs of infection (page 71).

Ask your doctor how long it will be before you get the results of your biopsy. Sometimes results come through within a few days, but they can take a week or more.



You can listen to our Lymphoma Voices podcast where Consultant Haematopathologist, Dr Bridget Wilkins, answers some of the most commonly asked questions about biopsies. You can hear it on our website, on Apple podcasts or on Spotify.

Bone marrow biopsy

A bone marrow biopsy checks whether you have lymphoma in your **bone marrow**. This is not usually needed because a PET/CT scan (page 30) can be used instead.

A bone marrow biopsy sample is usually taken from your hip bone (pelvis). You have a local **anaesthetic** to numb the area where the biopsy is taken. The doctor inserts a biopsy needle into the middle of the bone – either by hand or with a small electronic device that they use to collect a sample. The whole procedure usually takes 10 to 15 minutes.

A bone marrow biopsy is a safe procedure. However, you should contact your medical team if you develop increasing pain or redness where the sample was taken, bleeding that doesn't stop when you put pressure on it, or any signs of infection (page 71).

Scans

Different types of scans are helpful for different things. They might be used to:

- diagnose and **stage** lymphoma
- guide doctors as to the best place to take a biopsy sample from
- plan your treatment
- check your response to treatment
- check for any signs of **relapse**.

Usually, you have a scan at your local hospital as an outpatient. If your local hospital doesn't have the right scanning machine for you, you might have to travel to a hospital that's further away. Sometimes, it's possible to have a scan at a mobile unit.

Scans aren't painful, but you might find it uncomfortable if you have to lie still for a long time. Speak to a member of your medical team if you feel anxious about any aspect of having a scan. You might find it helps to talk through what to expect. In some cases, you might be offered a sedative – but ask about this in advance of the day, to see whether it's suitable for you and to allow time to arrange it.

PET/CT scans

Computed tomography (CT) scans and positron-emission tomography (PET) scans are among the most common scans doctors use for people affected by lymphoma.

Usually, they're done in the same appointment, as a 'PET/CT scan'. A PET/CT scan can help give a clear picture of which areas of your body are affected by lymphoma. Sometimes they need to be done as two separate appointments.

CT uses lots of X-rays to take pictures through your body. They're better than regular X-rays at taking pictures of the organs inside your body, including lymph nodes.

PET uses a harmless radioactive sugar to look at the level of activity of cells in your body. Cells that are more active, such as lymphoma cells, take up more sugar than less active cells. A special camera detects the radioactivity and these show up as 'hot spots' on the scan image.



CT scanner

You will be given advice on anything you need to do to prepare you for your scan. This might include being:

- asked not to eat or drink (known as fasting) for a few hours before you have your scan
- given a special dye (contrast agent) as a drink or an injection before your scan – this helps to show up certain parts of your body more clearly on the scan image
- given guidance about if and when to take any medication you usually take
- advised not to do strenuous physical activity in the 24 hours before your scan.

Staff will ask you to remove any metal you're wearing and whether you could be pregnant.

Some scans use very low levels of radiation. You will not be radioactive after a CT scan. However, with a PET/CT scan, you give off very low levels of radiation afterwards. Your medical team will tell you how long this is likely to be for. As a precaution, you should avoid being close to women who are pregnant during this time. It should be safe to be around pets, as long as they are not pregnant.

Ultrasound scans

Ultrasound scans use high-energy soundwaves to take pictures of the inside of your body. These soundwaves bounce off tissues and organs inside your body, making echoes. The echoes are recorded and can be used to help build up a picture of the inside of your body.

You might have an ultrasound scan to examine lymph nodes that are near the surface of your skin or to help your doctor find the best place to take a biopsy.

You'll be given information about how to prepare for your ultrasound scan. This will include whether to have a full or an empty bladder for the scan. You might also be asked not to eat anything for a few hours beforehand. Ultrasound scans are quick and painless, and you can go straight home afterwards.

X-rays

X-rays use high-energy waves, similar to radio waves. These take pictures through your body and build an image on a computer screen.

You might have an X-ray to check:

- for swollen lymph nodes inside your chest
- the position of a central line (central venous catheter) if you need one for chemotherapy (page 55).

You have to sit, stand or lie still to have an X-ray. It does not hurt and only takes a few minutes.

MRI scans

Magnetic resonance imaging (MRI) scans use strong magnets to take pictures of the inside of your body.

You might have an **MRI scan** if you are allergic to the contrast agents used in CT and PET/CT scans, or are pregnant, to avoid radiation.

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

For the scan, you lie on a bed that moves into a tube, and you have to lie very still for up to an hour. The MRI machine is very noisy – you should be offered earplugs and might be able to listen to music.

Tell your medical team if you:

- have any metal in your body, including a pacemaker, hip replacement, implantable defibrillators, ear (cochlear) implants, surgical staples and metal clips and plates put in after an injury. Your doctors will find out more about the type of metal in your body and decide whether it's safe for you to have an MRI scan.
- feel worried about being in an enclosed space (claustrophobic) so that they can help you to manage this. In some cases, you might be offered an anti-anxiety drug before the scan.

Test results

Your medical team gather as much information as possible from your tests. You then have an appointment to discuss the results of the tests. You can ask to take a family member or a friend to be with you if you would like to.

Many people find the uncertainty of waiting for the results of tests and scans very challenging to deal with. You can ask your doctor for an idea of how long you'll need to wait for your results.



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

Finding out you have lymphoma can be a shock. You're likely to experience a mix of feelings and emotions – there's no typical way to feel.



We offer a range of support services for anyone affected by lymphoma, including family and friends of those diagnosed. These include a Helpline, Online Support Meetings, trusted information in a range of formats, and personal stories from others with a lived experience of lymphoma. See our full range of support at lymphoma-action.org.uk/Support

“

In truth, I felt some relief that there was an answer to these strange symptoms that were just not going away. It wasn't just in my head and at least I now knew the cause of the symptoms and that, hopefully, with treatment things could improve.



Maddie, diagnosed with classical Hodgkin lymphoma

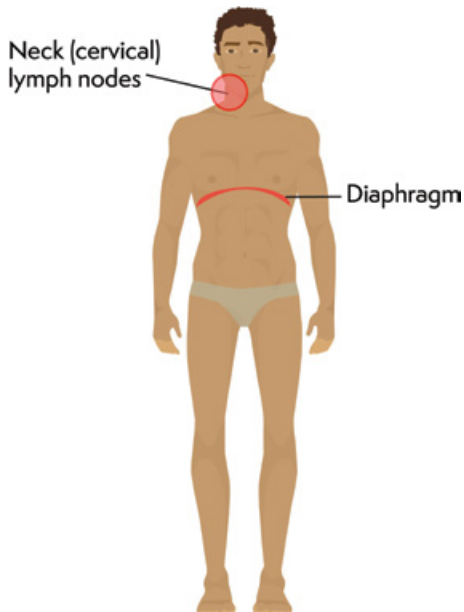
Staging

'Staging' is the process of working out which parts of your body are affected by lymphoma. The results of your tests and scans help doctors to work out the stage of your lymphoma. This is important because it helps your medical team plan the most appropriate treatment for you.

