

# High-grade non-Hodgkin lymphoma (NHL)



A guide to DLBCL and other fast-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 Consultant Haematologists Dr Kirit Ardeschna and Professor Tim Illidge, and Clinical Nurse Specialist Claire Barton, 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 109.

**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 (June 2018).

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# Introduction

This is a booklet for people with high-grade non-Hodgkin lymphoma (NHL), and for people who know someone with high-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, living with high-grade NHL, and where you can get support.

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See **page 16** for a list of different types of high-grade NHL and other sources of information.



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



It mainly talks about diffuse large B-cell lymphoma (DLBCL), the most common type of high-grade NHL, but lots of the information is relevant to everyone with high-grade NHL. Where we can we'll suggest other sources of information for different types of high-grade NHL. 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.

# High-grade non-Hodgkin lymphoma (NHL) at a glance

In most cases, we don't know what causes high-grade non-Hodgkin lymphoma (NHL). High-grade NHL is usually treatable and the treatment is often highly effective. Many people have a good long-term outlook, although for some people the disease is resistant to treatment, or comes back after responding well at first.

## **What is high-grade NHL?**

High-grade NHL is a cancer that affects white blood cells called lymphocytes.

There are many different types of NHL, which are grouped depending on how quickly the cancer grows. The two groups are: high-grade (or aggressive) lymphomas, which can progress quickly, and low-grade (or indolent) lymphomas, which usually progress more slowly.

In NHL, abnormal lymphocytes gather in 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 lymphoma is fast- or slow-growing, your healthcare team will classify it based on how advanced the lymphoma is and how many places it's found in the body. This is called the 'stage' of the cancer and it's important for making decisions about your treatment.

## **What causes high-grade NHL?**

In most cases we don't know what causes high-grade NHL. Factors like age and sex can affect how likely you are to get it.

Diffuse large B-cell lymphoma (DLBCL) is more common in older people and rarely seen in children. Other types of high-grade NHL such as Burkitt lymphoma are a little more common in children. There are some factors which can slightly increase your chance of getting high-grade NHL, for instance some viral infections or having a weakened immune system.

If you've got a slower-growing (low-grade) NHL, it could change into high-grade NHL. This is called transformation.

## What are the treatments for high-grade NHL?

Treatment for high-grade NHL usually involves chemotherapy and sometimes radiotherapy too. The amount of chemotherapy you have will depend on the stage of the cancer. If your treatment doesn't work, or if it works at first but then the cancer comes back (relapses), you may need different treatment, which could involve more chemotherapy or a stem cell transplant.

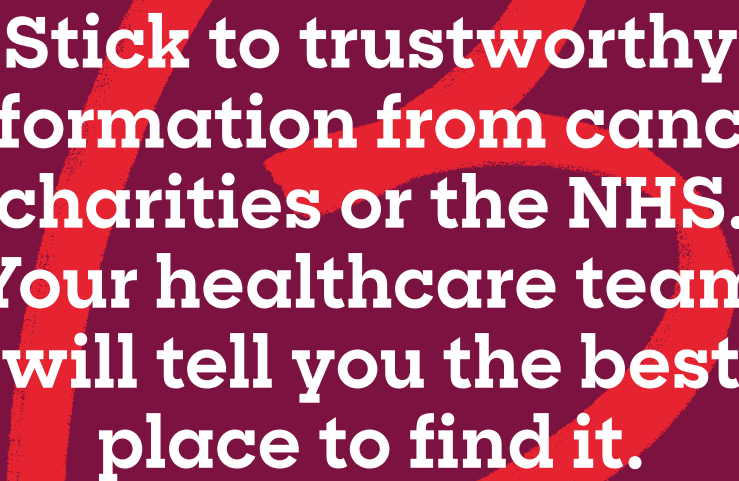
## What's the outlook?

Your outlook (prognosis) depends on a number of things, including the type of lymphoma you have, the stage of the disease, and how well it responds to treatment. Usually, treatment for DLBCL is aiming for a cure, and most people go into remission (which means there's no sign of lymphoma left) after the first round of treatment.



