

Hodgkin lymphoma



**Blood
cancer
UK**

About this booklet

We have produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. Thanks to Consultant Haematologists Dr Chris Hatton and Dr Graham Collins for their support checking the content of this booklet.

We're a community dedicated to beating blood cancer by funding research and supporting those affected. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. To find out more about what we do, see page 93.

bloodcancer.org.uk

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A list of references used in this booklet is available on request. Please email us at **information@bloodcancer.org.uk**

Disclaimer

We make every effort to make sure that the information in this booklet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

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Introduction

This is a booklet for people with classical Hodgkin lymphoma, and for people who know someone with classical Hodgkin lymphoma

Being told that you, or a loved one, have any type of cancer can be one of the hardest things you'll ever have to hear. There's sure to be a lot of information to take in at this time.

We hope this booklet will help you to understand your condition and feel in control. We'll cover the key aspects of diagnosis and care along the way, including symptoms, tests, treatment, living with Hodgkin lymphoma, and where you can get support.

Every person is different, with a different medical history. So when you're deciding what's right for you, discuss your situation with your specialist as well as getting information from this booklet and other trustworthy places.



Our Support Services Team offers practical and emotional support for anyone affected by blood cancer. Contact us on **0808 2080 888** or email **support@bloodcancer.org.uk**

If you have a type of lymphoma called nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL), you can get information from Lymphoma Action. Go to **lymphoma-action.org.uk** and search for 'nodular'

Hodgkin lymphoma at a glance

In the majority of cases, Hodgkin lymphoma can be treated successfully.

What is Hodgkin lymphoma?

Our bodies produce white blood cells which fight infection. Hodgkin lymphoma is a type of cancer which affects white blood cells called lymphocytes.

If you've got Hodgkin lymphoma, some of your lymphocytes become cancerous, which means they multiply in an abnormal way.

These cancerous cells cluster together in your glands (lymph nodes), attracting normal white blood cells and causing lumps to form.

Usually, the lumps will be in your neck, but you can get them anywhere you have lymph nodes.

Who gets Hodgkin lymphoma?

Children and adults of all ages can develop Hodgkin lymphoma, but it is most common in young adults and people over 75. About 2,000 people are diagnosed with Hodgkin lymphoma each year in the UK – that's around three people in 100,000.

What's the outlook?

Younger people tend to do well on treatment, as do many people over 50, although sometimes treatment may be slightly less successful in older, frailer people. It's really important to remember that everyone is different, so your consultant is the best person to ask about your outlook.

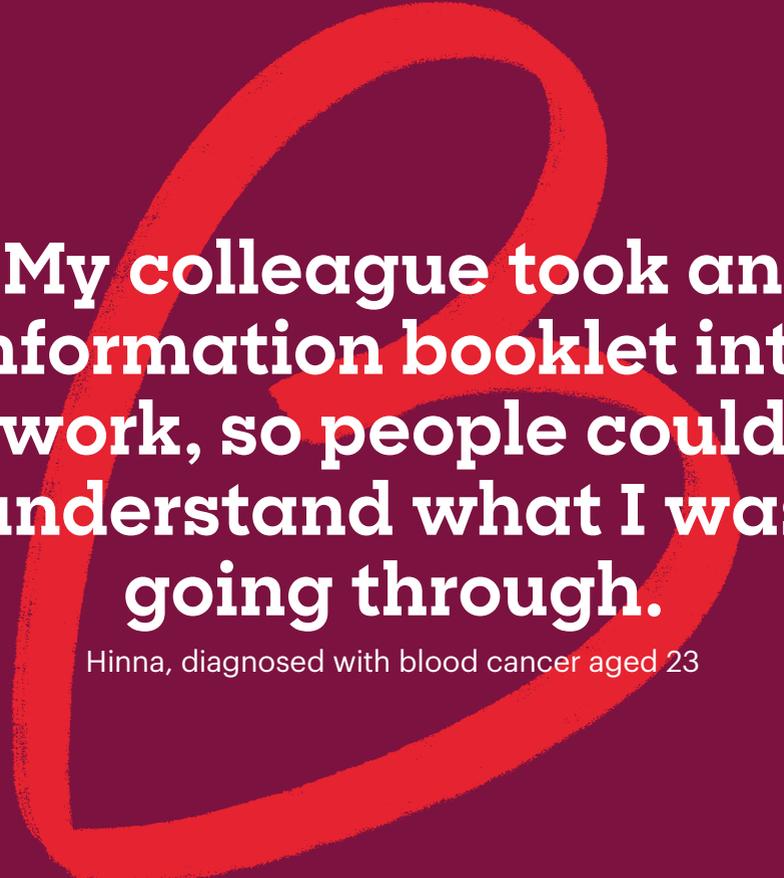
What are the treatments?

The decision on which treatment is best for you will depend on your age, general wellbeing and how far your Hodgkin lymphoma has spread (its stage). Most people with Hodgkin lymphoma will have treatment with anti-cancer drugs (chemotherapy), and sometimes with radiation (radiotherapy). Some people will also take drugs called steroids.

In a small number of cases Hodgkin lymphoma doesn't respond to standard treatment (refractory disease), or comes back after responding well at first (relapse). In these cases, your doctor may suggest using higher doses of chemotherapy followed by a stem cell transplant (sometimes called a bone marrow transplant).

Can Hodgkin lymphoma lead to any other conditions?

If you have Hodgkin lymphoma you often have a weakened immune system, meaning it's more difficult for your body to fight infection. This can sometimes lead to conditions such as shingles (an infection of a nerve and the skin around it). You may also develop anaemia, which is where the number of red blood cells you have is too low.



**My colleague took an
information booklet into
work, so people could
understand what I was
going through.**

Hinna, diagnosed with blood cancer aged 23

**Knowing the basics about
the immune system and
your lymphatic system
is useful.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Your immune and lymphatic system

It's a good idea to know a bit about the immune system and lymphatic system as your healthcare team are likely to talk about them.

Your immune system is a network of cells, tissues and organs which protects your body against infection. It's able to react quickly to infections it's seen before, and lymphocytes (a type of white blood cell that fights infection) play an important role in this.

Hodgkin lymphoma is a disease which affects your lymphatic system, which is part of the immune system. A network of thin tubes called lymph vessels runs around your body. These vessels collect fluid called lymph and return it to your blood.

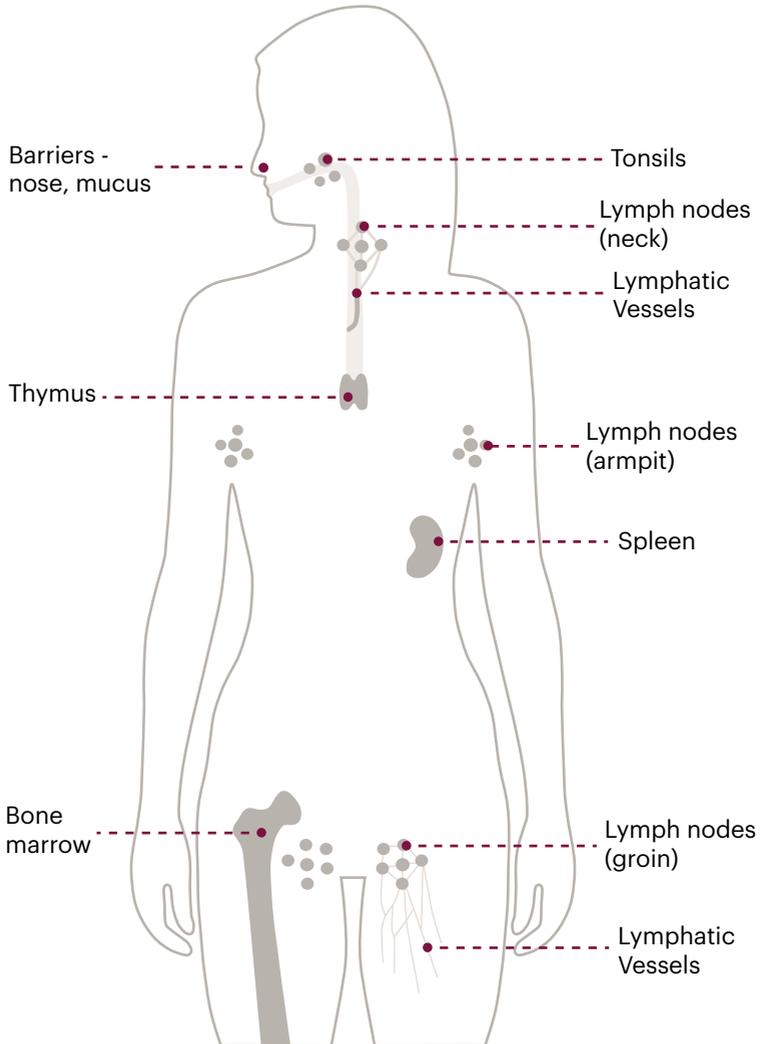
Lymph bathes all the cells in your body. It contains lots of lymphocytes, carries nutrients which feed the cells, and removes bacteria from infected areas.