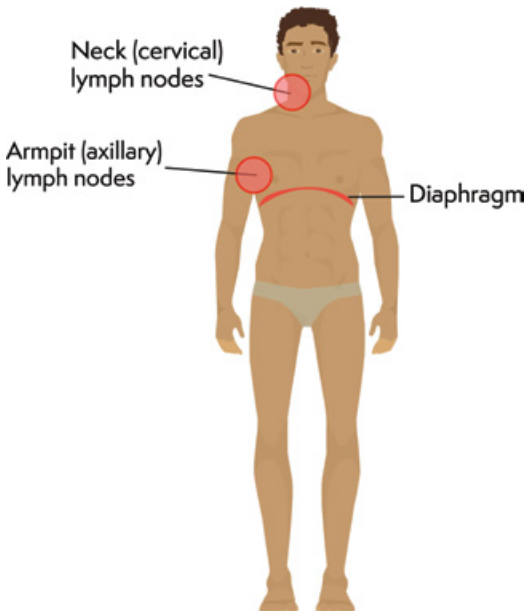
There are four main stages of lymphoma, numbered 1 to 4. These are sometimes written in Roman numerals (I, II, III and IV).

You might also have letters after your stage number. For example, you might be stage 2A, or stage 3E.

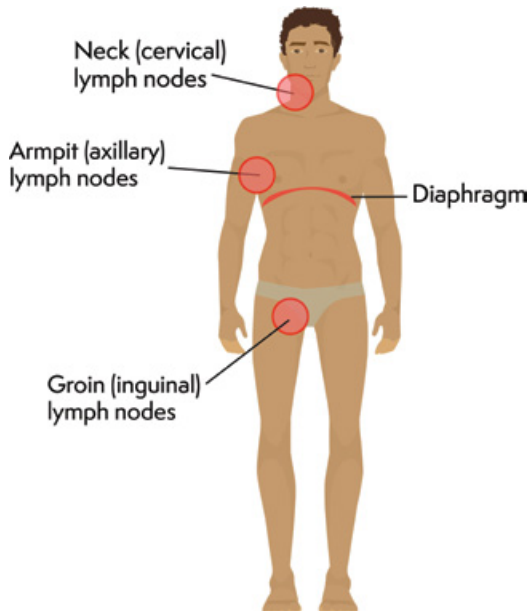
- A** You don't have any **B symptoms**.
- B** You have one or more B symptoms (weight loss, night sweats or fevers).
- E** Extranodal lymphoma means that the lymphoma started outside the lymphatic system.
- S** Lymphoma is in the spleen (part of the lymphatic system).
- X** One or more of your affected lymph nodes is considered to be large or 'bulky'.



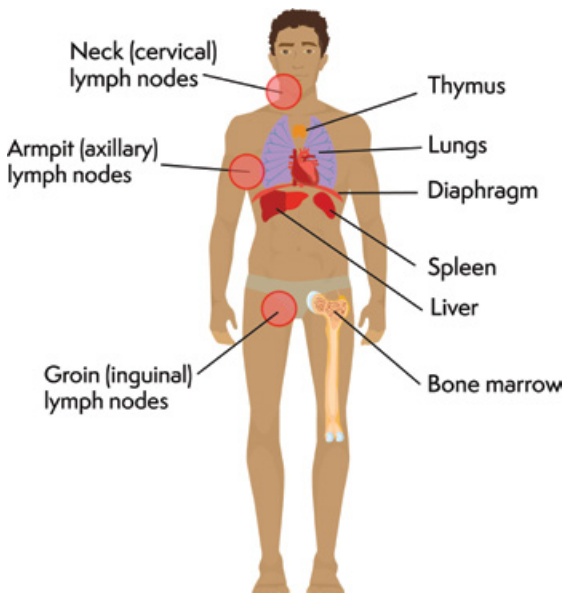
Stage 1 Lymphoma is in only one group of lymph nodes (glands). This could be anywhere in your body.



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



Stage 3 Lymphoma is in lymph nodes on both sides of your diaphragm.*



Stage 4 Lymphoma has spread from the lymph nodes to an organ outside of the lymphatic system (for example, to the liver, lungs, bone marrow or solid bones).

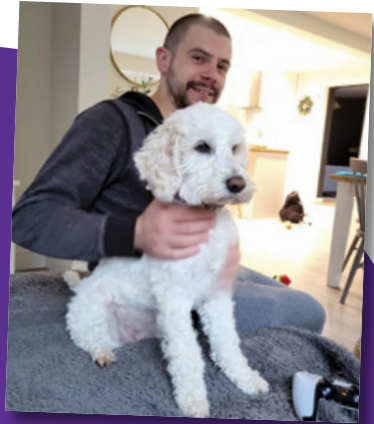
* Your diaphragm is the muscle separating your chest from your tummy.

Your doctors might talk about 'early' stage or 'advanced' stage lymphoma. 'Early' stage means either stage 1 or stage 2. 'Advanced' stage generally means either stage 3 or stage 4.

Your lymphatic system runs throughout your body, so, quite often, classical Hodgkin lymphoma is advanced when it is diagnosed. Unlike many other cancers, advanced stage lymphoma can be successfully treated.

“ *Hearing it was stage 4 was a gut punch, as for most cancers this would be awful news. But lymphoma is different because the lymphatic system is all over the body, so we were told it is common for lymphoma to be stage 4 when diagnosed. We were told it was likely to be highly treatable, which took some of the worry out in a way.*

Craig, diagnosed with classical Hodgkin lymphoma



Summary

- Classical Hodgkin lymphoma is usually diagnosed using a lymph node biopsy.
- You will have other tests such as blood tests and a PET/CT scan to find out which parts of your body are affected by lymphoma (staging).
- The results of your tests and scans help your doctor plan the most suitable treatment for you.
- Speak to a member of your medical team if you have questions about any tests you're having, or if you feel worried about having them.
- Your medical team can give you an idea of how long it will be before your test results are available.



“ *The doctor and nurses talked through everything really clearly and gently explained that they were going to start ABVD chemotherapy. I left that consultation feeling fairly positive after that discussion, which was surprising, but was certain I just wanted to get started with the treatment.*

Mark, treated with chemotherapy for classical Hodgkin lymphoma

Treatment

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Treatment aims

Classical Hodgkin lymphoma is treated with the aim of getting rid of all of it so that you go into complete **remission**. This means that there is no evidence of lymphoma on tests and scans.

Most people treated for classical Hodgkin lymphoma go into complete remission and do not need any further treatment.

Your medical team

Your treatment is planned by a **multidisciplinary team (MDT)** made up of different professionals, sometimes from more than one hospital. They each have knowledge and expertise in different specialist areas. This ensures you are offered the best care.

The team meets to discuss and plan your treatment, taking into account your individual needs, general health and preferences.

The person who has overall responsibility for your care is a doctor who specialises in treating people who have cancer. This is a consultant oncologist or haematologist.

You will have a key worker who you can contact with any questions or concerns. Usually, your key worker is your **clinical nurse specialist (CNS)**.

You should be given the name and contact details of your key worker – if you're not given this information, ask your lymphoma consultant for it.

Your key worker is often the member of your MDT who helps you to identify and manage any issues that arise from living with lymphoma. This includes any needs that are practical, financial, physical, emotional and social. To help with this, they sometimes use a questionnaire called a Holistic Needs Assessment or 'HNA'.

Children and young people aged 16 to 25 have an additional teenage and young adult multi-disciplinary team (TYA MDT). This team consists of health and social care professionals who specialise in treating young people with cancer. It can also include professionals such as play specialists and youth support workers, who organise fun and relaxing activities on the hospital ward.

Children and young people aged up to 25 years with classical Hodgkin lymphoma are often treated in a specialist children's cancer centre called a Principal Treatment Centre (PTC). Your nearest PTC might be some distance from your home. It might be possible to have some treatment at a hospital closer to home through a children's community nursing team. Having some appointments at the PTC and some at a local hospital is known as 'joint care' or 'shared care'.