For more information on low-grade (slow-growing) NHL, you can order or download our booklet **Low-grade non-Hodgkin lymphoma (NHL)**. See **page 106** for details.





**Stick to trustworthy  
information from cancer  
charities or the NHS.  
Your healthcare team  
will tell you the best  
place to find it.**

Wendy, diagnosed with blood cancer aged 46

**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](mailto:support@bloodcancer.org.uk)**

# Your lymphatic and immune systems

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.

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 your risk of getting infections.

## Your lymphatic system

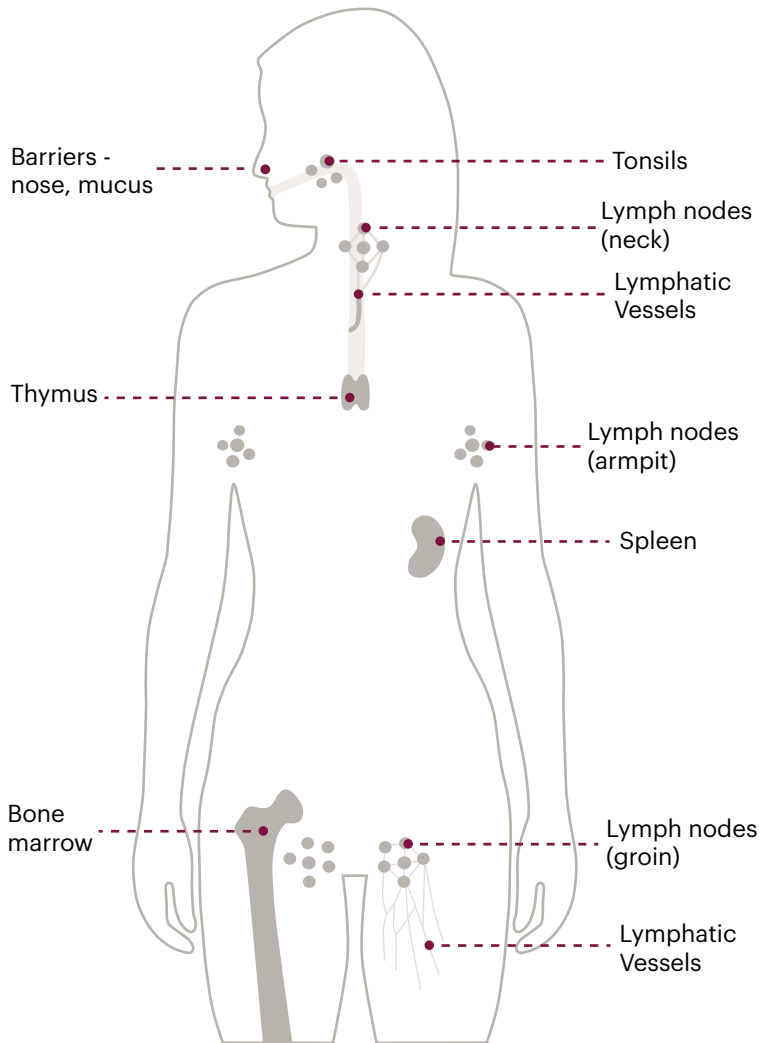
Your lymphatic system is part of your immune system. Within your lymphatic system there's a network of thin tubes called lymph vessels which run throughout your body. These vessels collect fluid called lymph from the body's tissues and return it to your blood. Lymph fluid bathes all the cells in your body. It 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.



Our fact sheet **Understanding infection** has more information about blood cancer and infection. See **page 106** for how to order.

