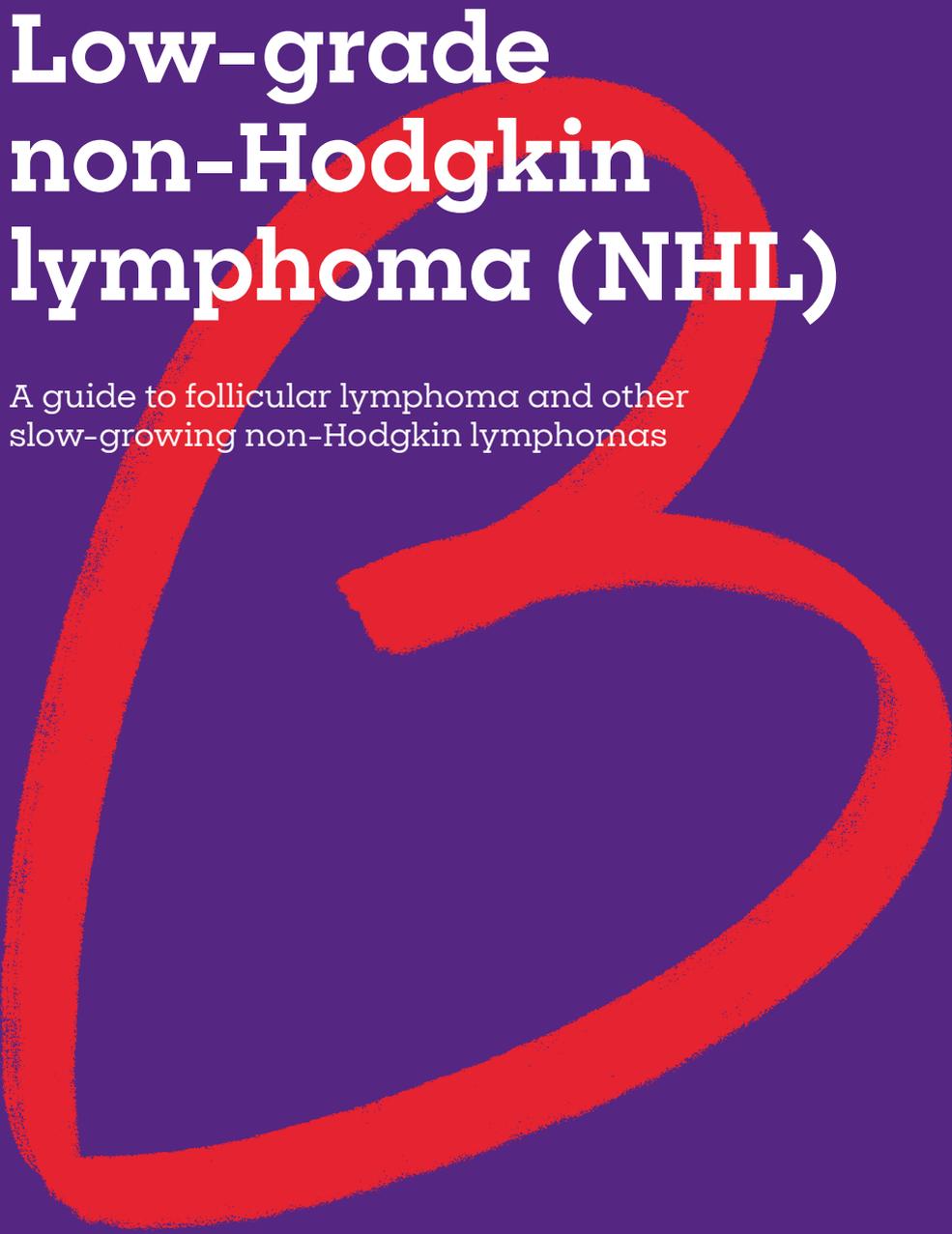


Low-grade non-Hodgkin lymphoma (NHL)



A guide to follicular lymphoma and other
slow-growing non-Hodgkin lymphomas

**Blood
cancer
UK**

About this booklet

We have produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Dr Robert Marcus, Dr John de Vos and Dr Chin Neoh 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 105.

bloodcancer.org.uk

0808 2080 888

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

support@bloodcancer.org.uk

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.

The information in this booklet is correct at the time it was printed (August 2018).

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Introduction

This is a booklet for people with low-grade non-Hodgkin lymphoma (NHL), and for people who know someone with low-grade NHL.

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 more in control. It'll cover the key aspects of diagnosis and care, including symptoms, tests, treatment and living with low-grade NHL, and where you can get support. It mainly talks about a type of low-grade NHL called follicular lymphoma, but lots of the information is relevant to everyone with low-grade NHL. Where we can we'll suggest other sources of information for different types of low-grade NHL.

We have another booklet on a faster-growing kind of NHL called high-grade NHL, which needs different treatment. Check with your healthcare team which information is right for you.

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.



For information on high-grade NHL, order or download our booklet **High-grade non-Hodgkin lymphoma (NHL)**. See **page 102** for details.

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**

Low-grade non-Hodgkin lymphoma (NHL) at a glance

In most cases, we don't know what causes low-grade non-Hodgkin lymphoma (NHL). As it's a slow-growing disease, it can often be controlled for many years, with some people never needing to have treatment.

What is low-grade NHL?

Low-grade non-Hodgkin lymphoma (NHL) is a blood cancer that affects white blood cells called lymphocytes.

There are two main types of NHL, which are grouped depending on how quickly the cancer grows. These are high-grade NHL, which develops quickly, and low-grade NHL, which develops more slowly.

In NHL, abnormal lymphocytes gather in lymph nodes (glands) or organs and cause lumps or swellings. The symptoms you have will depend on how big these lumps are and where they are in your body. So as well as confirming whether the NHL is fast- or slow-growing, your healthcare team will classify it based on your symptoms and where the lymphoma is in your body. This is called the 'stage' of the cancer and it helps your healthcare team plan your treatment.

What causes low-grade NHL?

In most cases we don't know what causes low-grade NHL. It's more common in older people, and it's rare in children.

What are the treatments?

The treatment you have for low-grade NHL mainly depends on the symptoms you have when you are diagnosed, as well as the stage of the disease. Some people with low-grade NHL might not need to have treatment. You may just have regular check-ups and careful monitoring of your condition. This is called 'watch and wait'.

If you do need treatment, you might have anti-cancer drugs (chemotherapy) along with drugs which boost your body's natural ability to fight disease (immunotherapy). More rarely, you might have treatment with radiation (radiotherapy).

If the treatment doesn't help (refractory disease), or if it does at first but then the cancer comes back (relapsed disease), you'll have more treatment. This could involve more chemotherapy, immunotherapy, new drug treatments through a clinical trial, or, sometimes, a stem cell transplant.

What's the outlook?

As low-grade NHL is a slow-growing disease, it can be controlled for many years, with some people never needing to have treatment.

Most people who do need to have treatment will get a good first remission, where there's no sign of lymphoma in the body. There's a chance that the low-grade NHL will come back (relapse), but if this happens other treatments (second-line treatments) are available.

For information and stories about being on watch and wait, go to **[bloodcancer.org.uk/watch-and-wait](https://www.bloodcancer.org.uk/watch-and-wait)**





**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

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

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

Your lymphatic and immune systems

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

Non-Hodgkin lymphoma is a disease which affects your lymphatic system. The lymphatic system is part of your body's natural defence against infection, which is known as the immune system.