Find out more about lymphoma in children and young people on our website. You can download or order a copy of our *Young person's guide to lymphoma* at lymphoma-action.org.uk/Books

Treatment options

Treatment for classical Hodgkin lymphoma usually involves **chemotherapy** (page 53), sometimes in combination with an **antibody-drug conjugate** (page 58). In some cases, this is followed by **radiotherapy** (page 59).

The exact treatment you need depends on the stage of your disease and how it is affecting you. Your medical team are likely to consider different treatment options depending on whether you:

- have early disease (stage 1 or 2) – page 49
- more advanced disease (stage 3 or 4) – page 51
- are over 60 or have other health concerns – page 52.

They also consider factors such as:

- your general health and fitness
- your feelings and preferences
- other factors that might be important to you in the future, such as having a family
- any potential side effects
- any potential late effects (health problems that develop months or years after treatment).

To help work out the best treatment for you, you might need to have more tests to check how well your heart, lungs, liver and kidneys are working.



There is ongoing research into classical Hodgkin lymphoma. This means that the specific treatments available are always being reviewed. For the latest information, visit lymphoma-action.org.uk/Hodgkin

Before treatment

Your medical team will talk to you about anything you should consider before starting treatment.

You should try and visit your dentist before you start treatment for lymphoma. You might not be able to have any dental work done during or soon after treatment because of an increased risk of infection.

Some lymphoma treatments can affect your fertility. If you might be considering having children now, or in the future, it is important to think about how your lymphoma treatment could affect your future fertility before your treatment starts. This includes considering fertility preservation (ways to help you become pregnant, or get someone pregnant, after treatment). In some cases, it can take some time to have fertility preservation, and this is important to take into account when starting lymphoma treatment. If your child has lymphoma, talk to your child's medical team about their future fertility before their treatment begins.



We have more information about fertility on our website at lymphoma-action.org.uk/Fertility

Taking general good care of your physical and mental health can help to prepare you for treatment. This is called prehabilitation and can include a good diet, taking physical activity and looking after your mental wellbeing.



You might be interested in our free online support and information service, *Preparing for Treatment*. Find out more at lymphoma-action.org.uk/Support

Clinical trials

Your medical team might ask if you'd like to take part in a clinical trial. These are research studies to find out what treatments work best for people with classical Hodgkin lymphoma. They might test new treatments or new ways to use existing ones.

If your medical team suggests a clinical trial, they should explain the risks and benefits of taking part. It is completely up to you whether you'd like to or not and you can withdraw from a trial at any time.



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

Treatment for early stage disease

For early stage classical Hodgkin lymphoma, your doctor considers the signs and symptoms you have before deciding what treatment is most likely to be effective for you and how long you should be treated for. These are sometimes called 'prognostic indicators'. They include:

- whether you have very enlarged lymph nodes in your chest, or in several areas of your body
- whether you have **B symptoms**
- whether your blood tests show you have a high level of inflammation
- how old you are
- whether you have any lymphoma outside your lymphatic system (extranodal disease).

You may be told you have 'early favourable' or 'early intermediate' (sometimes called 'unfavourable') Hodgkin lymphoma based on these factors. People with early favourable disease may need slightly less treatment, but early intermediate is still highly curable with standard treatment.

Early favourable Hodgkin lymphoma is most likely to be treated with two to three **cycles** of a **chemotherapy regimen** called ABVD. You are likely to have a **PET/CT scan**, known as an interim scan. Depending on the results of your scan, your doctor might recommend further chemotherapy and/or radiotherapy.

Early intermediate Hodgkin lymphoma can be treated in a number of ways. The most likely treatments are:

- four cycles of a chemotherapy regimen called ABVD, followed by radiotherapy
- two cycles of ABVD and four cycles of the regimen AVD, sometimes followed by radiotherapy
- two cycles of a chemotherapy regimen called escBEACOPDac and two cycles of ABVD, sometimes followed by radiotherapy.

More information on each regimen is given on page 56.

The exact treatment is chosen for each individual. For example, you might not need radiotherapy if:

- you do not have any B symptoms
- you do not have any lumps of lymphoma bigger than around 10cm
- a PET/CT scan shows all your lymphoma has gone after chemotherapy
- you are a young female and radiotherapy might affect your breast tissue.

Chemotherapy without radiotherapy is less likely to cause long-term side effects, but you have a slightly higher risk of your lymphoma coming back (relapsing). Your doctor should discuss the treatment choices with you and take your views and wishes into account.

Treatment for advanced stage disease

The most commonly used treatments for advanced stage classical Hodgkin lymphoma are:

- Two cycles of a chemotherapy regimen called ABVD, with further treatment depending on the results of a PET/CT scan. A negative scan will likely mean removing bleomycin from the regimen (the 'B' in ABVD) and having four cycles of AVD. If the scan shows active lymphoma your medical team are likely to recommend four more cycles of ABVD, or a regimen called BEACOPDac.
- Six cycles of a chemotherapy regimen called AVD, plus an antibody-drug conjugate called brentuximab vedotin (this might be referred to as 'AAVD' or 'A2VD').
- Four to six cycles of a chemotherapy regimen called escBEACOPDac.

More information on each regimen is given on page 56. Your consultant will discuss the treatment options with you.

You are likely to have a **PET/CT scan** after your first few treatment cycles. This is known as an interim scan. Depending on the results of your scan, your doctor might recommend changing to a different chemotherapy regimen or adjusting the number of cycles or chemotherapy drugs you need. Again, your consultant should discuss this with you.

You might also have radiotherapy if there are any areas of lymphoma left after your chemotherapy. Most people with advanced stage classical Hodgkin lymphoma do not have radiotherapy.

“

I started 6 months of ABVD chemotherapy treatment, following a round of fertility preservation. I had another PET scan after four chemotherapy sessions which showed a complete metabolic response. This meant I could cut down to 3 chemotherapy drugs rather than 4, which was positive as it meant less drugs going into my body – lessening the chances of long term problems as a result of treatment side effects.



Faye, treated with chemotherapy for classical Hodgkin lymphoma

Treatment if you are over 60 or have other health concerns

About 1 in 5 people diagnosed with classical Hodgkin lymphoma are over 60. Your doctor will consider your fitness and any other health problems you have. They might recommend a less intensive treatment if they think you have a higher risk of experiencing side effects. The aim is to give you a treatment that is as safe and effective as possible with the lowest risk of causing side effects.

The chemotherapy regimens considered for use in this age group include AVD, AAVD (AVD plus an antibody-drug conjugate called brentuximab vedotin) and ChlVPP.

Radiotherapy is more frequently used in older people as late effects are a less important consideration.

Chemotherapy

Chemotherapy is treatment with drugs. It works by either stopping lymphoma cells from dividing or triggering lymphoma cells to die.

Lymphoma cells are very sensitive to the effects of chemotherapy, which is why it is often the most suitable treatment. Unfortunately, chemotherapy also affects some of your healthy cells, particularly the ones that divide rapidly. This includes blood cells, hair follicles and cells in your gut, and it's often the cause of some of the common side effects of chemotherapy (page 68).



Watch our short animation explaining how chemotherapy works at lymphoma-action.org.uk/Chemotherapy

Before having chemotherapy you usually have blood tests to check that your blood counts are at a level considered to be safe for you to have treatment. If your blood counts are low, your medical team might advise waiting for a little while (sometimes just a few days) before having treatment, until they are higher. You might also be given treatment to help boost your blood cell counts.