Along the lymph vessels are small lumps of tissue called lymph nodes or lymph glands. There are many of these in your body. It may be possible for you to feel normal lymph nodes in the neck and groin, particularly if you're slim. If you get an infection when you're healthy, these can swell and become tender. People often talk about having 'swollen glands'.

As lymphocytes pass through the lymph nodes, these nodes are changed and 'activated' to fight certain types of infection.

Your spleen is also part of your lymphatic system. It can do some of the same work as the lymph nodes and helps to fight infection. It also filters out old or damaged cells from the bloodstream.

Your lymphatic system



There are many different types of lymphoma. Make sure to check with your specialist that this is the right booklet for you.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org**.

What is Hodgkin lymphoma?

Lymphoma is a cancer of the lymphatic system. Hodgkin lymphoma is a type of lymphoma where an abnormal white blood cell called the Reed-Sternberg is present.

Lymphoma

When you have lymphoma some of your lymphocytes become cancerous and don't work properly. Sometimes they aren't developed fully (immature), they divide in an abnormal way, or don't die when they should. These abnormal lymphocytes can build up in your lymph nodes, causing them to swell and form a lump.

Swollen lymph nodes can be in a place where they can be easily felt (such as your armpits, neck or groin) or deep inside your chest and stomach area (abdomen). The abnormal lymphocytes can affect how your immune system works, which can make you more likely to get infections.

Hodgkin lymphoma

There are two main kinds of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma. In Hodgkin lymphoma, abnormal cells called Reed-Sternberg cells are always present. Any lymphoma without these cells is called non-Hodgkin lymphoma. Reed-Sternberg cells are white blood cells called B lymphocytes that have become cancerous.

The most common place where people find a lump caused by Hodgkin lymphoma is in the neck or chest, but they can occur anywhere in the body where there are lymph nodes and also in some organs.



Lymphoma Action has information on nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL). Go to **[lymphoma-action.org.uk](https://www.lymphoma-action.org.uk)** and search for 'nodular'.

There are two main types of Hodgkin lymphoma:

- classical Hodgkin lymphoma
- nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

This booklet is for people with classical Hodgkin lymphoma, the most common type of Hodgkin lymphoma. Nine out of ten cases (90%) of Hodgkin lymphoma will be this type. Make sure to check with your specialist which is the right information for you.

**When you're diagnosed
with any cancer, one of the
first things you might think
is: why me?**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

What causes Hodgkin lymphoma?

Hodgkin lymphoma is quite rare, but there are still around 2,000 people diagnosed with it each year in the UK, which is about three people in 100,000.

It's important to understand that you can't catch lymphoma, or pass it on to someone else.

In most cases we don't know what causes Hodgkin lymphoma, but there are some things which can make the risk of developing the disease slightly higher.

Age

Children and adults of all ages can develop Hodgkin lymphoma, but it is most common in young adults and people over 75.

Sex

In the UK, Hodgkin lymphoma is slightly more common in men than in women – we don't know why.

Lowered immunity

You're more likely to get Hodgkin lymphoma if you have problems with your immune system. This might be the case if:

- you have HIV or AIDS
- you've had an organ transplant and are taking drugs to stop the new organ being rejected
- you have an auto-immune condition (where your immune system attacks healthy cells by mistake) such as rheumatoid arthritis.

Epstein-Barr virus

It's thought that people who've been exposed to the Epstein-Barr virus, which causes glandular fever, may have a slightly higher risk of getting Hodgkin lymphoma.

Researchers are working to find out more, as it's not clear at the moment exactly how the virus is linked to Hodgkin lymphoma. It's important to remember that although glandular fever is very common, Hodgkin lymphoma is not.

So if you've had glandular fever in the past your risk of getting Hodgkin lymphoma is still very low.

Family history

Hodgkin lymphoma isn't a hereditary disease (one that you inherit from your parents), though there's some evidence that having a parent, child, brother or sister with Hodgkin lymphoma or another blood or lymphatic cancer can slightly increase your risk. We don't know if this is because of a genetic fault or if it's because members of the same family are more likely to have the same type of lifestyle.

**Many of the symptoms
you get with Hodgkin
lymphoma are similar to
symptoms you get for other,
less serious illnesses.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Symptoms

There are a number of symptoms you might have before and after you're diagnosed. Not everyone will get the same ones.

Common symptoms

The most common symptom of Hodgkin lymphoma is one or more swellings in the neck or above the collar-bone. These are swollen lymph nodes. Usually the enlarged nodes are painless, but for some people they become painful after drinking alcohol.

You might also get swollen lymph nodes in your armpit or groin. However, if you have Hodgkin lymphoma you can get swelling in any of your lymph nodes (see page 13–14).

If the affected node is deeper in your body, rather than just beneath the surface of your skin, then the swelling may not be visible. However, you may experience other symptoms, caused by this lump pressing against another organ.

For example, if you develop Hodgkin lymphoma in your chest (which is quite common) you may have chest pain, a cough or breathlessness. This can sometimes be found during a routine chest X-ray, at a time when you have no other symptoms.

B symptoms

There are three specific symptoms of Hodgkin lymphoma known as B symptoms. Having or not having these can affect which treatment is right for you, because they can show how active the lymphoma has become. These symptoms are:

- fever (38°C or higher with no evidence of an infection)
- unexplained weight loss in the last six months (10% or more of your previous weight)
- drenching night sweats which soak your nightclothes and bedding.



Other symptoms

You may experience some other symptoms with Hodgkin lymphoma. These are not classed as B symptoms, so they won't be used as a guide for treatment decisions. They might include tiredness (fatigue) and itching (either widespread or in one place).

It's important to know and understand your diagnosis. You could ask your team to write it in this booklet, so you have it at hand.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Diagnosis

It's really important to have the tests you need to investigate your condition and get a clear diagnosis before you start any treatment. At any time, you can ask your healthcare team to tell you why you're having a certain test and what the results mean.

Tests to diagnose Hodgkin lymphoma

If your GP suspects you might have Hodgkin lymphoma, they'll refer you to hospital for more tests. You'll need to have a number of tests and scans to confirm whether you have Hodgkin lymphoma, including some blood tests and possibly a chest X-ray to look at your general health.

It can be a worrying time while you're waiting for the results of these tests. Many people say that it helps to keep themselves occupied and talk to family and friends, or other people who've been through the same thing.