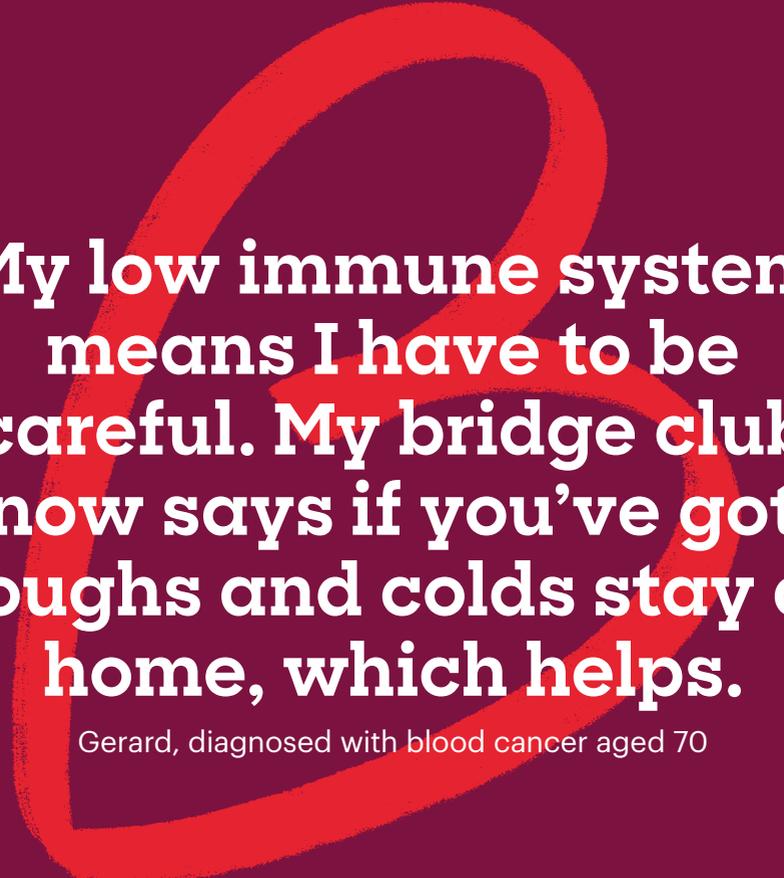
Your immune system

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

There are lots of different kinds of lymphocyte, but it's the ones called B cells and T cells which can be affected when you have lymphoma. When your B or T cells don't work properly, this can increase your risk of infections. Your healthcare team can tell you about ways to lower this risk.



For more information on managing your risk of infection, read our fact sheet **Understanding infection**. See **page 103**.



My low immune system means I have to be careful. My bridge club now says if you've got coughs and colds stay at home, which helps.

Gerard, diagnosed with blood cancer aged 70

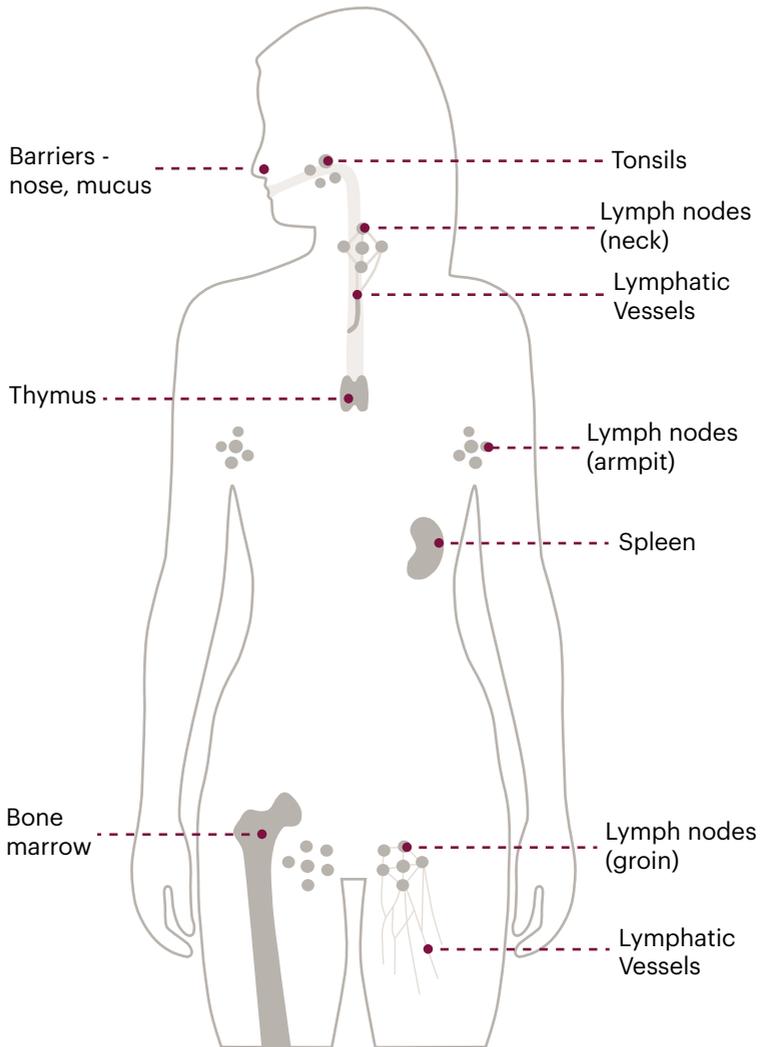
Your lymphatic system

Your lymphatic system is part of your immune system. It's made up of a network of thin tubes called lymph vessels which run throughout your body. These vessels carry a fluid called lymph. Lymph fluid bathes all the cells in your body and contains lots of lymphocytes (a type of white blood cell that fights infection). It also carries nutrients which feed your 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 your neck and groin, particularly if you're slim. If you get an infection when you're healthy, these lymph nodes can swell and become tender. People often talk about having 'swollen glands' – this is normal when you have an infection. As lymphocytes pass through the lymph nodes, they are changed and activated to fight certain types of infection.

Your spleen is also part of your lymphatic system. This is a fist-sized organ that sits on the left-hand side of your body, next to your stomach and behind your ribs. 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.

The lymphatic system



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

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

What is low-grade NHL?

Lymphoma is a cancer of the lymphatic system. Non-Hodgkin lymphoma (NHL) is a type of lymphoma which usually affects white blood cells called B lymphocytes or B cells. There are different types of NHL, which are grouped depending on how fast the lymphoma grows.

Lymphoma

When you have lymphoma some of your lymphocytes don't work properly. Sometimes these lymphocytes aren't fully developed (they're 'immature'), they multiply in an abnormal way, or they 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 they can be deep inside your chest or stomach area (abdomen). Lymphoma can occur anywhere in the body where lymphocytes collect.

The abnormal lymphocytes can affect how your immune system works, which can mean you're more likely to get infections.

Types of NHL

There are lots of different types of non-Hodgkin lymphoma (NHL). To make things clearer, doctors split them into two groups depending on how fast they grow.

- Low-grade NHL: this usually develops slowly and is said to be a more 'chronic' disease. This means that people may not need treatment for many years.
- High-grade NHL: this usually develops quickly and needs treatment straight away.

This booklet mainly talks about one of the most common types of low-grade NHL called follicular lymphoma, which affects B lymphocytes. There are some other types of low-grade NHL which behave and are treated differently from follicular lymphoma.