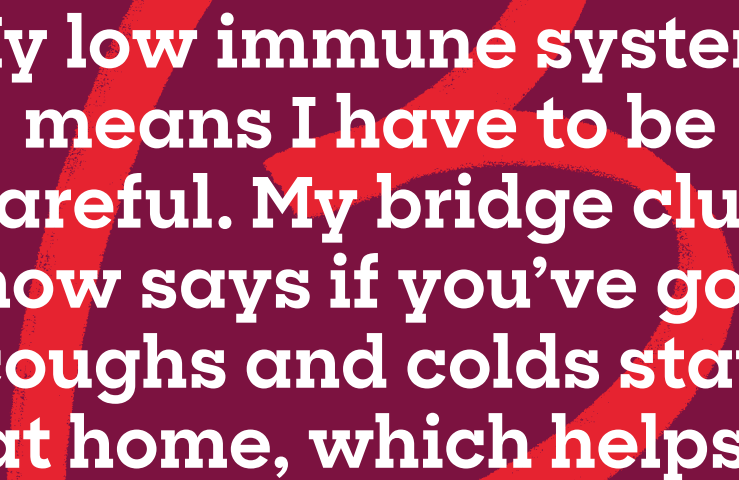
## The lymphatic system



If you get an infection when you're healthy, your lymph nodes can swell and become tender. People often talk about having 'swollen glands'.

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. 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.



**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

**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.uk](mailto:support@bloodcancer.org.uk)**



# What is high-grade NHL?

Lymphoma is a cancer of the lymphatic system. Non-Hodgkin lymphoma (NHL) is a type of lymphoma that 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.

## **What is lymphoma?**

Lymphomas develop when your lymphocytes divide in an abnormal way, or don't die when they should. In about 85% of NHL cases, and almost all high-grade NHL cases, it's B lymphocytes that are affected.

The 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). Lymphoma can occur anywhere in the body where lymphocytes collect.

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

## **Types of non-Hodgkin lymphoma**

There are lots of different types of NHL. To make things clearer, doctors put non-Hodgkin lymphomas 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.

The most common type of high-grade NHL is diffuse large B-cell lymphoma (DLBCL). This booklet mainly talks about DLBCL, although much of the information in this booklet will be relevant to everyone with high-grade NHL.

Some types of high-grade NHL behave differently from DLBCL, and so are treated very differently, such as types of NHL which affect T cells rather than B cells. See overleaf for a list of types of high-grade NHL.

## WHO classification of high-grade NHL

The type of lymphoma you have makes a big difference to how you'll be treated. While there can be overlap between different types of NHL, they're generally classified using the World Health Organisation (WHO) classification of diseases.



For more information on low-grade (slow-growing) NHL, you can order or download our booklet **Low-grade non-Hodgkin lymphoma (NHL)**. See **page 106**.

## Types of high-grade NHL affecting B cells include:

- diffuse large B-cell lymphoma (DLBCL)
- Burkitt lymphoma
- lymphoblastic lymphoma
- mediastinal large B-cell lymphoma.

## Types of high-grade NHL affecting T cells include:

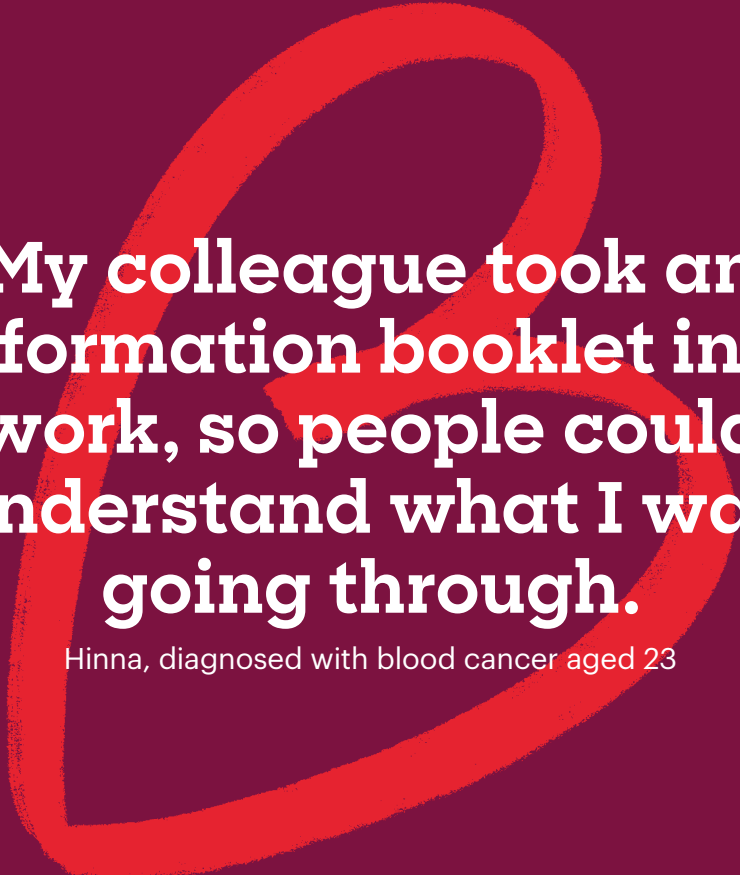
- peripheral T-cell lymphoma
- enteropathy-associated T-cell lymphoma
- anaplastic large cell lymphoma.