You usually have chemotherapy for classical Hodgkin lymphoma as an outpatient, in a day care unit or chemotherapy unit. You go to the hospital on treatment days and can go home afterwards.

Cycles

Chemotherapy is given as a number of treatments or 'cycles'. After each cycle of treatment, you have a rest period, to allow your body to recover. During each cycle, you might have to go to hospital once, or on a number of days. This depends on the exact chemotherapy you have.

Chemotherapy is given in cycles because the drugs work on cells that are in the process of dividing – they don't have much effect on cells that are not dividing. Having your chemotherapy in a number of treatments at different times increases the chances of it affecting dividing lymphoma cells.

In between your treatment days, you usually have medicines to take at home. Some of these might be part of your chemotherapy treatment plan (regimen). Others are to help control any side effects of treatment (page 67).

Having chemotherapy

Most chemotherapy is given **intravenously** (as a drip or injection into a vein).

Your nurse can inject some chemotherapy drugs over a minute or two. Other drugs have to be given more slowly through a drip (infusion). This could take anywhere from 30 minutes to a number of hours, depending on the drugs you have and which cycle you are on.

Intravenous (IV) drugs are given through a cannula or a central venous catheter.

- A cannula is a small, soft plastic tube that usually goes into a vein in the back of your hand or in your arm. You have a new one put in each time you go for treatment.
- A central venous catheter (or 'central line') is a longer plastic tube that goes into a larger vein near your heart. A central line usually stays in for the whole of your treatment. A line can also be used to give you other drugs and fluids and to take blood samples for tests more easily. They can save you the discomfort of repeated needle pricks.



There are different types of line. Visit lymphoma-action.org.uk/Chemotherapy to find out more.

Lines are put in during a small operation under local or general anaesthetic. Once it's in place, a line isn't usually painful. However, if you feel any discomfort, tell a member of your medical team. Once it's fitted, your line is covered with a dressing to protect it. You will be given instructions on how to care for it once you go home.

Lines can sometimes become infected. Occasionally, a blood clot can develop around them. Contact your hospital immediately if you develop any symptoms of infection, including:

- redness or heat around the area (site) of the line
- a high temperature (above 38°C/100.4°F)
- swelling in your arm.

Tell your nurse if you feel any discomfort when you are having IV chemotherapy. They can check that the drugs are going in properly and make any adjustments they need to.

Some chemotherapy drugs are given by an injection into muscle (intramuscularly).

Some chemotherapy can be taken by mouth (orally) as a tablet or capsule. Unless you've been told to by a member of your medical team, do not crush or open the tablets or capsules.

You should be given guidance about how to store and take any chemotherapy drugs that you're given to take at home. If you are not told how to do this, ask your clinical nurse specialist or pharmacist.

It is important that other people don't handle your chemotherapy drugs. If you are helping someone to take chemotherapy, wear protective gloves when handling the drugs.

Regimens

Chemotherapy drugs for lymphoma are usually given as a regimen – a treatment plan that includes more than one type of drug. You have these drugs all at once so that the different drugs can work on different phases of the cell cycle. Having them together helps to kill as many lymphoma cells as possible.

Your treatment is planned specifically for you. However, the most common **chemotherapy regimens** used to treat classical Hodgkin lymphoma are:

- **ABVD**. Made up of doxorubicin (**Adriamycin**[®]), bleomycin, vinblastine and dacarbazine. You usually have this regimen in 4-week cycles where you have treatment every 2 weeks, followed by a 2-week rest period. Bleomycin can be given by injection into a muscle (intramuscularly) or by drip into a vein. The other drugs are all given by drip into a vein.
- **AVD**. ABVD without bleomycin.
- **BEACOPDac**. Made up of bleomycin, etoposide, doxorubicin (**Adriamycin**[®]), cyclophosphamide, vincristine (**Oncovin**[®]) prednisolone (a steroid) and dacarbazine. You have all these drugs every 3 weeks. You have most of these drugs through a drip into a vein. You take prednisolone by mouth (orally), as capsules or tablets.
- **escBEACOPDac**. An 'escalated' version of BEACOPDac. This means that the drugs are given at higher doses than in the standard regimen.
- **ChlVPP**. Made up of chlorambucil, vinblastine, procarbazine and prednisolone (a steroid). Each treatment cycle is 28 days. You have vinblastine through a drip into a vein. You have the other drugs as tablets or capsules by mouth.

Safety precautions

Your medical team will give you guidance about any safety precautions you should take while you are having chemotherapy.

Take steps to lower your risk of infection. Be aware of the possible signs and symptoms of infection and who to contact if you notice any (page 71).

While you are on chemotherapy treatment, use a condom to avoid passing chemotherapy to your partner during vaginal, anal or oral sex. This also protects you against infection.

Talk to your medical team if you want to have a baby. People who have had chemotherapy for lymphoma are usually advised to wait for up to 2 years after finishing treatment before trying to start a family.



Find out more about chemotherapy, including answers to commonly asked questions, on our website at lymphoma-action.org.uk/Chemotherapy

Antibody-drug conjugate

Antibody–drug conjugates are monoclonal antibodies joined to a small dose of a chemotherapy drug.

The **antibody** is designed to stick to a protein on lymphoma cells and carry the chemotherapy drug directly to them.

This allows for a more targeted delivery of chemotherapy directly into the lymphoma cells and can result in fewer side effects than standard chemotherapy.

Brentuximab vedotin is a type of antibody–drug conjugate that sticks to a protein called CD30. You have brentuximab vedotin through a drip into a vein. It is given alone or in combination with the chemotherapy regimen AVD. This might be referred to as ‘AAVD’ or ‘A2VD’.

- **AAVD.** Made up of brentuximab vedotin (**Adcetris**®), doxorubicin (**Adriamycin**®), vinblastine and dacarbazine. You usually have this regimen in 4-week cycles where you have treatment every 2 weeks, followed by a 2-week rest period. The drugs are all given by drip into a vein.
- Given alone, you have brentuximab vedotin every 2 to 3 weeks for up to 16 cycles.

Radiotherapy

Radiotherapy uses high-energy X-rays (a type of radiation) to destroy cancer cells. It stops them from dividing, so that they die off in time. Lymphoma cells are very sensitive to radiotherapy.

The radiation is directed to precise areas of your body. This targets as many lymphoma cells as possible, while causing as little damage as possible to surrounding healthy cells. Radiotherapy is a ‘local’ treatment, which means that it affects only the parts of your body being treated. It is therefore usually used to treat lymphoma that is only in one or two places in your body.

Many people who have radiotherapy have it with the aim of getting rid of the lymphoma – this is known as ‘curative radiotherapy’. Sometimes, radiotherapy is given to help shrink the lymphoma. This can help control symptoms such as pain and is known as ‘palliative radiotherapy’.

You’ll need to go to hospital for your radiotherapy treatment to be planned, and each time you have it. Not all hospitals have a radiotherapy department, so you might need to travel a bit further to one that does.

Your treatment is carefully planned by a radiotherapy team, led by a clinical oncologist. Very often, they use a computed tomography (CT) simulator scan to help them work out:

- the total dose of radiotherapy to give you
- how many separate treatments (fractions) you should have
- exactly where the lymphoma is, so that they can direct radiotherapy to precisely this area.

Your radiotherapy team only give radiation that is known to be within safe limits. They also plan your treatment to avoid damaging critical structures such as your brain, heart and salivary glands.

To help make sure that radiotherapy goes to exactly the same place each time you have treatment, you might have some tiny permanent dot-like marks made to your skin, using a needle and ink. These are lined-up with the X-ray beams on the radiotherapy treatment machine to help make sure that the radiotherapy goes to exactly the right place.