Other types of low-grade NHL include:

- Marginal zone lymphoma (MZL) – This starts at the edges of areas such as the lymph nodes and spleen where B cells are found (the marginal zones). There are different types of MZL, including MALT lymphoma, nodal MZL and splenic MZL.
- Waldenström macroglobulinaemia (WM) – This is also called lymphoplasmacytic lymphoma (LPL). It's a blood cancer which affects your bone marrow (the spongy tissue inside your long bones where blood cells are made), and more rarely, your lymph nodes (glands).
- Small lymphocytic lymphoma (SLL) – This is very similar to chronic lymphocytic leukaemia (CLL), the most common type of leukaemia in adults. Both SLL and CLL affect your lymphocytes and usually develop very slowly. They are treated in the same way.



For more information on WM, order or download our fact sheet: **Waldenström macroglobulinaemia (WM)**.

If you've been diagnosed with SLL, order or download our booklet: **Chronic lymphocytic leukaemia (CLL)**.

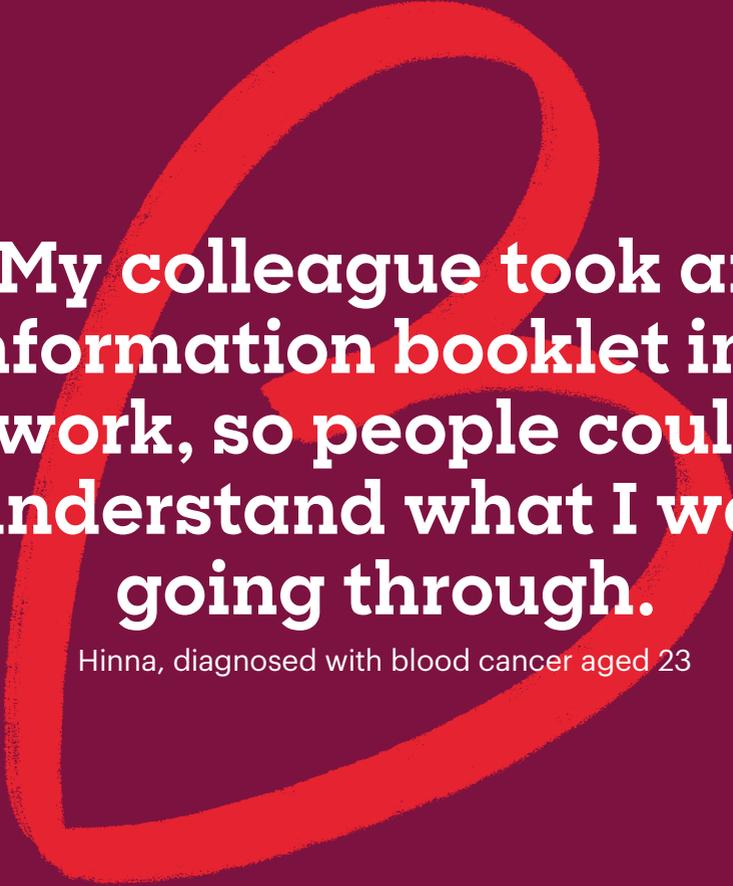
See **pages 102–103** for how to order or download our health information.

- Cutaneous lymphomas – These are types of lymphoma that develop in B cells in the skin.
- Mantle cell lymphoma – This is a type of lymphoma that falls between low-grade and high-grade NHL. Treatment will be different from the standard low-grade NHL treatments.

As each individual case of non-Hodgkin lymphoma is so different, it's best to ask your healthcare team about your type of lymphoma and your treatment, and check that this booklet is the right one for you.



For more information on MZL, cutaneous lymphomas and mantle cell lymphoma, go to the Lymphoma Action website **lymphoma-action.org.uk** and search for the disease name.



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

Hinna, diagnosed with blood cancer aged 23

**You're not alone.
About 4,000 people are
diagnosed with low-grade
NHL every year in the UK.**

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

What causes low-grade NHL?

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

In most cases, we can't say what causes low-grade NHL. But there are some factors that could make you more likely to develop low-grade NHL.

Age

You can get low-grade NHL at any age, but it mainly affects older people. The average age of someone diagnosed with follicular lymphoma is about 65. It's very unusual for people under 40 to get low-grade NHL and it's extremely rare in children.

Sex

Follicular lymphoma is slightly more common in women than men. Men are a bit more likely than women to develop other types of low-grade NHL. We don't know why.

Family history

It isn't really known if there's a definite link between family members getting NHL, although there may be a slightly increased risk if you have a close relative who has it. If you feel this is the case for your family, discuss it with your healthcare team.

Infections

You might have a higher risk of getting NHL if you've had some viral infections, including the HIV virus and human T-cell leukaemia/lymphoma virus (HTLV-1).

The Epstein-Barr virus (EBV), which causes glandular fever, can sometimes lead to NHL. It's a common virus, but only a very small number of people who get it go on to develop NHL.

It's important to remember that although viruses can be passed from person to person, you can't catch lymphoma from someone else. A lot of things have to happen after someone gets a particular virus for it to develop into NHL.

It's standard for healthcare teams to screen you for HIV and EBV when you're diagnosed with low-grade NHL.

Radiation

NHL has been linked to exposure to radiation, but it's very unlikely that anyone in the UK would be exposed to a high enough level of radiation in their normal environment to develop NHL.

Transformation of low-grade NHL

In some people, low-grade NHL can change in nature to become the faster-growing high-grade version. This is called transformation.

Each year, around 3% of cases of follicular lymphoma will transform to high-grade NHL – usually to a type called diffuse large B-cell lymphoma or DLBCL.

How common is NHL?

Over 10,000 people are diagnosed with a type of NHL every year in the UK.

About 40% of these people will get low-grade NHL. Follicular lymphoma is the most commonly diagnosed type of low-grade NHL.

If you get new symptoms after you've been diagnosed, or if you feel unwell, contact your healthcare team as soon as possible.

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

Symptoms

Some people who get low-grade NHL will have some of the symptoms listed below. It's important to remember that not everyone will get all, or even any, of these symptoms. Each person is different, and will have a different experience.

Main symptoms

The main symptom of low-grade NHL is having swollen lymph nodes, which feel like a lump. People often talk about having 'swollen glands'. These won't necessarily be painful.

The most common place for you to notice lumps would be in your neck, armpit or groin. In these areas the lymph nodes lie just under the skin, so you're more likely to notice if they're swollen.

Sometimes, the affected lymph nodes can be deeper in your body. You may not be able to see the swelling, but you might have other symptoms caused by this. The symptoms you get will depend on where the swollen lymph nodes are in your body, and which organs they're pressing against.

These symptoms might include:

- pain in the chest or stomach area (abdomen)
- bone pain
- skin lumps
- coughing or breathlessness.

If you have low-grade NHL, you may also have fatigue – this is when you feel tired most of the time. It's not the same as ordinary tiredness which improves with sleep or rest.

Other symptoms

You might also have some of the following symptoms. Together these are known as B symptoms:

- fever (higher than 38°C)
- drenching night sweats which soak your nightclothes and bedding (although this symptom is more common in high-grade NHL)
- unexplained weight loss in the last six months (10% or more of your previous weight).



Travelling after my
chemotherapy was an
amazing feeling.
It had kept me focused
throughout my treatment.

Wendy, diagnosed with follicular lymphoma aged 46

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

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

Diagnosis

You'll have a number of tests and scans to confirm whether you have low-grade NHL. These will also show how much the lymphoma has grown and developed. Doctors call this 'staging' the lymphoma, or they'll refer to the 'stage' of the condition. Doctors will also check your general health.