Lymph node biopsy

You'll need a lymph node biopsy to confirm the diagnosis of Hodgkin lymphoma. A biopsy is a minor surgical procedure where a sample of a tissue or organ is taken and examined in the laboratory.

Sometimes the whole lymph node is removed – this is called an excision biopsy. You'll need a small number of stitches after the biopsy, but you can normally go home on the same day and have the stitches taken out about a week later by your GP.

Alternatively, it may be possible to take samples of a swollen lymph node using a needle guided by ultrasound (ultrasound-guided biopsy). Ultrasound is a type of scan that uses sound waves to create a moving image of the part of the body being scanned. With the help of these images, several small samples (cores) of lymph node tissue will be taken. You'll be given a local anaesthetic to numb the area beforehand.

If the lymphoma is deeper in the body, sometimes a different type of biopsy is needed. For example, if there is a lump in your chest, you may need an operation called a mediastinoscopy. Your doctor will pass a thin tube with a tiny camera on the end through a small cut at the base of your neck. This allows them to have a look inside your chest and take a biopsy at the same time. It happens under general anaesthetic so you'll be asleep and won't feel anything.

These tests are really important in diagnosing Hodgkin lymphoma, because they show your healthcare team if your sample contains Reed-Sternberg cells. If they find these cells it is a clear sign that you have Hodgkin lymphoma rather than any other type of lymphoma.

PET/CT scan

You may have a PET/CT scan to help your healthcare team find out where the lymphoma is in your body and work out how advanced it is. This is called 'staging'.



See **page 30** for more information on PET/CT scans.

Staging

Staging describes how far a person's disease has spread. Your healthcare team will use a system based on the Roman numbers I – IV to categorise this.

Staging for Hodgkin lymphoma is based on the symptoms you have and how many sites in your body are affected by lymphoma. The stage will affect the treatment your consultant recommends for you.

For any stage of Hodgkin lymphoma, a letter 'A' or a 'B' can be added to your diagnosis. These letters indicate whether you have certain symptoms or not. So your diagnosis might be IA or IIB, for example.

As well as putting an A or a B after the stage, sometimes an X is added. This describes bulky disease, which means that the lumps caused by the lymphoma are quite large. Whether or not you have bulky disease can be important in deciding which treatment you should have.

Early-stage and advanced-stage Hodgkin lymphoma

Stages I and IIA are called early-stage disease. Stages IIB, III and IV are called advanced-stage disease. The treatment you receive will depend on the stage of the Hodgkin lymphoma.

Stage	Features
I	Only one group of lymph nodes is affected, in one place in your body.
II	More than one group of nodes is affected but all affected sites are on the same side of the diaphragm either above or below. The diaphragm is a sheet of muscle separating your chest from your stomach and hip area (abdomen and pelvis).
III	Lymph nodes on both sides of the diaphragm are affected, or the lymphoma has spread from lymph nodes into organs close to the affected node, or nodes.
IV	The lymphoma has spread to other organs, such as the lungs, liver or bone marrow.

Letter	Symptoms
A	No B symptoms (see below).
B	B symptoms are present: <ul style="list-style-type: none"> › fever (higher than 38°C) › drenching night sweats › unexplained weight loss in the last six months (10% or more of your previous weight).

Further tests

After you've been diagnosed, you'll have further tests so your healthcare team can find out which areas of your body are affected by Hodgkin lymphoma, and 'stage' the disease. Some of these tests need special preparation, like not eating or drinking beforehand. Your healthcare team will tell you about any tests where you may need to prepare in a certain way.

PET scan or PET/CT scan

You might hear this called either a PET scan or PET/CT scan, as some scanners do both PET and CT scanning. This scan is used:

- after you're diagnosed, to accurately stage Hodgkin lymphoma and find out which areas of your body are affected
- during treatment (usually after your first two courses of treatment) to check how you're responding and assess if you need to change treatments
- at the end of your treatment to confirm that you have no active cancer (remission).

Before you're scanned, you'll have an injection which contains radioactive sugar. This small amount of radioactivity is quite safe for you. The sugar will help to show up active lymphoma cells on the scan.

You'll be asked to lie on a table as you move through the doughnut-shaped scanner. This scan can take up to three hours, including preparation time.

Having a PET scan will make you slightly radioactive for a short time, so you may be told to stay away from pregnant women, babies and young children for a few hours after your scan.

Magnetic resonance imaging (MRI)

This scan shows up soft tissues (non-bony parts) and uses strong magnets and radio waves rather than X-rays. Not everyone will have one, but they can help your team look for affected lymph nodes in soft tissues around your body. You'll be asked to lie on a table which will move you through the scanner. It isn't painful but it can take up to an hour – some people may not like being enclosed and feel a bit claustrophobic. As with a CT scan, you might need to have a dye injected into one of your veins to get a better image.

Pregnant women may have an MRI in place of a PET scan, as there is no radioactivity involved in an MRI.

You'll need to remove any metal you're wearing before an MRI, including jewellery. If you have any metal in your body – for example a pacemaker or bone pins – you should tell the person conducting the scan (the radiographer).

Other tests

You may have a range of other tests, which will help your healthcare team check your general health and assess how well you might respond to certain treatments. These may include:

- a full blood count – this measures the amount of each type of blood cell in your blood: red cells, white cells and platelets
- tests on your heart, lungs, kidneys, liver and thyroid (a gland that plays an important part in turning food into energy)
- tests for HIV and two types of liver disease: hepatitis B and hepatitis C.

Your healthcare team

If you're diagnosed with Hodgkin lymphoma, your hospital will give you the names and contact details of your specialist doctor (consultant), clinical nurse specialist (CNS) and other members of your healthcare team. There's space to write them at the back of this booklet if you want to. You can then use these details to contact your team if you have any questions you want to ask when you're not at the hospital.

Your specialist doctor (consultant)

Most people with a blood cancer are treated by a haematologist – a doctor who specialises in treating patients with blood diseases. Some are treated by an oncologist (a cancer specialist). Either way, your consultant at the hospital will be an expert in treating your specific disease.

Your clinical nurse specialist (CNS)

People with cancer are normally given a key worker, usually a clinical nurse specialist (CNS). They're your point of contact with the rest of your healthcare team. You may like to have a meeting with them when you're first diagnosed, to discuss your condition. Your CNS will be with you every step of the way, so do make use of their help and expertise if and when you need it.

Your multidisciplinary team

Your condition should be discussed at regular multidisciplinary team (MDT) meetings. An MDT brings together doctors, nurses and other specialist staff who will be looking after you. They'll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

Talking to other people

You might want to ask your consultant or key worker if you can talk to someone who's had the same diagnosis and treatment as you. If you do this, remember that someone else's experience won't

always be the same as yours. For example, some people will experience side effects from a drug and others won't.

You may also want to contact a support organisation – many provide patient meetings or further online support. There's a list of support organisations on pages 71–76.

Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see – like your dentist or optician – about your diagnosis and any medication you're taking. They may need to check with your specialist or GP before giving you some types of treatment.

Finding out more

After you've been diagnosed, it's worth taking some time to think about what information you want to know, when and how. For some people, this is a way to have some control over what's happening.

- Let your consultant and CNS know how much information you'd like, and in what form. You can always ask for more information later.



You can read about the experiences of other people with blood cancer on our online community forum:

forum.bloodcancer.org.uk

- Write down any questions you have and keep them handy for when you see your consultant or key worker. If they can't answer your questions, they'll be able to tell you who to speak to.
- You might prefer to ask your clinical nurse specialist questions rather than your consultant, but do whatever works for you.
- Most people say they find it useful taking someone with them to appointments. If you think you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take – it doesn't have to be a family member.
- If you're staying in hospital it might be harder to have someone with you when you speak to your consultant. It could be useful to ask in advance what time the consultant is likely to see you, so you can try to arrange for someone to be with you at that time.
- Some people find that joining a patient support group is helpful. It may be easier to talk to someone outside of your family about your situation and being able to share similar experiences might also help you.