As each individual case of NHL is so different, your consultant is the best person to ask about your type of lymphoma and your treatment.



For more information on Burkitt lymphoma in adults, order or download our fact sheet **Burkitt lymphoma**. See **page 106**.

For more information on T-cell lymphomas, visit the Lymphoma Action website, **[lymphoma-action.org.uk](http://lymphoma-action.org.uk)**, and search for 'T-cell lymphomas'.



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

Hinna, diagnosed with blood cancer aged 23

**In most cases, we  
can't say what causes  
high-grade NHL.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# What causes high-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 high-grade factors that could make you more likely to develop high-grade NHL.

## Age

You can get high-grade NHL at any age, but it's more common in people aged over 65. Children rarely get DLBCL, but some other types of high-grade NHL can be slightly more common in children.

## Sex

Men are slightly more likely than women to develop high-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, then do 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.



## 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 a low-grade NHL called follicular lymphoma will transform to high-grade NHL (usually DLBCL).

## How common is NHL?

Over 13,000 people are diagnosed with NHL every year in the UK and DLBCL makes up about one third of all cases.



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Treatment for transformed NHL is explained on **page 61**.

**It's important to remember that not everyone will get all, or even any, of the symptoms listed - each person is different.**

If you're worried, get in touch on **0808 208 0888** or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Symptoms

If you're diagnosed with NHL there are some symptoms you might have noticed before your diagnosis. 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 high-grade NHL is having swollen lymph nodes. People often talk about having 'swollen glands'. Your glands will get bigger quite quickly but won't usually be painful.

The most common place for you to notice these 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, 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.

## **B 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
- unexplained weight loss in the last six months (10% or more of your previous weight).

If you have these symptoms, it might affect what type of treatment you have.

## **Other symptoms**

Although these are not classed as B symptoms (so they won't be used to guide treatment decisions) there are some other symptoms you may experience with NHL. These include a feeling of extreme tiredness that doesn't go away after rest or sleep (fatigue), and itching, which can be either widespread or in one place.

**It's important to know  
and understand  
your diagnosis.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Diagnosis

You'll have a number of tests and scans to confirm whether you have high-grade NHL. Further tests will show how much the lymphoma has grown and developed. Doctors will call this the 'stage' or 'staging' of the lymphoma. Your general health will be monitored and there'll be tests to see how you respond to treatment.

You might need to have some tests, such as blood tests, quite often. Some other tests will only happen when you're diagnosed or if your treatment changes. You might need to have more tests if you develop new symptoms.

Sometimes, you might need to prepare before a test. This could 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.

## **Getting your diagnosis**

Sometimes it takes time to confirm a diagnosis as people may have symptoms that don't clearly point towards high-grade NHL. You might go to the GP about a lump, and your doctor might ask you to wait to see if it goes down. If it doesn't, you'll be referred to a hospital for a biopsy, where a small sample of tissue is taken from the lump.