If you are having radiotherapy to your head, neck, armpit or chest, you might instead have a plastic radiotherapy mask (sometimes called a 'shell') to wear each time you have treatment so that the radiotherapy goes to exactly the right place.

Each radiotherapy session takes around 10 to 20 minutes. Most of this time is spent getting you into position – the radiotherapy treatment itself takes only a few minutes.

Having radiotherapy doesn't hurt. During the treatment, the radiotherapy staff have to leave the room but they can see you and hear you all the time.

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

Typically, you have radiotherapy treatment Monday to Friday for 2 to 3 weeks. However, your schedule might differ from this as your treatment plan is designed specifically for you.

It can be helpful to take someone with you to the hospital for emotional support. They'll need to wait outside the treatment room to avoid unnecessary radiation.



Read more about radiotherapy for lymphoma, including answers to frequently asked questions, on our website at lymphoma-action.org.uk/Radiotherapy

Some young people (under the age of 25) might be offered a type of radiotherapy called proton beam therapy (PBT). You can find out more about proton beam therapy on the NHS website. Search 'PBT' on www.england.nhs.uk

If Hodgkin lymphoma comes back

For most people, Hodgkin lymphoma goes into complete **remission** and needs no further treatment. In a small number of people, Hodgkin lymphoma does not respond to treatment (**refractory** lymphoma) or comes back after treatment (**relapsed** lymphoma).

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

- the type of treatments you've already had
- how your lymphoma responded to treatment and how treatment affected you
- how soon after treatment the lymphoma came back
- your age, general health and fitness.

Your medical team will plan the most appropriate treatment for you. Treatment might include:

- **Radiotherapy.** If your lymphoma is only in one place in your body, you might have radiotherapy to the affected area (page 59). However, most people need other treatments.
- **Chemotherapy.** Usually, this is a different type of chemotherapy than the one you had as your first treatment. Depending on your general health and fitness, it might also be stronger. Chemotherapy given to treat relapsed or refractory lymphoma is sometimes

called 'second-line' or 'salvage' therapy. You might have to stay in hospital to have some salvage chemotherapy regimens.

- **High-dose chemotherapy and stem cell transplant.**

If you respond to salvage chemotherapy and you are fit enough, your doctor might recommend a **stem cell transplant** (this is sometimes referred to as consolidation treatment). This involves having very high-dose chemotherapy with previously collected stem cells supporting your body through it. It is a very intensive treatment. You need tests beforehand to make sure you are fit enough to have it.



If your medical team thinks a stem cell transplant is suitable for you, they will talk to you in detail about it. We have information available on our website lymphoma-action.org.uk/SCT and in our book *Autologous stem cell transplant*.

- **Targeted treatments.** You might have treatment with an antibody drug conjugate, such as brentuximab vedotin (page 58), or checkpoint inhibitors like nivolumab or pembrolizumab.



Visit our website for more information on targeted treatments for lymphoma at lymphoma-action.org.uk/TargetedTreatments

“

I had another scan at the end of treatment. Unfortunately, not all the cancer had gone. It was explained that it now looked as though they would need to do a stem cell transplant using my own stem cells. I had to have a lot more intensive chemotherapy before the transplant, and had to stay in hospital at this time.



Mark, whose treatment for classical Hodgkin lymphoma included a stem cell transplant

Summary

- The aim of treatment for classical Hodgkin lymphoma is usually complete remission.
- Your treatment will be planned by a multidisciplinary team, taking into account your individual needs.
- Treatment for classical Hodgkin lymphoma usually involves chemotherapy, sometimes in combination with an antibody-drug conjugate.
- In some cases, radiotherapy is also used.
- The exact treatment you need depends on the stage of your lymphoma and how it is affecting you.



Notes



“ *I wasn't even done with the second dose and I was already tired. The truth was, at that moment I wanted to stand up and walk away from it all. But my nurse always looked on the positive side of things, which I loved.*

Reem, diagnosed with classical Hodgkin lymphoma

Side effects

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Common side effects

Treatment aims to destroy lymphoma cells, but it can also damage healthy cells, causing unwanted side effects.

Your medical team will give you information about any side effects you might experience. They base this on lots of factors, including the type of treatment you have, how much of it, and how often, as well as 'individual factors', such as your age. Different people can get different side effects, even if they're having the same treatment.

Some side effects are serious and need urgent treatment – contact your medical team if you are worried.

“ I found it counterintuitive that the chemo drugs made me feel more unwell than the lymphoma. I found it best to be proactive and honest about how I was feeling. I would tell my team about all the symptoms I had as they emerged and they would always know a medication or have a suggestion to help relieve my discomfort.

Mila, diagnosed with classical Hodgkin lymphoma



Usually, side effects are short-term and start to go away once you finish treatment. However, they can have a significant impact on your day-to-day life, including your emotional wellbeing.

Some of the common side effects of treatment include:

- **Fatigue.** Extreme tiredness that can be physical, mental or emotional. This can be worsened by the emotional impact of living with lymphoma.
- **Hair loss.** Some people experience hair loss or thinning. This can happen to the hair on your head, as well as elsewhere on your body.
- **Low blood counts and risk of infection.** Treatment can have a short-term effect on the number of blood cells you have. This can lead to **anaemia**, **thrombocytopenia** and **neutropenia** (page 71).
- **'Chemo brain'.** Cancer-related cognitive impairment can affect thinking processes such as memory and attention. Some people describe this as a 'mental fog'. You might find it difficult to plan, keep up with a conversation or remember things.
- **Sickness.** Nausea (feeling sick) and vomiting (being sick) are common side-effects. There are effective anti-sickness medicines (antiemetics) that can help.
- **Nerve damage** (peripheral neuropathy). Damage to the nerves of the peripheral nervous system (network of nerves outside of the brain and spinal cord) can cause symptoms such as increased or decreased sensitivity to touch and temperature, and numbness and tingling (pins and needles) in your hands and feet.
- **Bowel problems.** This includes diarrhoea, constipation (particularly with ABVD chemotherapy) and wind (flatulence).

- **Skin problems and irritations.** You might get dry, sore and itchy skin in some areas of your body.
- **Sore mouth** (oral mucositis). This can cause symptoms such as pain when you swallow, mouth sores (ulcers) that can lead to infection, and dry, sore mouth and lips.
- **Reduced fertility.** Your doctors should talk to you about whether your lymphoma treatment is likely to affect your fertility.

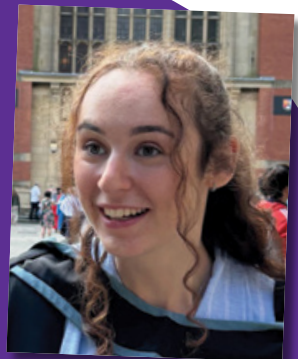
Talk to your medical team about any side effects you experience and how they are affecting you. There might be medications they can give you to help, or suggestions of things you can do yourself, such as sucking something cold to avoid mouth ulcers.



You can find out more about the potential side effects of lymphoma treatments and find tips to help live well with them at lymphoma-action.org.uk/SideEffects

“ *On top of physical side effects, I struggled with chemo brain, which can only be described as a type of brain fog. It was like trying to get dressed in the morning, but the room was pitch black and my clothes were all over the place.*

Sophie, diagnosed with classical Hodgkin lymphoma



Low blood counts

Treatment for lymphoma can temporarily damage your bone marrow. Your bone marrow makes your body's blood cells.