Sometimes, you might need to prepare before a test. This might include having nothing to eat or drink except water (fasting). Your doctor will tell you what each test will involve and if you need to prepare in any way.

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 low-grade NHL

Your healthcare team will use a test called a lymph node biopsy to confirm whether you have low-grade NHL.

Lymph node biopsy

A lymph node biopsy is a minor surgical procedure that takes a sample of the swollen lymph node. This sample is then examined under the microscope in a laboratory.

This test may be done under general anaesthetic, so you'll be asleep while the procedure is happening. You'll often have one whole lymph node removed – you might hear this being called an excision biopsy.

Alternatively, just part of a lymph node may be removed. This is called a core biopsy or incisional biopsy, and can be done under a local anaesthetic (which only numbs the affected area). An ultrasound or CT scan will be used to help with the procedure.

This is the test that will confirm your diagnosis of lymphoma. After this test, your lymphoma will be 'staged' to find out how much lymphoma you have



See **pages 38 and 41** for information on CT and ultrasound scans.

in your body. It usually takes about a week to get the result of a biopsy.

Other tests

After your diagnosis, you'll have more tests which will give doctors more information about your health and the lymphoma.

Blood tests

These will give your healthcare team a full picture of your general health before you start any treatment.

Full blood count

A full blood count (FBC) measures the number of each type of cell in the blood: red cells, white cells and platelets.

Although the full blood count is often not affected in low-grade NHL, the test is still important. The FBC will help doctors spot if you already have or if you develop anaemia (a condition caused by a lack of red blood cells which can lead to tiredness and breathlessness). Anaemia may develop because of your illness or your treatment. The FBC will also show if the lymphoma has affected your bone marrow (the spongy tissue inside your long bones where your blood cells are made) and if this happens, your treatment might be changed.

You'll usually have your FBC checked every time you have an appointment at the hospital.

Liver function test

This test checks if your liver is working normally. This is important if you're having chemotherapy because a lot of drugs are broken down in the liver. If your liver isn't working normally, your doctor might need to adjust the doses of your treatment drugs.

You'll usually have a liver function test every time you have an appointment at the hospital.

Urea and electrolytes test

You'll usually have this test to show how well your kidneys are working and, if you're having treatment, to help decide the doses of the drugs you'll need. It can also show if you're lacking fluid (are dehydrated). And it will show if the cancer or any treatment you've had has caused damage to your kidneys.

This is another test you're likely to have every time you have an appointment at the hospital.

Infection screening

It's now normal practice for you to be tested for some viruses which can cause infections.

If you have low-grade NHL, your body's ability to fight infection is weakened, so some viruses may cause you to become unwell very quickly. You'll be tested for hepatitis B, hepatitis C and HIV. Your test

results might help decide which treatments you have. If this is the case, your doctor will discuss this with you.

Cytogenetics

It's getting more common for doctors to look at the genetic information in your cells to give them more information about the type of low-grade NHL you have. Cytogenetic and gene sequencing tests look at the particular genetic abnormalities in lymphoma cells, and may help decide the treatment you have. These are done in the lab, normally using a bone marrow sample (see page 42).

Staging, grading and risk scoring

When you're first diagnosed, your doctor will carry out tests to stage, grade and 'risk score' the lymphoma.

Staging

Your doctors will want to know the stage of your lymphoma. Staging describes the nature of the lymphoma and where the lymphoma is.

Knowing the stage of your lymphoma will help your healthcare team decide whether you should start treatment immediately, and which treatment is right for you.

There's a standard system which all doctors use to stage low-grade NHL. It's mainly based on how many areas of your body are affected by the lymphoma.

Staging is also based on which symptoms you have when you're diagnosed. This is shown by a letter 'A' or 'B' – you can have A or B symptoms in any of the numbered stages.

Stage I or II with no B symptoms are described as early-stage disease. Stage I and II with B symptoms, stage III and stage IV are all classed as advanced-stage disease. This difference is important because sometimes there are different treatment options for early-stage and advanced-stage disease.

Grading follicular lymphoma

Grading is another way of measuring how follicular lymphoma is progressing. While staging describes where the lymphoma is and what the symptoms are, grading looks at cells called centroblasts (a type of B cell). It measures the proportion of centroblast cells compared to other blood cells. This can help doctors work out how fast the lymphoma is growing and decide on the best treatment.

Follicular lymphoma is given a grade from 1 to 3. Grade 3 can be divided into 3A and 3B (but unlike in staging, the A and B aren't related to particular symptoms).

Stage	Features
I (1)	Only one group of lymph nodes is affected, in one place in your body.
II (2)	More than one group of lymph nodes is affected but all of them 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 (abdomen) and hip area (pelvis).
III (3)	Lymph nodes on both sides of the diaphragm are affected.
IV (4)	The lymphoma is present in organs such as the lungs, liver or bone marrow. (This is much rarer than lymphoma affecting the lymph nodes).

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 which soak your nightclothes and bedding – unexplained weight loss in the last six months (10% or more of your previous weight).

Grades 1, 2 and 3A will be treated as follicular lymphoma. Grade 3B follicular lymphoma will be treated as a high-grade (fast-growing) non-Hodgkin lymphoma.

Risk scoring

There are several things about you and your condition that will help your doctor predict how well the treatment will work. This is known as risk scoring.

The things your doctor will consider include:

- your age
- your 'performance status' – how well you manage in daily life at home (for instance, how independent you are)
- the stage of your lymphoma
- the level of a protein called haemoglobin in your blood
- the levels of a substance called lactate dehydrogenase (LDH) in your blood



See **page 102** for how to order or download our booklet
High-grade non-Hodgkin lymphoma (NHL)

- the level of a substance called B2 microglobulin or B2M (sometimes written as β 2M) in your blood
- the size of the largest mass of cancer cells (the largest swollen lymph node or nodes)
- any signs that your bone marrow is affected.

Staging tests

You'll have a series of tests which will help your doctors to find out the stage of the low-grade NHL. You may have heard of some of these tests, but others might be less familiar. You can always talk to your healthcare team if you have any questions.

Scans

Doctors will use scans to help with your diagnosis and staging. These often use a form of radiation, but your healthcare team will always make sure that you're not exposed to more radiation than is absolutely necessary.

It may take a few weeks to get the results of all these tests, which can be a worrying time for many people. It's really important that doctors take the time to get an accurate diagnosis and stage the lymphoma correctly, as this will help decide what treatment you have.

X-rays

X-rays provide good images of the denser tissues in your body, such as bone. They are also done if doctors need to check for infection.

Computerised tomography (CT or CAT) scan

CT scans look at your soft tissues (the non-bony parts of your body).

It's likely that you'll have a full body CT scan, which gives a detailed picture of your internal organs and any swollen lymph nodes.

The scan isn't painful. You'll lie on a table that moves through a doughnut-shaped machine while the pictures are taken. Your body is never completely enclosed and you'll be able to talk to the person who takes and assesses the images (the radiographer) all the time.

You might need to have a dye injected into one of your veins, to help get a better image. If you're feeling anxious about this procedure, you may be given a sedative to make you feel sleepy beforehand.



Fluorodeoxyglucose positron emission tomography (FDG-PET scan, PET scan or PET/CT scan)

Most patients will have a PET scan (or sometimes a combination scan called a PET/CT scan) to help stage the cancer.

For this scan, you'll have an injection that contains radioactive sugar. This small amount of radioactivity is quite safe for you. As with CT scans, you'll lie on a table as you move through a doughnut-shaped scanner. The scan can take up to three hours, including preparation time.