Telling people

Many people tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

You might find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated on your behalf. Another idea is setting up a blog or Facebook page, so you or other people can post information on it that everyone can read. You might not want to tell many people – or anyone at all – about your condition. This is ok too, whatever works for you.

Talking to children and teenagers

Talking to children and teenagers about your condition can be a difficult thing to do. There are many organisations to support you and offer advice on how to explain it to children of different ages.

Telling your GP

Your team at the hospital will keep your GP informed about your condition and any treatment you're having. They'll usually send your GP a letter with this information. As the patient, you'll often be sent a copy too. These letters can have a lot of medical terms in them which you might not have heard before, or there might be something in it which

worries you. If this is the case, let your hospital or GP know – a quick chat with them might help to reassure you.

Cancer and work

Consider telling someone at work about your diagnosis. It can be hard asking for time off at short notice if no one knows about your illness, and your colleagues and human resources department might be able to offer support.



We have more information and personal stories about cancer and work on our website: **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

There's more information about cancer and how it can affect your work or study on **page 66–67**.

The treatment you decide on with your healthcare team will depend on the stage of your Hodgkin lymphoma, your age and general wellbeing.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Treatment

Treatment for Hodgkin lymphoma is usually very successful. The treatment you have depends on the results of your tests and what stage the Hodgkin lymphoma is, but typically includes chemotherapy and in some cases radiotherapy, steroids and – if the Hodgkin lymphoma comes back – a stem cell transplant.

Clinical trials

If there's a clinical trial (study) available that's suitable for you, your consultant may recommend that you consider this. Clinical trials are widely used in the treatment of Hodgkin lymphoma.

Clinical trials are done for several reasons, including to look for new treatment options and to improve existing treatments. Taking part in a clinical trial has many advantages, such as the opportunity to have the newest available treatment which may not be given outside of the trial. You'll also be very closely monitored and have detailed follow-up.

In a clinical trial, the best current treatment is compared to one that's at least as good, and could be better. Your safety and wellbeing is always the first priority when taking part in a clinical trial.

Taking part in a clinical trial does come with uncertainties, and you may prefer not to take part in one. If you don't want to be in a trial, or there isn't a suitable trial available, you'll be offered the best treatment available which is appropriate for your individual condition.

Risks to fertility

Treatment for Hodgkin lymphoma can affect fertility in men and women. The level of risk depends on the specific treatment you've had. If you're a woman, the risk to your fertility becomes higher as you get older, because there is a possibility that chemotherapy may lead to an earlier menopause.

After you've been diagnosed, and before you begin treatment, it would be a good idea to discuss with

your doctor the options available to protect your fertility.

All men will be offered the opportunity to store sperm and women will have the opportunity to discuss potential egg freezing or embryo preservation.

Treatment planning

Your healthcare team will look at a number of things when deciding what treatment to recommend to you – such as your test results, the symptoms you have, what stage the Hodgkin lymphoma is and your general age and fitness.

If you have any concerns about treatment you should discuss these with your consultant or key worker.

Early-stage disease

If you have early-stage disease (I or IIA) your treatment will usually be two to six courses (cycles) of chemotherapy. You may also have local radiotherapy, specifically on the affected lymph nodes. Radiotherapy is used to try to prevent the disease coming back. Your healthcare team will discuss the risks and benefits of radiotherapy with you.

Advanced-stage disease

If you have advanced disease (stage IIB to IV), your treatment will usually be six cycles of chemotherapy, and possibly some radiotherapy as well.

Treatment if you're under 25 years

If you're under the age of 25, you can be treated in a teenager/young adult centre (TYA centre). You'll be treated in a TYA centre if you're still attending school and you'll also have the option if you've already left school. These centres also provide psychological and social support, which you can access even if you're not being treated there. Your healthcare team can refer you to your nearest TYA centre.

Chemotherapy

Most people with Hodgkin lymphoma will have chemotherapy. This is usually a combination of drugs known as ABVD. This stands for:

- A Adriamycin™ (also known as doxorubicin or hydroxydaunorubicin)
- B bleomycin
- V vinblastine
- D dacarbazine

Some hospitals may offer a different type of chemotherapy drug combination. These include stronger combinations such as escalated BEACOPP. Children and young adults under 18 years old often have a drug combination called OEPA.

Your healthcare team will discuss what's right for you. All of the drugs used to treat Hodgkin lymphoma work by interrupting the growth of cancerous cells in your body.

How is chemotherapy given?

The treatment is usually given in an outpatient clinic, which means you will only have to make a daytime visit to the hospital. However, you may need to stay overnight in hospital on some occasions and with some particular drugs.

Chemotherapy is usually given in courses called cycles – you'll have treatment for a day if you're on ABVD, or for a few days with other drug treatments.

ABVD chemotherapy is given every two weeks. One cycle is two lots of the same chemotherapy, so it's completed in four weeks. Patients with advanced-stage Hodgkin lymphoma will typically have two courses of ABVD chemotherapy followed by a PET/CT scan. If the result of the scan is good, you'll have four more cycles of chemotherapy without bleomycin (AVD).

If you have had more intensive chemotherapy at the start (such as escalated BEACOPP), then you may need only four cycles of chemotherapy in total. This will depend on the result of your PET scan after two cycles of treatment.

Chemotherapy for Hodgkin lymphoma is usually given directly into a large vein in your arm. This is known as an intravenous or IV infusion.

Sometimes it's given through a central line (an IV line into the chest). Having a central line can be useful, as it means you don't have to have the treatment injected each time (which can sometimes be uncomfortable after several cycles of treatment).

There are three main types of central line:

- A PICC line (peripherally inserted central catheter) is where a long thin tube is passed up a vein in your arm to your chest.
- A central line is put into the main vein in your chest – the end comes out of the skin on your chest so drugs can be given through it. You might hear it being called a Hickman™ line.
- A 'port' is put into your chest and doesn't come out through your skin – drugs are injected into it instead.

Central lines can usually be put in at an outpatient clinic using local anaesthetic to numb the area. So you won't need to stay in hospital overnight.

Your healthcare team will tell you how to look after your central line. Central lines can be removed easily after your treatment.

Steroids

You may be given steroids as well as chemotherapy drugs. Steroids can make some chemotherapy treatments more effective and reduce any sickness you may get. The steroid normally given to reduce sickness is called dexamethasone, which is given as an injection or as a tablet.

Radiotherapy

Radiotherapy uses high energy rays to kill cancer cells in a specific area. It can be an effective treatment for diseases such as lymphoma which affect a particular part of the body.

It is more common to have radiotherapy if you have early-stage disease (I or IIA) in only one or a couple of areas of the body. Occasionally you might have radiotherapy in later stage disease to try and shrink swollen lymph nodes (see page 10).

Before you have radiotherapy, you'll have scans so your doctors know exactly where to target it, and they'll mark this on your body. The actual treatment only takes a short time and it isn't painful. You lie still inside a doughnut-shaped scanner with the treatment area exposed.

You normally have radiotherapy as an outpatient (so no need to stay in hospital overnight) for up to three weeks. You'll come to hospital for treatment every day during this time, apart from weekends.

Radiotherapy doesn't make you radioactive and it's fine to be around other people as normal.

Side effects

You may experience some side effects from the different types of treatment you have.

Chemotherapy

For most people with Hodgkin lymphoma, side effects from chemotherapy aren't severe and they usually go away when treatment stops.

They may include:

- fever
- difficulty pooing (constipation)
- tiredness
- cough/breathlessness
- hair loss
- bleeding and/or bruising
- anaemia (a lack of red blood cells) which can cause paleness, tiredness and breathlessness
- mouth sores
- feeling sick (nausea) and vomiting
- poor appetite (loss of taste)
- weight changes.