It might take several weeks for the full results to come back and for you to be given a final diagnosis. This is because it can take a while to get a biopsy, then analyse and interpret the results. Your healthcare team will want to check that you actually have lymphoma, and that you get the right treatment.

## **Diagnostic tests**

You may feel anxious if you're waiting for a diagnosis. If you've got any questions or worries, your healthcare team will be able to talk to you about them.



You'll have several tests that will help your doctor tell if you have high-grade NHL. It's getting more common for doctors to look at the genetic information in your cells to find out more about the type of high-grade NHL you have. That information comes from samples from your bone marrow and lymph node biopsies.

### 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.



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For more information on bone marrow biopsies, see **page 36**.

See **pages 37–41** for information on scans.

A lymph node biopsy 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 in your body.

## **Staging**

Your specialist will carry out tests to stage the high-grade NHL. Staging describes how many places (sites) in your body are affected by lymphoma.

It's very important to understand the stage of the NHL as this is likely to influence the treatment that you will have.

There's a standard system which all doctors use to stage high-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 number stages.

The staging groups and their features are shown opposite:

<b>Stage</b>	<b>Features</b>
I (1)	Only one group of lymph nodes is affected, in one place in your body.
II (2)	More than one group of 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 and hip areas (abdomen and pelvis).
III (3)	Lymph nodes on both sides of the diaphragm are affected.
IV (4)	Lymphoma is found in organs such as the lungs, liver or bone marrow.

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

You might also hear doctors referring to the letters 'E' and 'X' in your staging – these can give more detail on how your disease is progressing.

E stands for 'extranodal', which means that a part of the body is affected outside of the lymph nodes. Primary extranodal NHL is when the lymphoma started in an organ outside of the lymph nodes.

X stands for 'bulky disease', and is used to describe the NHL if one of your affected lymph nodes is more than 10cm across, or there's a lump in your chest that takes up more than a third of its width.

## Early stage and advanced stage NHL

Early stage disease usually means your NHL is either at stage I(A) or stage II(A), with no bulky disease. Early stage disease, especially stage I(A), may be treated differently from advanced stage disease.

Advanced stage disease means stage III or IV, stage I(B) or II(B), or stages I and II with bulky disease. Many cases of high-grade NHL tend to be diagnosed in an advanced stage. But it's important to remember that it's often a very treatable disease, even at this stage.



For more information on clinical trials see **page 49**.

## Performance status

Your performance status is a way for doctors to describe how well you are when you're diagnosed with high-grade NHL.

The most commonly used scale is called the ECOG (Eastern Cooperative Oncology Group) Scale:

- Grade 0: you're fully active, and able to carry on more or less as you were before your illness.
- Grade 1: you're unable to do heavy physical work, but can do anything else you were able to do before your illness.
- Grade 2: you're up and about for more than half the day. You can look after yourself, but you're not well enough to work.
- Grade 3: you're in bed or sitting in a chair for more than half the day. You need help to look after yourself – for example to wash and dress.
- Grade 4: you're not able to get out of bed or a chair, and you need lots of help to look after yourself.

Your doctor will use your performance status to help recommend the best treatment for you. It might, for example, help them decide if you're well enough to take part in a clinical trial.

## Bone marrow biopsy

Most people will have a bone marrow biopsy (sample) taken soon after diagnosis, to see whether the bone marrow is affected by the lymphoma. This may give doctors another opportunity to confirm your diagnosis and provide more information about the disease.

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 the bone marrow sample under a microscope. You don't need to stay overnight in hospital for a bone marrow biopsy. It's usually quite quick but it might be uncomfortable while the sample is being taken from the marrow – you can take painkillers if you need to.

Some people will also have a bone marrow trephine. This is similar to a bone marrow aspirate, but a slightly larger piece of bone marrow is taken from the hip bone using a larger needle.

You might experience some discomfort around the area where your bone marrow sample was taken. If you like, you can take some paracetamol to help with the pain. Any discomfort is usually gone after 24–36 hours.