As the lymphoma cells take up more of the radioactive sugar than normal cells, doctors will be able to measure how much lymphoma is in your body. You'll get more information and advice about this scan from your hospital.

You may have this scan again halfway through or at the end of your treatment to see if the treatment has been successful.

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) scan

MRI uses strong magnets and radio waves to produce very detailed images of soft tissues (non-bony parts of your body), which are then analysed on a computer.

During the test, you'll lie on a table which will move you through the scanner. As with a CT scan, you might need to have some fluid injected into a vein using a needle.

It'll take around an hour to carry out the scan. It's not painful but the MRI machine is noisy – you might be given headphones so you can listen to music during the scan.

MRI scans are not routine as part of the staging for NHL. Pregnant women may have an MRI scan instead of a PET scan, as there is no radioactivity involved in MRI.

You'll need to remove any metal you're wearing before an MRI scan, 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).

Ultrasound scan

Ultrasound scans produce a picture of your organs using information from a probe that the sonographer (the person doing the scan) moves over your skin. A lubricating gel helps the probe move more smoothly. This is the same scanning technique as used to monitor a pregnancy.

An ultrasound scan can be used to give more information on your condition. For example, it could be used to measure the size of your spleen, which is often enlarged in people with lymphoma. Ultrasound can also be used as a guide when doctors carry out a lymph node biopsy.

Bone marrow biopsy

You may have a sample of your bone marrow (a biopsy) taken soon after you're diagnosed, to see whether your bone marrow is affected by lymphoma. This gives doctors another opportunity to check your diagnosis and get more information about your condition.

During the procedure a small amount of bone marrow is sucked from the hip bone using a fine needle (an aspirate). Your doctors will then look at your bone marrow sample under a microscope.

You can have this procedure as an outpatient, so you won't need to stay in hospital overnight. It's usually quite quick but will be uncomfortable while the sample is being taken. You'll be given a local anaesthetic to numb the area, and may be given gas and air (Entonox) to help you relax, or a sedative to make you feel sleepy.

At the same time as the bone marrow aspirate, you'll also have what's called a bone marrow trephine. This involves a slightly larger piece of bone marrow being taken from the hip bone using a larger needle. You might experience some discomfort around the area where your bone marrow samples were taken, but you can take some paracetamol to help with the pain if you like. Any discomfort is usually gone within 24–36 hours.

Not everyone will need a bone marrow biopsy at diagnosis.

Further tests

Your doctors will also do several other tests on your blood and/or bone marrow samples. These will help predict how well your treatment is likely to work. These are known as prognostic markers.

Beta-2 microglobulin (B2M) test

You'll have a test that looks at the level of a protein called beta-2 microglobulin (B2M – sometimes written as β 2M) in your body. Some people with NHL will have higher amounts of B2M than normal, and this can tell doctors how advanced the low-grade NHL might be.

Lactate dehydrogenase (LDH) test

When cells break down, they release a chemical called lactate dehydrogenase (LDH). If you have NHL, you can have more LDH in your body because more cells are being produced and broken down. Knowing how much LDH is in your body can tell doctors how advanced the low-grade NHL might be. It's very common for the LDH level to be normal in low-grade NHL, and raised in high-grade NHL.

Your healthcare team

If you're diagnosed with low-grade NHL, 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 in the hospital.

Your specialist doctor (consultant)

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

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 as and when you need it.

Your multidisciplinary team (MDT)

Your condition should be discussed at regular MDT meetings. An MDT brings together doctors, nurses and any 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 CNS or consultant 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 (see pages 85–90). Many provide patient meetings or further online support.

Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see (such as 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.
- 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 CNS questions rather than your consultant. 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.



Read about the experiences of other people with blood cancer on our online community forum:

forum.bloodcancer.org.uk

- 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. It’s entirely up to you.

Telling children and teenagers

Talking to children and teenagers about your cancer diagnosis can be difficult. There are organisations that are able to support you and offer you advice about how to explain cancer 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 one 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 HR department might be able to offer support.



There's more information about cancer and how it can affect your work or study on **page 80**.

We also have information and personal stories about cancer and working on our website: **bloodcancer.org.uk/living-well**

The treatment you decide on with your healthcare team will depend on your health, your individual condition and your wishes.

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

Treatment

The treatment that's best for you will largely depend on your symptoms as well as the stage of the low-grade NHL. Your healthcare team will always discuss your treatment options with you, explain why a certain treatment has been recommended and take your wishes into account when planning your treatment.

You can choose not to have treatment, even if your doctor recommends it, but you can't insist on starting treatment if your doctor doesn't think that it's in your best interest. If you have any concerns about treatment you should discuss these with your consultant or clinical nurse specialist (CNS).

Aims of treatment for low-grade NHL

It's rare that we can say that a person's low-grade NHL has been 'cured'. However, it can be controlled for many years, and survival rates are getting better all the time.

The aim of your treatment will be to get as good a response as possible in terms of shrinking the lumps caused by the lymphoma, with the fewest side effects.

Some people might not need to have treatment straight away – in fact they might not need to have treatment for some years, or at all. This is known as being on 'watch and wait'. Around half of the people diagnosed with low-grade non-Hodgkin lymphoma will be on watch and wait at first.

Risks to your fertility

If you need to have treatment for low-grade NHL, and you're thinking about having children, or considering having them at some point in the future, it would be good to discuss this with your healthcare team before you begin treatment. They will be able to advise you of your options to protect your fertility (your ability to get pregnant or father a child).

If you are a man having treatment, the risk to your fertility can be high. A common option for men is to have sperm frozen and stored.

If you are a woman having treatment, the risk to your fertility is low, but it may get higher as you get older. This is because some treatments can lead to an earlier menopause (when you stop having periods). You may be able to freeze and store eggs, embryos (fertilised eggs), or tissue from your ovaries (where eggs are produced), before treatment starts.

Clinical trials

If you need treatment and there's a clinical trial available that's suitable for you, your consultant may recommend that you consider this.

A clinical trial is a research study involving patients. 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 a new test or treatment which may not be available outside of the trial.

Your safety and wellbeing is always the first priority. in a clinical trial. As with all treatments, you'll be very closely monitored and have detailed follow-up.

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 available treatment which is appropriate for your individual condition.

Treatment plans

The type of treatment you have – or whether you have treatment at all – depends on your symptoms, the type of lymphoma you have, your individual circumstances and the stage of the lymphoma.

When treatment isn't needed - watch and wait

If you don't have any symptoms when you're diagnosed, your consultant might recommend that you don't start treatment immediately – this is called 'watch and wait'. Instead, you'll have regular appointments with your healthcare team and you'll be carefully monitored.

In the first year after your diagnosis, you'll usually have appointments every three months. In the second year after your diagnosis, you'll have appointments every three to four months. After two years, your appointments will be further apart, as long as the disease isn't progressing. You may have more scans to look at glands inside your body



We have information on watch and wait for people with all types of blood cancer, their family, friends and employers. Go to **[bloodcancer.org.uk/watch-and-wait](https://www.bloodcancer.org.uk/watch-and-wait)**

Join our online community forum, visit **forum.bloodcancer.org.uk**

and check for signs of the disease progressing, but only if your healthcare team thinks it's necessary.

It can be hard to find out that you have cancer but won't be treated immediately, and this may make you feel anxious. It's important to understand that being on watch and wait won't change how effective the treatment will be if you do need any treatment in the future. There's no harm or disadvantage in delaying treatment if you feel well.

If you have any questions or worries, do discuss them with your healthcare team. Our online community forum is also a good place to connect with other people on watch and wait.