You're unlikely to have all of these side effects.

You'll be given drugs called anti-emetics to stop you feeling sick and to help with the vomiting you might get with certain treatments. If you have any other side effects, tell your healthcare team as they may be able to help.

Some side effects are associated with specific drugs. For example the bleomycin drug in ABVD can cause a cough or breathlessness. Let your doctor know straight away if this occurs during or after treatment.

Also, the dacarbazine drug in ABVD may cause some pain at the spot where it's given. If this happens there are things which can be done to help, so you should tell your nurse or doctor immediately if you feel pain.



For more information about cancer drugs and their side effects, go to **macmillan.org.uk** and search the name of the drug or drug combination.

Steroids

Side effects from steroids can include:

- feeling agitated
- weight gain
- a build-up of water around your face and ankles (water retention)
- increase in appetite
- raised blood sugar, particularly in people with diabetes.

Radiotherapy

The side effects from radiotherapy will depend on the area of the body being treated but common side effects are tiredness (fatigue), and redness in the treated area. Your healthcare team will speak to you in more detail about this.

Supportive care

You may also need what's known as supportive care, during and after treatment. Supportive care includes prevention and treatment of infection, blood transfusions, mouth care, dietary advice, pain management and dealing with complications associated with your illness or your treatment.



You can find out more about stem cell transplants in our booklet **Blood stem cell and bone marrow transplants: the seven steps**. See **page 90** for details of how to order.

Relapsed or refractory disease

In a small number of people, Hodgkin lymphoma doesn't respond to the first treatment (refractory disease), or comes back although it responded well at first (relapse). If this is the case for you, it's important to remember that there's still a good chance of a successful outcome.

In these cases, if you're otherwise fit and well, your doctor may recommend using higher doses of chemotherapy followed by a stem cell transplant, sometimes called a bone marrow transplant.

Stem cells are produced in the bone marrow at the centre of some bones and develop into different types of blood cells.

A stem cell transplant aims to give you healthy stem cells to replace those which are destroyed by the high-dose chemotherapy. These stem cells then produce normal blood cells. There are two main types of stem cell transplant.

Autologous stem cell transplant

An autologous transplant is when your own healthy stem cells are collected before the high-dose chemotherapy, then given back to you through a drip afterwards.

Allogeneic stem cell transplant

An allogeneic transplant uses stem cells from a donor. This type of transplant is less common, but may be considered for a small number of people whose autologous transplants weren't successful, or for people who didn't respond well enough to their initial treatment to have an autologous transplant.

Other treatments for relapsed or refractory disease

You may be given a drug called brentuximab vedotin if you relapse following an autologous transplant, or don't respond well to other treatments and a stem cell transplant isn't currently an option for you. Brentuximab vedotin is what's known as an antibody drug conjugate (ADC) - a combination of an antibody and a chemotherapy drug. Antibodies are proteins which fight infection and are produced naturally by white blood cells, but they can also be created in a laboratory for use in drug treatments. ADCs deliver chemotherapy in a way that's much more targeted than usual, and may cause fewer side effects.

Two new drugs called nivolumab and pembrolizumab can now be used to treat people whose Hodgkin lymphoma has relapsed after a stem cell transplant, and treatment with brentuximab vedotin hasn't been successful. Nivolumab and pembrolizumab are what's known as immunotherapy drugs. They help activate your

immune system so it's more effective at fighting the cancer.

Follow-up

If your condition responds well to initial treatment, there's a high chance that you won't need further treatment. However, it's really important that you still come for follow-up checks and monitor yourself for any symptoms, because unfortunately the disease can return. This is known as relapse. The earlier a relapse is identified, the better the chance of a successful outcome.

The number and timing of follow-up appointments varies widely. You may carry on having appointments for up to two years, but you could stop having appointments more quickly than that. Your healthcare team will tell you how often you should come for follow-up checks.

After treatment you may wonder whether there are any specific signs or symptoms you should be looking out for. An obvious reason to contact the hospital team would be any new swellings. Similarly, fever, sweats or unexplained weight loss should be reported. It's a good idea to tell the hospital team of any changes in your general health or any new signs or symptoms you notice.

Vaccines and blood transfusions

Once you've completed your treatment and you're in remission (you have no active cancer), you shouldn't receive live vaccines such as yellow fever, measles and shingles, as these may cause serious illness. Ask your healthcare team for more advice about vaccines.

People with Hodgkin lymphoma must not receive blood (or any other blood product such as platelets) that hasn't been treated with radiation (irradiated). It's important you carry a card to inform other medical teams of this risk. Your healthcare team should give you one of these cards – if you haven't been offered a card yet, you could speak to your key worker or doctor about it on your next visit. You may also want to wear a special bracelet to give this information to doctors caring for you if you're unconscious or unable to explain.

In an emergency, if you need a blood transfusion as a life-saving intervention, non-irradiated blood can be used so the transfusion isn't delayed.



For information and support on living with and beyond blood cancer, go to **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

You can get a bracelet or 'dog tag' from a charity called MedicAlert. Go to **[medicalert.org.uk](https://www.medicalert.org.uk)** or call **01908 951 045**.



I learned to live day by day. If I felt panicked by something, I would try to concentrate on the next 24 hours.

Louise, diagnosed with Hodgkin lymphoma aged 51

**Every person is individual,
so your consultant and
healthcare team are the
best people to ask about
your likely outlook (your
prognosis).**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

The outlook

For most people with Hodgkin lymphoma, your healthcare team will be aiming for a cure. People generally cope well with their treatment and have few long-term side effects.

In general, the long-term outlook for people with Hodgkin lymphoma is good, especially if it's diagnosed early. Treatment leads to a cure in the majority of cases. However, the outlook and treatment options for individual people depend on a range of things, including their age, general health and whether they have any other specific health problems.

Your healthcare team will describe you as being cured if you go into complete remission, which

means that no lymphoma can be seen on your scans. If there's a reduction in the amount of lymphoma, but it's not completely gone, this is called partial remission.

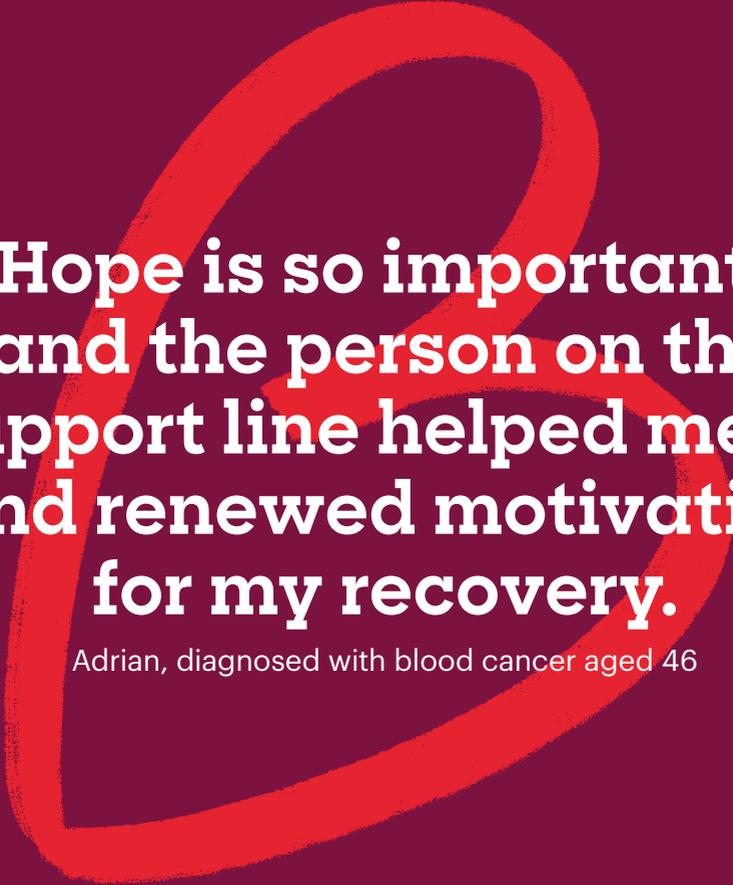
People generally cope well with treatment and have few long-term side effects. However, as with any type of chemotherapy or radiotherapy, there is always at least a small risk of ongoing effects. These include an increased risk of second cancers, and problems with the thyroid, heart or lungs. The risk of long-term side effects will depend on how many cycles of treatment you've had and if you received a transplant or not. However, every case is individual, so your healthcare team will talk to you about this in more detail before your treatment.