It is common to have low blood counts during your treatment. Your medical team regularly check your blood counts and make any adjustments to your treatment plan as necessary.

Neutropenia (low white blood cell count)

Having a low neutrophil (a type of white blood cell) count doesn't usually cause any symptoms but it means you have a higher risk of infection than normal. If you do get an infection, it can be serious, sometimes even life-threatening. An infection in someone with neutropenia needs urgent treatment. You usually have to stay in hospital for intravenous (IV) antibiotics and careful monitoring.

Possible symptoms and signs of infection include, but are not limited to:

- fever (temperature above 38°C/100.4°F)
- hypothermia (temperature below 35°C/95°F)
- shivering (even if you do not have a fever, which is more likely if you're taking steroid medication)
- chills and sweating
- feeling generally unwell, confused or disoriented
- blocked nose, earache, sore throat or mouth
- cough, yellow or green phlegm or snot (mucus), difficulty breathing

- redness and/or swelling of the skin, pain and redness around intravenous (IV) lines
- diarrhoea or vomiting
- a feeling of burning or stinging when you wee, or needing to wee more often than usual
- vaginal discharge or itching
- unusual and new stiffness of the neck with discomfort around bright lights
- new and increasing pain.

Contact your medical team if you have any of these signs or symptoms, no matter how minor they might seem.

Anaemia (low red blood cell count)

If you have a low red blood cell count, you don't have enough haemoglobin (the protein that carries oxygen around your body). This is called **anaemia**. It might make you feel tired or short of breath. If your red blood cell count is very low, you might need treatment with a blood transfusion – a drip (infusion) of donated blood or blood products given into one of your veins.

Tell your doctor if you feel short of breath, unusually tired, dizzy or have new aches and pains. This could be a sign of anaemia that needs treatment.

Thrombocytopenia (low platelet count)

Thrombocytopenia is a shortage of **platelets**. You might bruise easily, bleed more or bleed for longer than usual if you hurt yourself if you are thrombocytopenic.

Thrombocytopenia often gets better on its own quite quickly. However, if your platelet count is very low, or you are at particular risk of bleeding, your medical team might adjust your treatment or offer treatments to help. In some cases, a transfusion of platelets is needed.

Possible symptoms and signs of thrombocytopenia include:

- nosebleeds
- bleeding gums after brushing your teeth
- heavier or longer periods than is usual for you
- bleeding for longer than you'd expect after a cut or scratch
- bruising more easily than usual
- red or purple patches or spots called 'purpura' or 'petechiae' on your skin (often on your legs), your lips or in your mouth
- blood in your sick (vomit)
- blood in your wee
- blood in your poo (this might be obvious, bright red blood or it can make your poo black and sticky)
- persistent headache, blurred vision or a change in your level of consciousness.

Contact your medical team if you develop any of these symptoms.

If you have a low platelet count, take precautions to reduce your risk of bleeding. For example, avoid contact sports (such as rugby) and high-impact sports (such as football and martial arts). Wear gloves to protect yourself from injury while doing activities such as gardening, DIY and crafts such as sewing.

Managing side effects and symptoms

Speak to your medical team for advice about how to manage any side effects or symptoms you experience. Your medical team can offer suggestions about how to cope and might also offer suitable prescriptions to help.

For example, you might be offered:

- anti-sickness drugs (antiemetics)
- painkillers
- antibiotics
- steroids
- growth factors.

In some cases, you might also be offered a referral to a specialist who can provide further support.



Visit our website for top tips on how to manage the symptoms of lymphoma and the side effects of treatment, from people with a lived experience:
lymphoma-action.org.uk/TopTips

“ *I experienced a number of side effects, including being violently sick. My medical team tried so many drugs to try and stop it before finding one that worked. The support from my clinical nurse specialist and consultant was amazing. I always felt reassured that no matter what side effect I had they would find something to help.*



Emma, diagnosed with classical Hodgkin lymphoma

If you have low white blood cell counts (page 71) you should consider ways to reduce your risk of picking up any infections.

Tips to help lower your risk of infection

Keep good personal hygiene

- Wash your hands before eating and after using the toilet. Take antibacterial hand sanitiser gel or wipes with you if you are out and about.
- Have a warm bath or shower each day. Check with your medical team for advice about bathing and showering if you have a central line (central venous catheter) in place.
- Keep good dental hygiene. Use a soft toothbrush and an alcohol-free antiseptic/antibacterial mouthwash.

Minimise contact with germs

- Avoid places where you have a higher risk of catching an infection, such as swimming pools, busy shops and public transport at peak times.
- Avoid contact with people who are unwell, for example with a cold, tummy bug or chickenpox.
- Prepare food safely and don't eat anything that is past its sell-by-date – use refrigerated food within 24 hours of opening. You can find out more about food safety on the World Health Organization (WHO) website and the Food Standards Agency website.
- Take care when handling pets – avoid bites or scratches and wash your hands after any contact with an animal. If possible, ask someone else to deal with pet care jobs that involve animal poo, such as cleaning out litter trays.

Protect your skin

- Protect yourself from cuts and scratches by wearing gloves for gardening, wearing shoes when you are outside and avoiding walking barefoot indoors.
- Keep your skin moisturised with a body lotion or moisturiser if it becomes dry or cracked.
- Allow spots and scabs to heal without picking at them.

Summary

- Treatment destroys lymphoma cells but it can also damage healthy cells, causing side effects.
- Side effects usually go away in time.
- Different factors affect which side effects you have, including the treatment types you have, how much and how often.
- Talk to your medical team about any side effects you experience so that they can offer support and advice to help you to manage them.



“ *When I was told I was in remission, I remember feeling euphoric. But very soon afterwards I felt numb – and then I felt bad for feeling that way. You’re trying to adjust to the emotional impact of being ill, then being in remission, and it’s really hard. You experience such a range of emotions and it all feels a little like a dream.*

Raveen, diagnosed with classical Hodgkin lymphoma

After treatment

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Follow-up

After finishing treatment for lymphoma, your medical team are there to support you in your physical and emotional recovery.

End-of-treatment appointment

You have an end-of-treatment appointment with your clinical nurse specialist or another member of your medical team.

You'll be asked about your health and wellbeing, for example, about how you're feeling, any symptoms you have and how you're adjusting to life after treatment. To help guide the conversation, your clinical nurse specialist might use a questionnaire, which is sometimes called a holistic needs assessment (HNA).

You might also be examined and have blood tests. You usually have a scan at the end of your treatment to check how well your lymphoma has responded. However, scans aren't routinely used as part of ongoing follow-up as there is no evidence to suggest that they change lymphoma treatment or outcomes. Doctors prefer to keep scans for when they're considered to be helpful, which minimises radiation.

Your end-of-treatment appointment is also a chance to ask any questions you might have about your lymphoma and the impact it has on your life.

Some people find it helps to write down any questions they have before their appointment. You could also note

down the answers or key points of discussion during the appointment.

Our *Introduction to lymphoma* book includes suggested questions you might like to ask your medical team, including about follow-up and recovery after treatment. See page 102 for information about how to get a copy.

Personalised care plan

Together, you and your medical team put together a care and support plan that is specific to your individual needs. This is known as personalised care and support. It includes needs that are physical, emotional, social or financial, for example, about day-to-day life, work, vaccinations and travel.



As well as the support your medical team offer, there might also be a health and wellbeing event of interest to support you in your recovery. For example, we have a peer-led self-management Live your Life programme. Find out more at lymphoma-action.org.uk/LyL

During your follow-up period

Your follow-up appointments might be in person, over the phone or by video call. The aims are to check:

- your recovery from treatment
- for any signs that your lymphoma has come back (**relapsed**)
- for any **late effects** (page 90).