When treatment is needed

If you have symptoms and your healthcare team recommends treatment, your first treatment is likely to involve chemo-immunotherapy. Chemo-immunotherapy combines chemotherapy (anti-cancer drugs) with drugs that help the body's immune system to find and attack cancer cells.

If you have chemo-immunotherapy you'll take a combination of chemotherapy drugs injected into a vein (intravenously). The most common drug combination is CVP (cyclophosphamide, vincristine and the steroid prednisolone), or you may have a drug called bendamustine. Other drug treatments may also be used.

With both CVP and bendamustine, treatment with a monoclonal antibody will also be recommended. Monoclonal antibodies stick to a specific protein on the surface of lymphoma cells. This marks out the lymphoma cells and helps your immune system to find and kill them.

The most commonly used antibody is called rituximab. Alternatively, you may have an antibody called obinutuzumab.

For some people who are less fit, chemotherapy might not be appropriate, but rituximab can still be given and can be effective on its own.

Rituximab is usually given through a drip into a vein (an infusion), but it may sometimes be given as an injection under the skin (subcutaneously). Obinutuzumab is given into a vein.

Maintenance therapy

After you've finished your first round of treatment, you'll usually be offered maintenance therapy, which aims to stop the low-grade NHL coming back for as long as possible. For your maintenance therapy you'll receive treatment with rituximab. You'll have this treatment as a hospital outpatient (so you won't need to stay overnight), every two months over a period of two years. This should give you a longer period when there is no sign of lymphoma in your body (known as remission).

Radiotherapy for early-stage disease

A small number of people (around 10-15%) will have early-stage disease when they are diagnosed. This means NHL at stage IA or IIA. In other words, the lymphoma is in one general area and you may have no symptoms aside from a lump. It's also called localised lymphoma, which means that the glands affected by the cancer are close together.

If you have early-stage disease, your healthcare team will normally recommend having radiation treatment that's given directly to the area where the lump is (localised radiotherapy). You'll usually have this every day, with a rest at weekends, for a total of around 12-17 days. Generally, you'll have it as a hospital outpatient, so you won't have to stay overnight.

After radiotherapy, if your healthcare team is confident that all the lymphoma cells have been killed, you might not need any more treatment. You'll be monitored carefully.

If the radiotherapy hasn't killed all the lymphoma cells, your healthcare team will discuss an alternative treatment plan with you.



See **pages 33–37** for more information on staging NHL.

Remission

Your healthcare team will monitor how well your first treatment has worked and will describe the result in one of four ways:

- Complete remission means all the lymphoma has gone and no lymphoma can be detected on scans. Sometimes the term ‘complete metabolic remission’ is used. This means that a PET/CT or other scan is entirely normal (or negative).
- Partial remission is a clear reduction in the amount of lymphoma (with more than 50% of the lymphoma being killed) but lymphoma is still detected on scans.
- Stable disease describes a reduction in the amount of lymphoma (with less than 50% of the lymphoma being killed) but some lymphoma can still be detected on scans.
- Progressive disease means that the lymphoma has grown.

This way of measuring remission can help your doctors decide if you need any more treatment. Most people will go into complete or partial remission after their first treatment.

Relapse

Unfortunately, even if you initially go into complete remission, the low-grade NHL will often come back. This is called a relapse.

If you've relapsed, your treatment will depend on how long it's been since you were diagnosed. The longer you have been in remission before you relapse, the better your outlook is likely to be. Your consultant will usually want to take another biopsy and repeat the staging tests, because there is a risk of transformation to a high-grade NHL.

Intermediate relapse

If the disease comes back less than five years after your first diagnosis, you'll have several treatment options, usually including further chemotherapy. Your healthcare team may also want to discuss the option of following this with a stem cell transplant.

Late relapse

If the disease comes back more than five years after your first diagnosis, your treatment may be very similar to the treatment you've already had.

Refractory disease

Sometimes, the lymphoma will not respond to your first treatment and you won't go into remission. This is called refractory disease. If this is the case for you, your healthcare team will discuss further treatment options with you.

Treatment of relapsed and refractory low-grade NHL

Trial drugs

If you take part in a clinical trial for low-grade NHL, doctors will typically be testing a new medicine in combination with existing drugs to treat the disease.

There are a number of studies looking at the effectiveness of these trial drugs. If your healthcare team think that these drugs are appropriate for you, they will discuss the possibility of joining a trial.

Stem cell transplants

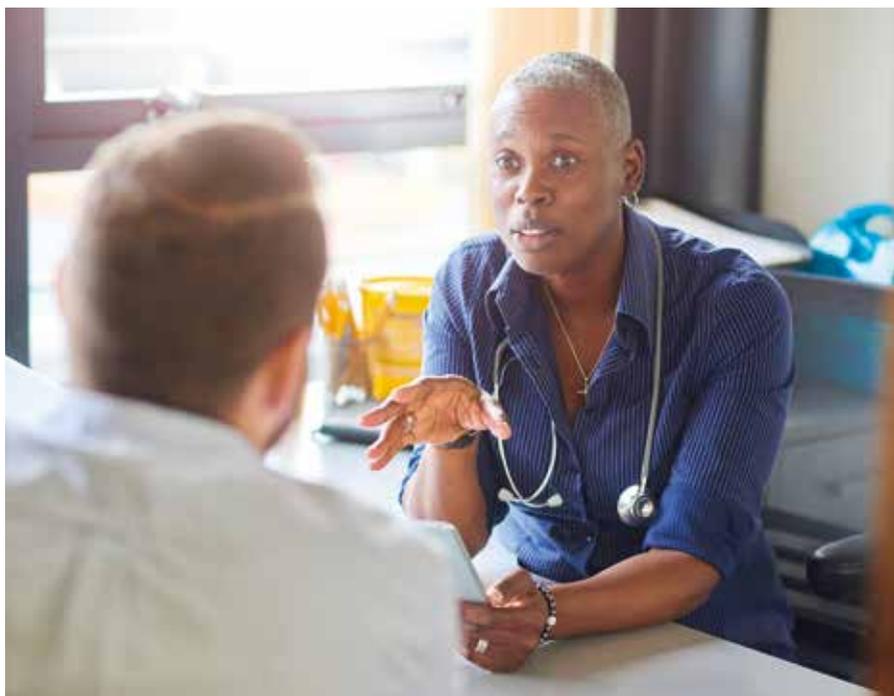
In some cases, a stem cell transplant might be an option for people with relapsed or refractory low-grade NHL. This may be an autologous stem cell transplant, which uses your own stem cells, or an allogeneic stem cell transplant, which uses cells donated by someone else.

A stem cell transplant isn't a routine option for people with low-grade NHL.



For more information on clinical trials, see **page 53**.

See **page 102** for how to download or order our booklet **Blood stem cell and bone marrow transplants: the seven steps**.



They're usually only recommended for people who have had an early relapse, and are medically fit enough to have this type of intensive treatment. This is because stem cell transplants have more side effects than other treatment options.

If either type of stem cell transplant is an option for you, your healthcare team will discuss the potential benefits and risks with you before you make a decision.

Side effects from treatment for low-grade NHL

Most people who have low-grade NHL won't have major side effects from the drugs they are given. Often people can cope with the treatment quite well.

If you do have some side effects from your treatment, they're usually temporary and often go away when you've finished your treatment.