If you want to find out more

If you would like more detailed information on the general outlook for Hodgkin lymphoma, go to cancerresearchuk.org and search 'survival Hodgkin lymphoma'. Remember that statistics can only give an overall picture. Your own outlook is individual to you and will depend on your age, general health and specific condition.

Our Support Services Team can talk to you about any questions you have about your outlook.

Contact us on **0808 2080 888** or
support@bloodcancer.org.uk



**Hope is so important,
and the person on the
support line helped me to
find renewed motivation
for my recovery.**

Adrian, diagnosed with blood cancer aged 46

Your healthcare team will look after your emotional needs, as well as your physical ones.

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Living with Hodgkin lymphoma

If you've been diagnosed with Hodgkin lymphoma you might experience a range of emotions at different times. There can be a physical impact on your day-to-day life too.

Looking after yourself emotionally

Being told that you have cancer can be very upsetting and will almost certainly bring many different emotions. Friends and family may be able to offer support, but it may be harder for them to understand the long-term emotional impact that you might experience.

Your healthcare team should look at your emotional, spiritual, social, practical and physical needs – this is called a holistic needs assessment. You'll have one a few times throughout the course of your treatment and beyond, as your needs might change.

Looking after yourself physically

Changes in your condition

When you've finished your treatment it's important to contact your healthcare team at the hospital straight away if you notice any new symptoms – don't wait for your next check-up. Symptoms to watch out for are:

- new swellings
- fever
- sweats
- unexplained weight loss
- any changes to your general health.

Keeping active

You might feel tired a lot (fatigue). This might be caused by the Hodgkin lymphoma or its treatment and isn't the same as normal tiredness which improves with rest and sleep.

While even the idea of doing something can be tiring if you've got fatigue, try to keep as active as you can because evidence shows that this could help to reduce the symptoms of fatigue.

Although we know that staying active may help, there's no evidence that any particular exercise programme can improve your condition or how you respond to treatment.

Diet and infection risk

Similarly, there's no evidence that any special diet will improve your condition or your response to treatment. However, you're likely to feel fitter and healthier if you follow general advice on a good diet from your hospital or GP.

Because your immune system may not be working as normal, you'll need to take extra care to avoid infections that you might get from food. Your body won't be able to destroy germs and resist infection as easily, so be careful about food use-by dates and things like keeping cooked and raw meat separate in the fridge. You may also be advised to be extra careful about takeaway food and eating out while you're having treatment.



You can talk to other people living with blood cancer or read their experiences at **forum.bloodcancer.org.uk**

We have more information and tips about coping with emotions and keeping active on our website at **bloodcancer.org.uk/living-well**

A diet for people with a weakened immune system is known as a neutropenic diet. Your healthcare team will advise you on any changes you need to make to your eating habits.

Other infection risks

If you're having chemotherapy, speak to your healthcare team about whether it's OK for you to do gardening and housework. Avoid fresh cut flowers and vases with old water in, as these carry germs that might cause infection.

Smoking

To reduce some of the risk of long-term side effects caused by treatment, it's essential that you give up smoking. Smoking is especially harmful to those who've previously had chemotherapy and it'll increase your risk of developing a new, second cancer or lung problems in the future.

Shingles

Shingles is the infection of a nerve and the skin around it. It can affect you if you've had chickenpox, even if you had it a long time ago, as it's caused by the same virus which can lie dormant (stay inactive) in your body for years. You're more likely to get shingles if your immune system isn't working well – for example, if you have Hodgkin lymphoma.

Shingles has some quite obvious symptoms. If you think you have it, let your GP or specialist know as quickly as possible (within 24 hours of the rash appearing is best). If it's treated early, the symptoms won't be as bad. Symptoms include:

- a rash (blisters filled with fluid which burst and form sores which then crust over) usually on one side of the body
- pain where the rash is
- an itching, tingling or burning feeling.

You can't catch shingles from someone who has it, but you can catch chickenpox from someone with an open shingles sore, if you haven't had chickenpox already.

Try to avoid people with shingles, chickenpox and other viruses.

Sex and pregnancy

If you're a woman receiving chemotherapy, it's essential to take precautions to avoid becoming pregnant while you're under treatment. Once you're in remission, talk to your doctor if you are planning to have a child.

People who are having chemotherapy should use condoms (and continue to do so for a week after their treatment has finished) because chemotherapy drugs can be present in all bodily fluids. We also do not fully understand what effect chemotherapy may have on sperm.

Complementary therapies

Complementary therapies are treatments like massage, meditation or acupuncture that are used alongside standard medical treatments with the aim of making you feel better.

There's no evidence to suggest that these therapies can treat or cure blood cancer, but there's some that suggests some of them may help you manage your symptoms or the side effects of your treatment. Other therapies may just help you relax or improve your general sense of wellbeing.

Alternative therapies

There's an important difference between complementary therapies, which are used alongside standard medical treatments (like chemotherapy and radiotherapy), and alternative therapies, which are offered instead of these treatments. We don't



Find out more about risks to fertility on **page 40–41**.

recommend that you use any alternative therapy in place of proven medical care, but you may be interested in using complementary therapies alongside your treatment.

Keeping yourself safe

If you're thinking about using complementary therapies, you should let your healthcare team know, so you can discuss what's safe for you. They may advise you to avoid certain therapies because of specific risks to do with your condition or the treatments you're receiving. In other cases, they may say a therapy is OK as long as you take specific precautions, like visiting a complementary therapist who's a member of the relevant professional association or register. Your healthcare team can explain how to check this.

Some hospitals will have a complementary therapies team that offers sessions free of charge, while others might have a specialist who visits once or twice a week. Sometimes these therapies are there for your partner or close relatives, too. Your healthcare team will be able to tell you what's on offer.

If your hospital doesn't offer complementary therapies, there may be a local cancer centre or charity that you could visit instead. Speak to your healthcare team to see if they can recommend anywhere nearby.

Some people choose to see an independent complementary therapist. If you do this, it's important to make sure they will keep you safe. Speak to your healthcare team about what you need to keep in mind when finding a therapist.

Practical support

Work, education and home life

If you work or are studying you might want to contact your employer or college, or ask someone to do it for you. Most will do everything they can to help.

You might need to make a short-term arrangement with your employer or college when you're diagnosed so you can have time off when you need to be at the hospital. If you have to stay in hospital for your treatment, or you're not well enough to go to work or college, you'll probably need to make a more formal agreement.

You may need to bring in written proof of your diagnosis from your healthcare team, which makes clear the effect your diagnosis and treatment could have on your ability to work or study.

Another thing you might want to consider is taking time out from work during your treatment. You may receive varying advice on this but it's entirely your decision, so consider discussing it with your

healthcare team and think about the demands of the specific work you do. Similarly, if you're studying at college or university, you might want to think about whether you want to continue with your course, or delay it for a short time.