Most hospitals offer follow-up appointments for at least 2 years after you finish treatment. This is an important time in terms of your recovery from treatment and is the time when risk of relapse is higher.

You usually have check-ups every 3 to 4 months at first, then every 6 months. If it is suitable for you, you might be offered a supported self-management system, although this isn't available at all hospitals. The idea is that you are supported to develop the skills, knowledge and confidence to book your own follow-up appointments, as-and-when you feel you need one.

You can contact your medical team at any time. Don't wait until your next appointment is due if you are worried.

“ *I had follow-up checks every three months, then six months, then annually. The advice at the sessions slowly changed from checks to make sure I was clear of the original problems, to longer-term health advice. This included staying fit and eating healthily.*

John, diagnosed with classical Hodgkin lymphoma



After your follow-up period

Depending on the usual practice of your hospital, you might be referred back to your GP for health checks after a certain number of years in remission. This depends on factors such as the treatment you have had and how long it's been since you completed treatment. Follow-up might differ if you were treated as part of a clinical trial.

Your GP usually becomes your main point of contact if you have any concerns or notice any new symptoms. Most hospitals also offer a phone number to call if you have any concerns about relapse. If you are not given this information, ask for it.

Your GP should have a record of your diagnosis and all the treatment you've had. However, it's a good idea to remind them that you have had treatment for lymphoma. You should also tell any health professional who treats you in the future, including your dentist.

Note that if you need to have a blood transfusion in the future, you should only have blood that has been irradiated (treated with X-rays). This is to help prevent transfusion-associated graft-versus-host disease (TAGvHD), which is a rare but very serious complication.

Feelings and emotions

Finishing treatment for lymphoma can bring a range of emotions. Some of these are likely to be positive but others might be harder to cope with. You might feel differently at different times.

Some people feel anxious and low once their treatment finishes. You might start to really think about the reality of what you and those close to you have experienced, which can bring a new sense of shock, anger or sadness.

Many people miss the reassurance of frequent contact with their medical team after treatment. You might worry about the future and any changes you need to make to your plans. It can be an added difficulty if friends and family expect you to feel happy – for some people, this leads to feeling irritated and isolated, as though those around them don't understand that this continues to be a challenging time.

“ *The support I had from my medical team during treatment was fantastic. But the enormity and consequences of cancer didn't stop - I just came off autopilot and having to get through one round of treatment to the next. Once that stopped it hit me and I thought 'Now what?'.*

Emma, diagnosed with classical Hodgkin lymphoma

“ *I quickly realised that to become better I had no option but to set myself on the tramlines laid out for me – the tests, the treatment, the consequences of the medicine, the joys of remission and the very surprising emptiness that followed.*

Pete, diagnosed with classical Hodgkin lymphoma



Talking to someone about how you feel can help you to make sense of challenging feelings. You could speak to a family member or friend, or you might like to talk to a member of our Helpline team.

If you'd like to talk about how you're feeling, call our Helpline freephone on 0808 808 5555, 10am to 3pm, Monday to Friday.

You might find it helpful to talk to someone who's been affected by lymphoma – our Helpline team might be able to link you with a peer-support buddy who has personal experience of lymphoma (see page 101).

You can also consider getting support from a counsellor. Speak to your GP or clinical nurse specialist if you're interested in counselling. They might be able to offer you a referral on the NHS. You can also search for a private therapist in your area using the British Association of Counsellors and Psychotherapists online tool: bacp.co.uk/search/Therapists



We have information on our website that can also help.

- Search ‘health and wellbeing’ on our website to find a range of resources to help with your physical and emotional wellbeing.
- We have information about recovery from treatment, including about adjusting to life after treatment. Search ‘recovery’ on our website.
- You might also be interested in our tips to help you communicate with the people around you. Search ‘communicating’ on our website.
- We also have a list of useful organisations on our website, including those that can help with aspects of emotional wellbeing. Visit lymphoma-action.org.uk/UsefulOrgs

Find out more about how we can support you on page 101.

“ *Throughout treatment I had been running on adrenaline and was in practical mode, but after that finished and the intense medical side of things had died down, I was left trying to get my head around what actually happened.*

Tom, diagnosed with classical Hodgkin lymphoma

Healthy living and day-to-day life

Following a healthy lifestyle puts you in the best position to live well, with and beyond lymphoma. This includes:

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

Your medical team can also tell you about any late effects to be aware of (page 90) and give you advice about other aspects of your life, such as safety precautions to take if you travel to another country.



We have more information about these lifestyle factors on our website and in our book *Living with and beyond lymphoma*

You might need to make some short-term or longer-term changes in your day-to-day life. For example, with practicalities such as work, studying and social activities. Your medical team should support you in finding ways to manage these aspects of your life.

Your employer must, by law, make any 'reasonable adjustments' that allow you to continue working during and after your treatment. Under the Equality Act 2010, this applies forever, not just while you are having treatment or for a limited time after finishing.

There is a range of possible sources of support available to people who are looking after a family member or friend who has lymphoma. For example, you might be entitled to financial support. If you are employed, you could also speak to your employer about making adjustments to your work and about taking time out, for example, to support the person you care for by going to medical appointments with them.



For more information about where to find support with practicalities, visit lymphoma-action.org.uk/DayToDay

If you are a young person, you can find information about adjusting to life after treatment for lymphoma in our book *Young person's guide to lymphoma*.

If you drive and are diagnosed with nerve damage called peripheral neuropathy (page 69), it's important to tell the Driver and Vehicle Licensing Agency (DVLA). You can find information on the UK government's website about how to notify them. Search 'peripheral neuropathy driving' at www.gov.uk



If someone close to you has lymphoma, we have information for you on our website at lymphoma-action.org.uk/Caring. We also have a book for family and friends *When someone close to you has lymphoma*, which offers practical tips and emotional support. You can order a free copy at lymphoma-action.org.uk/Shop

Late effects of treatment

Late effects are health problems that develop months or years after treatment for lymphoma. Your medical team should talk to you about the possible late effects of your treatment before it starts.

While it's not possible to say for certain whether you'll develop late effects, your medical team can give you an idea based on your specific lymphoma, the treatment you've had and individual risk factors, such as your age and lifestyle.

You can't always prevent late effects. However, noticing problems early gives you a better chance of treating or managing them effectively if they do arise.

We outline some of the possible late effects of treatment for Hodgkin lymphoma below.



You'll find more information on our website at lymphoma-action.org.uk/LateEffects

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with radiotherapy to the chest and with the chemotherapy drug bleomycin.

If the damage is slight, you might not have any symptoms. If it is more severe, it can affect the type and amount of physical activity you're able to do. Your medical team can give you advice about exercise that is suitable for you.

You are more likely to develop lung problems after lymphoma treatment if you smoke. If you smoke and would like free support to help you stop, talk to your GP or visit nhs.uk/smokefree

Heart problems

Radiotherapy to your chest and some chemotherapy drugs can damage your heart. This includes doxorubicin, a component of the ABVD, BEACOPP and AVD **chemotherapy regimens** commonly used to treat classical Hodgkin lymphoma.

Heart problems generally don't start until at least 10 years after treatment, but they can develop sooner. Your risk of heart problems stays higher than usual for several decades after your treatment.

You can lower your risk of developing heart problems by not smoking, maintaining a healthy weight, eating well and staying active. You should also have your blood pressure, blood sugar level and cholesterol level checked regularly. Ask your GP surgery for information about how to book these.