Possible side effects of treatment for low-grade NHL include:

- feeling achy
- frequent watery poos (diarrhoea)
- difficulty pooing (constipation)
- skin rash
- hair loss (alopecia)
- extreme tiredness (fatigue)
- infections
- fever
- bruising
- risk of bleeding
- shortness of breath
- mouth sores
- feeling sick (nausea)
- upset stomach and vomiting
- loss of appetite
- weight changes
- reduced ability to have a child (infertility).

If you have any side effects from your treatment, let your healthcare team know. They will also advise you about the effects of treatment on your ability to get pregnant or father a child.

Supportive care

You might need supportive care alongside your other treatment. Supportive care involves dealing with complications of your illness or your treatment. This could include:

- medicines to stop you feeling sick (anti-emetics)
- medicines to prevent or treat infections
- avoiding or treating constipation
- preventing gout, which causes painful swelling in the smaller joints of your hands and feet
- advice on mouth care
- pain management
- diet planning
- blood transfusions (rarely).



See **page 52** for more information about risks to your ability to have a child.

We have general information about side effects and how to manage them at **bloodcancer.org.uk/side-effects**

Transformation of low-grade NHL to high-grade NHL

Sometimes low-grade NHL can develop into a faster-growing lymphoma called high-grade NHL.

This is called transformation, and happens in around 3% of people with follicular lymphoma each year. Transformed follicular lymphoma is treated as high-grade NHL. Doctors can check for transformation through a lymph node biopsy.

Follow-up

Your follow-up arrangements will depend on what type of treatment you have and how well the lymphoma responds to treatment.

Your healthcare team will explain how often you should come for follow-up checks.

It's very important that you don't miss these appointments. A normal pattern for people with low-grade NHL is to have periods of remission followed by relapses, so your doctor will need to monitor you in case this happens.



See **page 102** for how to order or download our booklet **High-grade non-Hodgkin lymphoma (NHL)**.

It's also important to report any new signs or symptoms, such as swollen glands, to your healthcare team, so that they can investigate.

If the lymphoma responds well to treatment, it might be many months, or even years, before you need any more treatment.

Some people don't feel as happy about finishing treatment as they expected. It can be a bit scary when you stop seeing your healthcare team as often, and this may be the time when you are most in need of emotional support. Talk to your healthcare team about how you feel, as they can reassure you. They may also refer you for counselling if you feel this would help.

**Every person is different,
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

Your outlook will depend on what stage of low-grade NHL you have, your risk score, the treatment you've had, and how the disease has responded to the treatment. Your consultant is the best person to ask about your outlook, as they know you and the treatment you've had.

Low-grade NHL is rarely 'cured', but it can be treated so that you can live normally and enjoy a good quality of life.

For most people, the disease is slow to develop. Average survival rates have increased significantly in recent years. And some people who have no symptoms may not need any treatment at all in their lifetime.

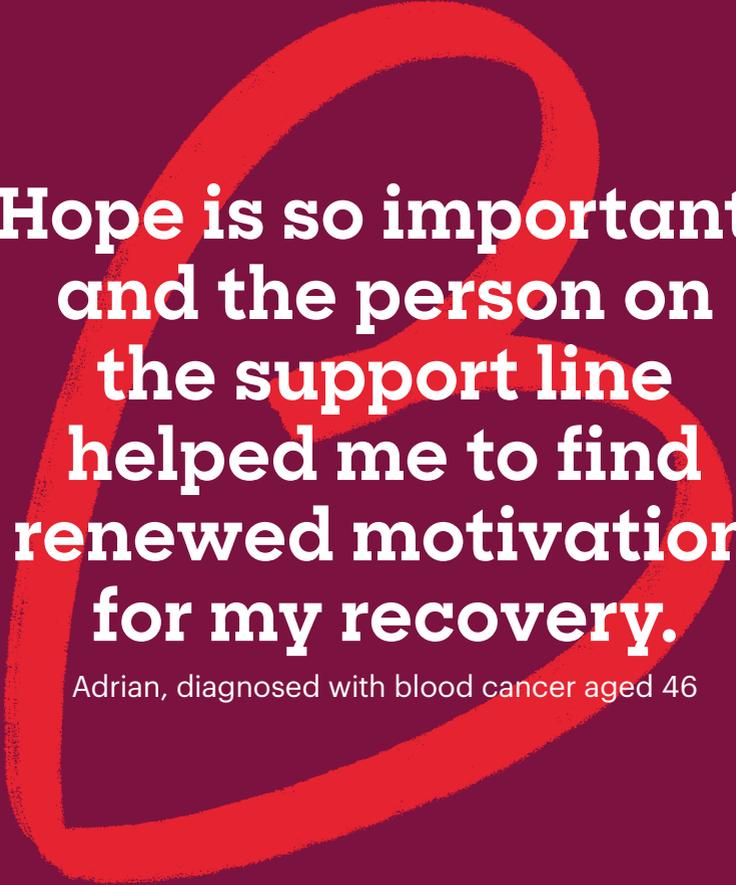
Most people who do need treatment will go into remission and might be in remission for a long time. However, it's likely that the lymphoma will return at some point and then further treatment will be necessary.

If you want to find out more

If you would like more detailed information on the general outlook for non-Hodgkin lymphoma, go to cancerresearchuk.org and search 'survival non-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 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
should 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 low-grade NHL

If you've been diagnosed with low-grade NHL 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 hard for them to understand the long-term emotional impact that you might experience.

Your healthcare team should discuss your emotional, spiritual, social, practical and physical needs and talk about how they can be met. This is called a holistic needs assessment. You should 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 completed your treatment you may wonder whether there are any specific signs or symptoms you should look out for. It's likely that your ability to fight off infection (your immune system) will be weakened at certain times, which means that a minor infection could become more serious if it's not treated.

It's always a good idea to contact your healthcare team if you have any symptoms after your treatment or any changes in your general health. There are lots of possible symptoms you could have – everyone's experience will be different depending on which part of their body has been affected.



There's more information on managing your risk of infection in our fact sheet **Understanding infection**. See **page 103** for how to order or download a copy.

If you find any new swellings, make sure you contact your healthcare team.

Symptoms of infection might not be very clear to you. Your illness might make symptoms less obvious, especially if you're taking paracetamol-based medicines. If you're in any doubt you should seek medical advice straight away.

Signs of infection include:

- a raised temperature (usually above 38°C)
- coughing or a sore throat
- confusion or agitated behaviour, especially if this comes on suddenly (this is more common in older people)
- rapidly feeling more poorly
- fast heartbeat and breathing
- difficulty weeing (passing urine) or producing little or no urine
- pain which comes on quickly and gets worse
- shivering or shaking and feeling cold.

Even if you're not sure if your symptoms are significant, it's good to talk to your healthcare team. They're experts in their field and will be able to decide if any of the symptoms you're having need investigation.

Keeping active

You might feel tired a lot (fatigued). This could be caused by the low-grade NHL 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 there's no evidence that any specific exercise programme can improve your condition or how you respond to treatment, we do know that staying active is good for your general physical wellbeing and your mood.

Diet and infection risk

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

Some people think that a sugar-free diet will help during your treatment for NHL, but there's no evidence that cutting sugar from your diet has any effect on lymphoma and this is not generally recommended.

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 keep cooked and raw meat separate in the fridge. You may also be advised to be extra careful about having takeaways and eating out while you're having treatment.

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.



We have more information, tips and videos about keeping active, eating well and coping with emotions on our website at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

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 NHL.

Shingles has some quite obvious symptoms. If you think you have it, let your GP or healthcare team 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 (with blisters filled with fluid which burst and form sores that 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.