If you're a parent or a carer, you may need support during your treatment. You might have unplanned stays in hospital because of infection, for example. It's helpful to have plans in place just in case.

Cancer and the law

People with cancer, or any other serious disease, are covered by a law called the Equality Act. For the purposes of the Act, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with disabilities and can't discriminate against you. An example of a reasonable adjustment would be allowing you time off to go to hospital for treatment.



Consider seeking legal advice about your rights from **[acas.org.uk](https://www.acas.org.uk)** or **[citizensadvice.org.uk](https://www.citizensadvice.org.uk)**

Getting to hospital

If you're being treated as an outpatient (not staying in overnight) you might need to be at the hospital a lot over a long period of time. If you find this hard because of transport or any other reason, you can ask your consultant if you can have any of your treatment nearer to where you live. It might not always be possible but sometimes it is – it depends on the healthcare facilities close to your home and the type of treatment you're having.

If this isn't possible and transport is a problem, you can ask about hospital transport. You might also be able to apply for support with travel costs. If you'd like to know more about this support, you can speak to your team at the hospital or a benefits advisor. The organisations signposted opposite can also advise you.

Financial support

Your finances might be the last thing on your mind if you've just been diagnosed with cancer, but there are lots of places you can get help and advice.

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. This might be especially useful if you're on a low income or are unemployed. If you're worried you can ask to speak to an advisor as soon as possible after your diagnosis. Alternatively, your hospital may be able to arrange for an advisor from somewhere else to visit you.

If you normally pay for your prescriptions but are being treated for cancer (including the effects of cancer or the treatment) you can apply for a medical exemption certificate for any drugs you need to support your care. Application forms are available from your GP surgery or hospital clinic.



We have more information and practical tips about dealing with work and money when you have blood cancer at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

Blood Cancer UK offers information and support to anyone affected by blood cancer. You'll find other useful organisations listed here as well.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Places you can get help and support

Blood Cancer UK

We are here for anyone affected by blood cancer, whether it's you who's been diagnosed or someone you know.

We offer free and confidential support by phone or email. We provide information about blood cancer and life after a diagnosis. And we have an online forum where you can talk to others affected by blood cancer.

- bloodcancer.org.uk
- 0808 2080 888 (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)
- support@bloodcancer.org.uk
- forum.bloodcancer.org.uk

General information and support

Macmillan Cancer Support

Offers practical, medical, financial and emotional support.

- 0808 808 0000
- macmillan.org.uk

Cancer Research UK

Offers information about different conditions, current research and practical support.

- 0808 800 4040
- cancerresearchuk.org/about-cancer

Lymphoma Action

Provides emotional support and information to anyone with lymphatic cancer and their families

- 0808 808 5555
- lymphoma-action.org.uk

Leukaemia Care

Offers information and a support line for people affected by leukaemia and other blood cancers.

- 08088 010 444
- support@leukaemiacare.org.uk
- leukaemiacare.org.uk

African Caribbean Leukaemia Trust (ACLT)

Aims to increase the number of black, mixed race and ethnic minority people on UK stem cell registries by raising awareness and running donor recruitment drives.

- 020 3757 7700
- info@aclt.org
- aclt.org

Anthony Nolan

Runs the UK's largest stem cell register, matching donors to people with leukaemia and other blood-related disorders who need a stem cell transplant.

- 0303 303 0303
- anthonymolan.org

Maggie's

Provides centres throughout the UK, run by specialist staff who provide information, benefits advice and psychological support.

- 0300 123 1801
- enquiries@maggies.org
- maggies.org

Marie Curie

Runs hospices throughout the UK and offers end of life support to patients in their own homes, free of charge.

- 0800 090 2309
- mariecurie.org.uk

MedicAlert

Offers personalised jewellery that provides vital medical information to emergency professionals.

- 01908 951045
- info@medicalert.org.uk
- medicalert.org.uk

Tenovus (Wales)

Provides information on all aspects of cancer, plus practical and emotional support for people living in Wales.

- 0808 808 1010
- tenovuscancercare.org.uk

Financial advice

Citizens Advice

Offers advice on benefits and help with filling out benefits forms.

- 03444 111 444 (England)
- 03444 77 2020 (Wales)
- in Scotland and Northern Ireland, contact your local Citizens Advice
- citizensadvice.org.uk

Department for Work & Pensions (DWP)

Responsible for social security benefits. Provides information and advice about public services including financial support, rights and employment.

- gov.uk/government/organisations/department-for-work-pensions

Travel insurance

Macmillan Cancer Support

Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

- 0808 808 0000
- macmillan.org.uk

British Insurance Broker's Association (BIBA)

Offers advice on finding an appropriate BIBA-registered insurance broker.

- 0370 950 1790
- enquiries@biba.org.uk
- biba.org.uk



**The Blood Cancer UK
Online Community Forum
means I never feel alone
because there's always
someone there to talk to,
who really understands.**

Carina, diagnosed with blood cancer aged 43

Questions for your healthcare team

It can be a good idea to write down any questions you have before your next appointment. Here are some things you might want to ask while you're waiting to receive your diagnosis, or once you've been diagnosed.

Tests

What tests will I have?

What will they show?

Where will I have them done?

Are there any risks associated with the tests?

Will any of the tests be painful?

Do I need to know anything about preparing for them, for example not eating beforehand?

How long will it take to get the results?

Who will explain the results?

What is the exact type of lymphoma I have and what stage?

Treatment - general

Will I need to have treatment? If so, when?

What does the treatment do?

Is there a choice of treatments?

Is there a clinical trial that I could join?

What's likely to happen if I decide not to have the treatment my healthcare team recommend?

If I don't need to start treatment straight away, how will I know when I need to start it?

Who do I contact if I take a turn for the worse?

Who can I contact if I have any questions?

Type of treatment

Chemotherapy

What type of chemotherapy will I have?

Will I have to stay in hospital?

If not, how often will I need to go to hospital as an outpatient?

What chemotherapy treatment will I be given? Will I be given it by mouth, injection or drip (into a vein)?

How long will my treatment last?

Will my treatment be continuous or in blocks of treatment (with a break in between)?

What side effects could I get from my treatment?

Can side effects be treated or prevented?

Will side effects affect me all the time or only while I'm taking certain drugs?

What are the fertility risks with treatment and what options are available to me to protect my fertility?

What effect is the treatment likely to have on my daily life?

Will I be able to carry on working/studying?

Will I need to take special precautions, for example against infection?

Will I need to change my meal times or work my drugs around these?

Stem cell transplant

Is a transplant an option for me?

If I am having a transplant: How long will I be in hospital for?

Do I have to be in isolation?

How long will it be before I get back to normal?

Choosing the right treatment for you

If you're asked to choose between treatments, you might like to ask your consultant these questions about each one:

What's the best outcome I can hope for?

How might the treatment affect my quality of life?

Follow-up

How will the cancer be monitored after my treatment?

How often will I need to have follow-up appointments?

Is there anything I need to watch out for after my treatment?

Who can I contact if I have any questions or worries?

Relapse

How will doctors know if the cancer has relapsed?

What are the options for more treatment?

What will the treatment involve? Will it be different from my initial treatment?

Will there be any side effects from more treatment?

Is my outlook likely to change with more treatment?



**At times I felt
overwhelmed with the
treatment and side
effects, but having a chat
with my CNS always
made me feel so much
better.**

Emma, diagnosed with blood cancer aged 35

Glossary

Cancer can sometimes feel like it has its own language. Here are some of the most common words you might hear:

Anaemia

Anaemia is where you don't have enough haemoglobin (found in red blood cells) in your blood. This can mean that your muscles don't get as much energy as they need, most commonly leading to tiredness or shortness of breath.

B lymphocyte

A type of white blood cell normally involved in producing antibodies to fight infection.