## Further tests

You'll have a series of tests which will provide more information to help stage the high-grade NHL. These tests will also help doctors predict how you'll respond to treatment. You'll 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.

The results of any tests can take a little while to reach your healthcare team, so don't worry if you don't find out your results straight away.

## Scans

Doctors may use body 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.

## X-rays

X-rays, particularly chest X-rays, might be used during diagnosis to help stage the cancer. They provide good images of the denser tissues in your body, such as bone.

You might have more X-rays during your treatment, to find out how your body is responding and to check for infections.

## Computerised tomography (CT or CAT) scan

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

You may have a full body CT scan to give a detailed picture of your organs and help stage the cancer.

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 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.

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

It's getting more common to 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 a small amount of radioactive sugar. 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 cancerous cells take up more of the radioactive sugar than normal cells, doctors will be able to see more clearly where the lymphoma is in your body. You'll get more information and advice about this scan from your hospital.

You'll have this scan again at the end of your treatment to see if the treatment's 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)

MRI is only used in certain situations to help with diagnosis. You might have this scan to see if your central nervous system (brain and spinal cord) has been affected by the lymphoma.

An MRI scan uses the effect of a strong magnet on your body to produce very detailed images of soft tissues, which are then analysed on a computer. During the test, you'll lie on a table which will move you through the scanner. To help the computer create a better picture, 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. 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).

Pregnant women may have an MRI scan in place of a PET/CT scan, as MRI doesn't involve radioactivity.



For more information on how high-grade NHL can affect your central nervous system, see **page 63**.

## Ultrasound scans

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.

## Blood tests

You'll be given a series of blood tests as part of your diagnosis. These will also give your healthcare team a full picture of your general health before, during and after your treatment.

## Full blood count (FBC)

A full blood count (FBC) measures the number of each type of cell in the blood: red cells, white cells and platelets. You might have been sent for this test by your GP as part of a routine check-up. Other people might have one when they're in hospital for something else.

The FBC will help doctors spot if you develop anaemia (a condition caused by a lack of red blood cells which leads to tiredness and breathlessness). Anaemia may develop because of your illness or your treatment. If the lymphoma has affected your bone marrow, this may also show up in the results.

### Liver function test

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

### Urea and electrolytes test

This test checks how well your kidneys are working. You'll usually have it every time you visit hospital for treatment. It's done to see whether you're ready to have your next course of treatment, and whether any doses of chemotherapy need to be changed.

### Lumbar puncture

You might need a lumbar puncture if there is a high risk of the lymphoma spreading to your central nervous system (your brain and spinal cord).

During a lumbar puncture, a very fine needle is carefully inserted between the bones of your lower spine (backbone), and a small sample of cerebrospinal fluid (CSF) is taken. You'll be given a local anaesthetic to numb the area first.

## **Your healthcare team**

If you're diagnosed with high-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 patients with blood diseases. 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 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 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 – many provide patient meetings or further online support.

## 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.
- Write down any questions you have and keep them handy for when you see your consultant or CNS. 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.
- 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. Being able to share similar experiences might also help.

## 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.



There's more information about cancer and how it can affect your work or study on **page 83**.

You can join our online community forum at **[forum.bloodcancer.org.uk](http://forum.bloodcancer.org.uk)**



## 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.

**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](mailto:support@bloodcancer.org.uk)**

# Treatment

The treatment that's best for you will depend on the stage of the high-grade NHL, your individual condition and your general health. 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.

## **Clinical trials**

If 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 given outside of the trial.

Your safety and wellbeing is always the first priority. You'll also be very closely monitored and have detailed follow-up.

Taking part in a clinical trial does come with uncertainties, and may involve extra visits to hospital. 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 standard treatments that are appropriate for your individual condition.

## **Types of treatment**

There are several treatment options that doctors will consider for NHL, depending on your particular circumstances.