Vaccination

It's a good idea for all people with low-grade NHL to have the flu vaccine each year. Your GP may contact you about this, but if they don't then you can request the vaccine yourself. It's also a good idea to be vaccinated against pneumonia and meningitis as your ability to fight off these infections may be affected either by having NHL or being treated for it. Your consultant can advise you on which vaccinations you should have, if relevant. It's currently recommended that people with NHL do not have the shingles vaccination.

Blood transfusion

If you've been treated with certain types of drugs, it might affect your blood count, and this can lead to anaemia, a condition which can make you feel tired and breathless. If this is the case, you might need a blood transfusion.

Some people may have special requirements such as needing blood that has been treated with radiation before they receive it. Your healthcare team will be able to explain more about this if it applies to you.



For more information, download or order our fact sheet **Blood transfusions**. See **page 103** for details.

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 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 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're working or studying you might want to contact your employer or college about your condition, or ask someone to do it for you.

You may 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. If you are well enough to work but need to lower your risk of infection, you might want to discuss whether it's possible to work from home.

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.



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

Another thing you might want to consider is taking time out from work during 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 at college or university, you might want to think about whether you need to delay your study 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 a disability are protected by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland.

For the purposes of these acts, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with cancer and can't discriminate against them. An example of a reasonable adjustment would be allowing you time off to go to hospital for treatment.

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, 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 find out more about this support, you can speak to your team at the hospital or a benefits advisor.

Financial support

There are lots of places you can get help and advice if you are worried about money.

Your hospital will normally have social workers or welfare rights (benefits) advisors who can advise on which benefits you may be able to receive. These might be especially useful if you're on a low income or you're unemployed.

If you're worried, ask to speak to an advisor as soon as possible after your diagnosis. Alternatively, your hospital might be able to arrange for an advisor from somewhere else to visit you.

If you normally pay for your prescriptions but you're being treated for cancer (including the effects of cancer or its 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 tips on dealing with the financial impact of 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 lymphoma and their families, carers and friends.

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

Maggie's

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

- 0300 123 1801
- enquiries@maggies.org
- www.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 which provides vital medical information to emergency professionals.

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

Tenovus (Wales)

Provides an information service on all aspects of cancer, and practical and emotional support for people with cancer and their families 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 20 20 (Wales)
- in Scotland or 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 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 the tests, for example not eating beforehand?

How long will it take to get the results?

Who will explain the results?

What is my exact diagnosis and what stage is the low-grade NHL?

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 feel unwell?

Who can I contact if I have any questions?

Treatment - types 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)?

Will my treatment be continuous or in blocks of treatment with breaks in between?

How long will my treatment last?

What side effects could I get from my treatment?

Can the side effects be treated or prevented?

Will they 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 protect my fertility?

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

Will I be able to carry on working or studying?

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

Will I be able to plan taking drugs around my meal times, or will I need to change when I eat?

Stem cell transplant

Is a transplant an option for me?

If I'm 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

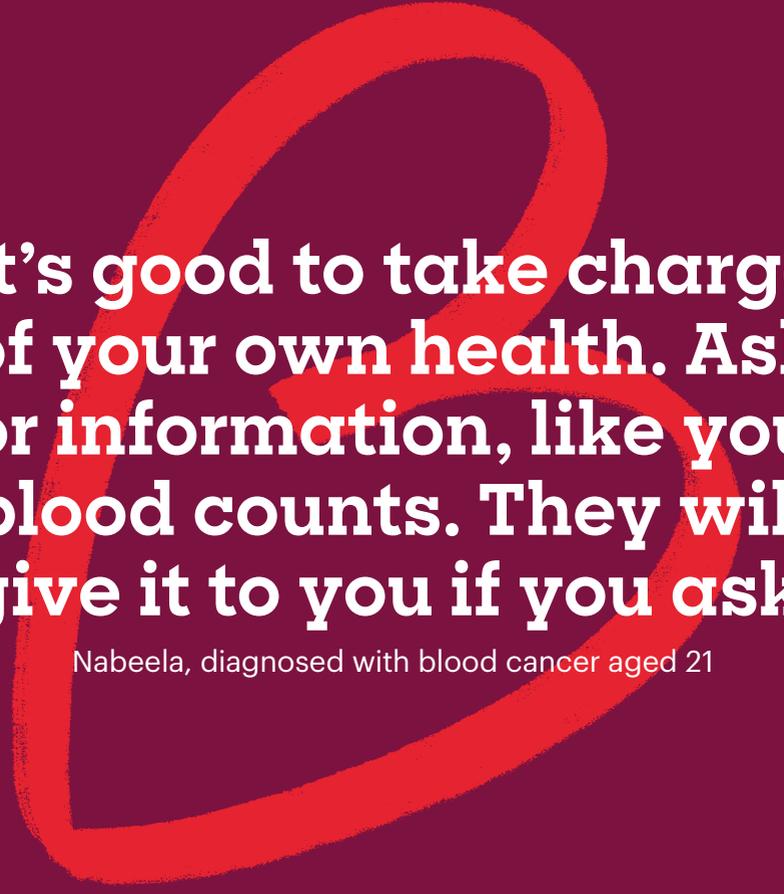
How will doctors know if the cancer has relapsed?

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?



**It's good to take charge
of your own health. Ask
for information, like your
blood counts. They will
give it to you if you ask.**

Nabeela, diagnosed with blood cancer aged 21

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 or B cell

A type of white blood cell normally involved in producing antibodies which 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 cancer cells or stop them growing and dividing. Although it's aimed at the cancer cells, chemotherapy also affects normal cells. This can cause side effects.

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, lymphoma, myeloma 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 patients 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

A feeling of extreme tiredness which doesn't go away after rest or sleep. It may be caused by the NHL itself or it 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.

Immunotherapy

Treatment using drugs which support the body's immune system to find and attack cancer cells. It can be combined with chemotherapy.

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.

Lymph node or lymph gland

Bean-shaped organs that act as a filter to catch viruses, bacteria and other potentially harmful particles that enter your body. They contain white blood cells, which fight infection.

Lymph vessels

A network of small tubes which run throughout your body. They carry a fluid called lymph.

Neutropenia/neutropenic

An abnormally low number of neutrophils (a type of white blood cell that helps fight off infections) in your blood.

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.

Spleen

A fist-sized organ that filters the blood. It sits 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.

Transformation

The process where low-grade lymphoma changes in nature to become a faster-growing high-grade lymphoma.

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 112**



**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

Notes

A series of horizontal dotted lines for writing notes.



Go to **bloodcancer.org.uk/donate**, call us on **0808 169 5155** or complete and send this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George Street, Edinburgh, EH2 4JN**

Full Name

Address

Email Phone



As a supporter, you're at the heart of everything we do. 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**

I'd like to donate £10 £25 £50 Other

I enclose a cheque/CAF voucher made payable to Blood Cancer UK

OR please debit my Visa Maestro Mastercard CAF card

Cardholder's name

Card number (Maestro only)

Start date Expiry date Issue number

Make your donation worth an extra 25p for every £1 at no extra cost to you!

giftaid it

I'd like Blood Cancer UK to claim Gift Aid on this donation and any donations I make in the future or have made in the past 4 years.

*By ticking this box I confirm that I'm a UK taxpayer and I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it's my responsibility to pay any difference.

*Today's date

If you stop paying tax, change your name or address, or if you have any further questions about Gift Aid, please contact our Supporter Relations Team on **0808 169 5155**.

*Information required for Gift Aid declaration to be valid.

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 over the 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 102)

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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

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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