Blood count, full blood count or FBC

A blood test that counts the different types of cells in your blood.

Bone marrow

The spongy material inside your long bones that produces blood cells.

Chemotherapy

Treatment using anti-cancer drugs. It can be a single drug or a combination of drugs. Chemotherapy is used to kill cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells which divide quickly, such as those in the hair and gut. This is why some people lose their hair when they have high-dose chemotherapy.

Clinical nurse specialist (CNS)

A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers while others may specialise in leukaemia, myeloma, lymphoma or another specific area. Your CNS can provide information and expert advice about your condition and treatment, and can be a good link between you and your doctors.

Clinical trial

A planned medical research study involving patients. They can be small trials involving only a few people or large national trials. Clinical trials are always aimed at improving treatments and reducing any side effects they cause. You need to sign a consent form to participate in a clinical trial, so you'll always be aware if your treatment is part of a trial.

Fatigue

Fatigue is a feeling of extreme tiredness which doesn't go away after rest or sleep. It may be caused by the Hodgkin lymphoma itself or might be a side effect of treatment. It's one of the most common problems that people with cancer can have. If you experience fatigue, your healthcare team should be able to offer guidance on helpful ways to manage it.

Immune system

The network of cells, tissues and organs that protect your body against infection.

Lymphoma

The range of different cancers which affect blood cells called lymphocytes, and cells which produce lymphocytes.

Lymphocytes are a type of white blood cell and are part of the immune system, which defends the body against infection. In lymphoma, abnormal lymphocytes are found in lymph nodes (glands) or other lymphoid tissues, so people with lymphoma usually develop lumps, which may be just under the skin or deeper inside the body.

Lymph node or lymph gland

A bean-shaped organ that acts as a filter to catch viruses, bacteria and other potentially harmful particles that enter your body. It contains white blood cells, which fight infection.

Lymph vessels

Small tubes which make up a network which runs around your body. They carry a fluid called lymph.

Radiotherapy

The use of radiation in treatment. Radiotherapy kills cancer cells in the area of the body being treated, so it can be an effective treatment for diseases which affect a particular part of the body, such as lymphoma.

Reed-Sternberg cell

An abnormal white blood cell that usually confirms a diagnosis of Hodgkin lymphoma.

Spleen

A fist-sized organ that filters the blood. It sits under your ribs on the left-hand side of your body, next to your stomach and behind your ribs. The spleen has three main jobs: to control the level of blood cells in your body, to remove old red blood cells and to help protect your body from infection.

Staging

An assessment of how a cancer is growing or spreading through your body. It's important for deciding on the best treatment.

Stem cells

Cells that develop into other cell types. Stem cells act as a repair system for your body and create a new supply of cells to replace the ones that die. Blood stem cells are found in the bone marrow.



**I remember feeling as if
I was in a weird bubble
with the world going
by on the outside, like a
parallel universe.**

Erica, diagnosed with blood cancer aged 53

Our health information

Find out more about blood cancer, its treatments and living with blood cancer. All our information is produced with expert medical professionals and people affected by blood cancer. It's available to anyone to download or order for free.

Symptoms guide

A credit-card sized guide that folds out to explain the symptoms of blood cancer.

Booklets

Leukaemia

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

Lymphoma

- Hodgkin lymphoma (HL)
- High-grade non-Hodgkin lymphoma (NHL)
- Low-grade non-Hodgkin lymphoma (NHL)

Other blood cancers

- Myeloma
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

Treatment and beyond

- Blood stem cell and bone marrow transplants: the seven steps
- Eating well with neutropenia
- Diary for anyone affected by blood cancer

My information folder

An A5 folder to keep your information in.

Fact sheets

Conditions

- Burkitt lymphoma
- Monoclonal gammopathy of undetermined significance (MGUS)
- Waldenström macroglobulinaemia (WM)

Treatments

- Blood transfusions
- Donating stem cells
- What is CAR-T therapy?
- Watch and wait - What you need to know
- Watch and wait - My blood counts
- Watch and wait - A quick guide for partners, carers, family and friends
- Watch and wait - A quick guide for employers
- Watch and wait - A toolkit for GPs and practice nurses

Side effects

- Managing sickness and vomiting
- Sore mouth or gut (mucositis)
- Understanding infection

Living with blood cancer

- If your employee or colleague has blood cancer
- My activity planner

To order or download information

Visit **[bloodcancer.org.uk/information](https://www.bloodcancer.org.uk/information)**

Call **0808 2080 888** (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

Email **support@bloodcancer.org.uk**

Or use the order form on **page 100**



**We're a
community
dedicated to
beating blood
cancer.**

About us

We're the scientists who dedicate our careers to finding cures.

We're the nurses who find the right words in the darkest moments.

We're the campaigners and volunteers standing up for the people we love.

We're the bucket-collectors, race-runners and cake-bakers who make our research possible.

We're the friends, parents, children and grandparents affected by blood cancer.

Why?

Because we've invested over £500 million in life-saving research.

Because the finish line's in sight.

Because it's time to beat blood cancer.

Because we give people the support they need

People with blood cancer and their family and friends have unique support needs.

We offer free and confidential support by phone or email, provide information about blood cancer and life after a diagnosis, and have an online forum where you can talk to others affected by blood cancer.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Because our research is saving lives

The money raised by our community has meant we've been able to invest £500 million in research, which has changed the outlook for people with blood cancer. Our research has led to better treatments that have dramatically increased survival rates. Right now, we're funding research projects across the UK that are finding out more about blood cancer and the best way to treat it.

Find out more: **bloodcancer.org.uk/research**



Because we campaign for better treatment and care

We work to make sure people affected by blood cancer are at the heart of Government and NHS decision-making.

We're campaigning to end delays to diagnosis, improve access to the latest treatments and help people with blood cancer get the mental health support they need.

Find out more: [bloodcancer.org.uk/campaigns](https://www.bloodcancer.org.uk/campaigns)

Because we'll beat it together

Donate

A quick way to help. Every pound brings us one step closer to beating blood cancer:

bloodcancer.org.uk/donate

Fundraise

Sign up to one of our events, or do something you enjoy with family and friends – there are lots of ways to fundraise: **bloodcancer.org.uk/fundraise**

Join your local community group

Local community groups raise money and awareness in their local area. Volunteer for yours to meet new people and get involved in local activities:

bloodcancer.org.uk/local-community-groups

Volunteer

Give your time, meet new people and experience new things by volunteering with us. There are lots of ways you can help, from your own home or in your local community: **bloodcancer.org.uk/volunteer**

Get your organisation involved

From funding a project, to becoming a corporate partner, find out how your organisation can help us:

bloodcancer.org.uk/corporate-partnerships

Or call us on **0808 169 5155**



**I love being part of the
Blood Cancer UK family.
Being involved has
helped me and my family
cope with my diagnosis.**

Anna, diagnosed with blood cancer aged 39

Order information from Blood Cancer UK

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form on the previous page.

You can order more information by:

- visiting **bloodcancer.org.uk/information**
- emailing **support@bloodcancer.org.uk**
- calling **0808 2080 888**
- or completing and sending this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George St, Edinburgh, EH2 4JN**

Please send me some information

Full Name

Address

Email

Phone

Please tell us the publications you would like us to send you, free of charge (see page 90)

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Keep in touch

We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**



My details

My name and hospital number

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My NHS number

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My condition

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My contacts

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My consultant

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My key worker (usually CNS)

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Haematology ward

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Haematology clinic

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Out of hours

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Other contacts

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Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- Free and confidential support by phone or email
- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

[bloodcancer.org.uk](https://www.bloodcancer.org.uk)

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Your feedback on this booklet can help us improve – please send any comments to **information@bloodcancer.org.uk**



**Blood
cancer
UK**

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