### **Chemotherapy**

Chemotherapy is treatment with anti-cancer drugs, which stop the cancer cells growing and dividing. They are usually given into a vein (intravenously) and travel to most parts of the body. You'll find more details of the most common chemotherapy drug combination on page 54 – the dose you're given will depend on your overall health and the stage of the NHL.

## Radiotherapy

Radiotherapy uses X-rays to kill the cancer cells in the specific area of the body being treated.

## Biological therapies

Biological therapies support the body itself to attack cancer cells or control their growth. Some types of biological therapy drugs may also be referred to as immunotherapies. It's likely that your treatment plan will include a biological/immunotherapy drug called rituximab.

Rituximab identifies a specific protein on the surface of B cells affected by the lymphoma, so it is able to find and kill these abnormal cells. It's usually given as an infusion (a drip into the vein), but may be given by injections under the skin (subcutaneously).

While you're taking rituximab, you might have some immediate side effects, like a high temperature, a rash, shortness of breath or tightness in the chest. You'll be given paracetamol and anti-histamine before you start taking the drug to reduce the chance of this happening.



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You can find out more about clinical trials in the UK at **[beartofresearch.nihr.ac.uk](http://beartofresearch.nihr.ac.uk)**

Most people don't have any reactions. However, if you do have a reaction, you'll be given some more anti-histamine. If you keep having problems, your healthcare team might give you a different drug to take instead.

If you're on drugs to lower your blood pressure (anti-hypertensive drugs) let your treatment team know – they might ask you not to take your normal dose on the day you're having rituximab.

## Steroids

Steroids are drugs that are very effective in killing lymphoma cells and are often included in treatment programmes alongside chemotherapy and biological therapies, but can sometimes be used alone to shrink the lymphoma. They're also used to prevent sickness, to help improve your appetite and stop allergic reactions.

## Growth factor injections (GCSF)

Growth factor injections encourage your bone marrow to make white blood cells. You might have these injections as part of your treatment if:

- you have a high risk of developing infections
- you've had chemotherapy before, which caused you to be admitted to hospital
- you're having higher doses of chemotherapy.

These injections are given under the skin (subcutaneously) for around five days – although the number of days can vary depending on your particular treatment programme.

## CAR-T cell therapy

Researchers in the UK and abroad have developed a new type of treatment called CAR-T cell therapy. This is where a patient's T cells are removed from the body and genetically engineered in a lab to make them more effective at killing cancer cells. They are then put back into the body.

At the time of publishing this booklet, CAR-T cell therapy is available to a small number of people in the UK with relapsed or refractory DLBCL, whose lymphoma has continued to grow after at least two treatments.

Speak to your healthcare team if you want to find out more about this treatment.



You can find general information about treatment types and decisions at **[bloodcancer.org.uk/treatment](https://www.bloodcancer.org.uk/treatment)**

We have a fact sheet about CAR-T cell therapy: **What is CAR-T therapy?** See **page 106** for how to order.

## First treatment

Your first treatment may involve chemotherapy, radiotherapy, a biological therapy, or a combination of these.

## Treatment programmes

There are many different treatment programmes (also called regimens) used to treat high-grade NHL. Your healthcare team will talk you through the different options and explain why they're recommending a certain treatment programme for you.

The drugs you take will depend on where the lymphoma is in your body and on other factors such as the stage of the cancer.

## R-CHOP

The most common combination of drugs is called R-CHOP, which includes the following drugs:

- rituximab – one of a group of drugs called monoclonal antibodies, a type of biological therapy
- cyclophosphamide – a chemotherapy (anti-cancer) drug
- hydroxydaunorubicin, also called doxorubicin – a chemotherapy drug



- vincristine (which used to be called Oncovin) – a chemotherapy drug
- prednisone – a steroid tablet.

If you're not fit enough to have the full R-CHOP treatment, you might be given a lower dose which is safer but still known to be effective. You'll have this treatment as an outpatient, so you won't need to stay overnight in hospital. It's given through a drip into your vein, called an infusion.

## **Staging and your treatment**

The stage of your high-grade NHL will affect the first treatment you have.