Visit the British Heart Foundation website for information about heart problems and advice on keeping your heart healthy at bhf.org.uk

“ *There was mention of longer-term effects of chemotherapy on the heart. I knew from regular checks that I had slightly high blood pressure, and eventually I was put on blood pressure tablets. Although I felt fine, I wanted to take a longer-term view of my health.*

John, diagnosed with classical Hodgkin lymphoma



Other cancers

Treatment for Hodgkin lymphoma can increase your risk of developing another cancer in the future.

The type of cancer you might be at risk of depends on the exact treatment you had, the dose you had, how old you were when you were treated and how old you are now. Ask your medical team what cancers you might be at higher risk of developing. Make sure you know the symptoms of these cancers. Cancer is usually more treatable if diagnosed early.

Lifestyle can be a significant factor, so take steps to follow a healthy lifestyle (page 88). You can ask your medical team about any screening programmes you should be aware of.



Find information online about screening programmes available in your region of the UK. Go to lymphoma-action.org.uk/UsefulOrgs

Hormone problems

Treatment for lymphoma can affect the production of chemical messengers (hormones) in your body.

If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid (hypothyroidism). This is where your thyroid gland makes less of the hormone thyroxine than it should. Thyroxine controls how your body uses energy. If you have too little of it, you might feel tired, sensitive to the cold and constipated. You might also gain weight easily. The risk of developing hypothyroidism is highest within the first 5 years of having treatment. It stays increased after this time compared with if you had not ever had treatment for lymphoma. Hypothyroidism is diagnosed by a blood test and is easily treated. You might be offered regular blood tests to keep checks on your thyroid functioning.

You can find out more about hypothyroidism on the British Thyroid Foundation's website btf-thyroid.org

Some treatments for lymphoma can affect women's ovaries and men's testicles, leading to reduced fertility. This can happen with radiotherapy given to your tummy (abdomen) area or to the area below your belly button (pelvis). It can also happen with chemotherapy. Less is known about the effects of newer, targeted treatments. In women, treatment can also lead to an early menopause.



We have information about reduced fertility on our website, [lymphoma-action.org.uk/Fertility](https://www.lymphoma-action.org.uk/Fertility). This includes about fertility preservation options for men and women, and about early menopause.

Summary

- After treatment, you have a follow-up period. This is to check your recovery and to help you manage any side effects or late effects of treatment. It also gives you a chance to talk to your medical team about questions or concerns you might have.
- Many people feel a wide range of emotions when they finish treatment. There is support available to help you through this time.
- A healthy lifestyle can help in your recovery and help you to live well, with and beyond lymphoma.
- After treatment, you might need to make some short or longer-term adjustments to your day-to-day life. This might include to your work or studies.
- Late effects are health problems that can develop months or years after treatment. Your medical team should talk to you before you begin treatment about any you might experience.

Glossary

Anaemia	shortage of haemoglobin (or red blood cells) in your blood stream
Anaesthetic	drugs given to make a part of the body numb (local anaesthetic) or put your whole body into a sleep-like state (general anaesthetic)
Antibody	a specialised protein made by white blood cells that helps to fight infections by sticking to proteins on the surface of cells that don't belong in your body
Antibody-drug conjugate	a treatment using an antibody joined to a chemotherapy drug that can deliver the chemotherapy directly to the target lymphoma cell
B symptoms	a set of symptoms: fever, drenching sweats and unexplained weight loss
Biopsy	a biopsy looks at a sample of cells under a microscope to check for lymphoma cells
Bone marrow	the spongy material at the centre of larger bones where blood cells are made
Chemotherapy	treatment with anti-cancer drugs

Chemotherapy regimen	a chemotherapy treatment plan
Clinical nurse specialist (CNS)	a nurse who specialises in looking after people with lymphoma. They are usually your key worker
CT scan	computed tomography scan: uses X-rays to take pictures or 'slices' through your body
Cycle	a round of treatment followed by a rest period to give you time to recover before the next round of treatment
Immune system	the system in your body that fights off and prevents infection
Intravenous (IV)	into a vein
Late effects	health problems that develop months or years after treatment has ended
Lymphatic system	part of your immune system, the lymphatic system is a network of tubes, nodes and organs that filters out germs and toxins, helps destroy cells that are old or damaged and drains waste fluids from your tissues

Lymph nodes	small, oval swellings (glands) that are spread throughout your lymphatic system; they help your body fight infections and drain away waste fluids from tissues
Lymphocytes	a type of cell that grows out of control if you have lymphoma. There are three main types of lymphocyte – B cells, T cells and natural killer cells
MRI scan	magnetic resonance imaging: a scan that uses magnetic waves to take pictures of the inside of your body
Multidisciplinary team (MDT)	group of health professionals who meet to plan and manage your care and treatment according to your individual needs and preferences
Neutropenia	low levels of neutrophils (a kind of white blood cell) in the blood; can result in the body allowing infections to develop
PET scan	positron-emission tomography: a scan that uses a radioactive form of sugar to look at how active cells are
PET/CT scan	a test that combines a PET scan and a CT scan

Platelets	a type of blood cell that helps your blood to clot
Radiotherapy	a type of treatment for lymphoma that uses radiation to destroy cancer cells
Refractory	lymphoma that does not respond well to the first choice of treatment
Relapse	lymphoma that comes back after successful treatment and a period of remission
Remission	no evidence of lymphoma in tests or scans
Spleen	an organ that filters blood
Stage	a measure of how much of your body is affected by lymphoma
Stem cell transplant	a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells
Thrombocytopenia	a shortage of platelets in the blood that increases the likelihood of bruising and/or bleeding
Thymus	a small gland behind your breastbone where some of your immune cells develop

- Ultrasound scan** a scan that uses high-energy soundwaves to take pictures of the inside of your body
- White blood cell** a cell found in the blood and in many other tissues that helps our bodies to fight infections. There are several different types, including lymphocytes and neutrophils
- X-ray** a form of radiation that is used to take pictures of the inside of the body and for radiotherapy

Information and support

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



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



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



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



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



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

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

 @lymphomaaction   lymphoma_action

[More information](#)

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

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

- *Introduction to lymphoma*
- *Young person's guide to lymphoma*
- *Living with and beyond lymphoma*
- *When someone close to you has lymphoma*
- *Autologous stem cell transplant*
- Easy Read books.

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

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



Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites. If you don't find what you are looking for, please contact our Helpline (page 101).

British Association for Counselling and Psychotherapy provides a list of accredited counsellors in your area.

Cancer Research UK has information on all types of cancer and a nurse-led helpline: 0800 800 4040.

Carers UK offers advice, information and support for carers.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.

Maggie's provides practical, emotional and social support to people with cancer and their family and friends.

Mind offers support and advice to anyone experiencing a mental health problem.

Teenage Cancer Trust provides cancer services and support for young people affected by cancer.

Young Lives vs Cancer provides emotional and practical support for young people with cancer and their families.



Visit lymphoma-action.org.uk/UsefulOrgs for a list of other organisations you might find helpful

How you can help us

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

We continually strive to improve our resources and are interested in any feedback you might have. Can you spare five minutes to give feedback on this book? It will help us plan future versions. Please scan the QR code to complete our short survey. Alternatively, please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.



References

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

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Notes



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

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

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

This book describes what classical Hodgkin lymphoma is, how it typically affects people, how it is treated, and what to expect after treatment.

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

We're here for you.



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



information@lymphoma-action.org.uk



www.lymphoma-action.org.uk



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

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