### **Stage I high-grade NHL**

Because high-grade NHL tends to be fast growing, only a small number of people are at stage I when they start their treatment. If you are at stage I, you'll usually receive three courses of R-CHOP chemotherapy, along with radiotherapy to the affected area.

### **Stage II, III and IV high-grade NHL**

Most people with high-grade NHL will fall into this group. Your treatment will usually involve six courses of R-CHOP.

## **Risks to your fertility**

R-CHOP and other chemotherapy treatments may affect your fertility (being able to get pregnant or father a child in the future). If this is a concern for you, speak to your healthcare team about the options available before you start your treatment.

## **Side effects of treatment**

Treatment can cause some side effects. Let your healthcare team know about any side effects you have, as often they'll be able to help you manage them – for example, by prescribing you anti-sickness drugs (anti-emetics). Everyone is different and you're unlikely to have all of the potential side-effects.

## **Side effects of chemotherapy**

Some of the possible side effects of chemotherapy include:

- feeling achy
- hair loss (alopecia)
- frequent watery poos (diarrhoea)
- difficulty pooing (constipation)
- extreme tiredness (fatigue)
- infections
- loss of appetite
- bruising
- risk of bleeding
- being short of breath
- mouth sores
- feeling and being sick (nausea and vomiting).

Having chemotherapy can also slightly increase your risk of getting a new, second cancer. Your healthcare team will be able to discuss this with you.

### Side effects of vincristine

- a tingling or numbness in your fingers or toes, which might make it hard to do things like doing up buttons – you’ll be assessed for this before each chemotherapy session and if it’s severe you might take a lower dose of vincristine or stop taking it entirely
- constipation – your healthcare team might give you some medicine (a laxative) to help with this.

### Side effects of steroids

- mood changes such as being abnormally or excessively active (hyperactivity), feeling emotional, elated, low or lacking energy
- increase in appetite
- inability to sleep (insomnia) – check with your healthcare team whether you can try taking your tablets in the morning rather than the evening
- changes in blood sugar, causing you to wee more often, have an unexplained thirst or feel dizzy and light-headed. If this happens, contact your healthcare team.

## Remission

Once you've finished your treatment, you'll have an FDG PET/CT scan (see page 38) to see if all the lymphoma cells have been destroyed. This scan can tell the difference between scar tissue that remains in your body (which is unimportant) and lymphoma cells (which might need some extra treatment).

### Complete remission

Complete remission is when there are no lymphoma cells in your body. You may hear your specialist use the term 'complete metabolic response'.

### Partial remission

Partial remission is when the amount of lymphoma in your body has gone down by more than half, but there are still some lymphoma cells in your body.

## Relapsed and refractory high-grade NHL

Occasionally, high-grade NHL comes back after the first treatment, or the first treatment doesn't work and you don't go into remission. Your doctor might use the following names for the NHL in these circumstances:

- Relapsed high-grade NHL: this is when the NHL comes back three months or more after the end of treatment. Relapse is most likely to happen in the first two years after finishing treatment, but could happen later.

- Refractory high-grade NHL: this is when the NHL hasn't responded to initial treatment, or the NHL has come back within three months of finishing treatment.

## **Treatment for relapsed or refractory high-grade NHL**

If your first treatment hasn't worked, you'll need more treatment. You may be asked if you'd consider taking part in a clinical trial, if there's a suitable one available. Or you'll be offered one of the following treatment plans:

### **Chemotherapy**

You'll have a different type of chemotherapy from the one you had in your first treatment. You might hear this second round of chemotherapy being called 'salvage chemotherapy'.

Together, you and your healthcare team will discuss treatment options and you'll choose an alternative treatment plan.

The drugs below are commonly used for a second or third round of treatment (called second-line or third-line treatment) and are drugs that you might take before a stem-cell transplant:

- ESHAP – etoposide, methylprednisolone, cytarabine and cisplatin
- ICE – ifosfamide, carboplatin and etoposide
- IVE – ifosfamide, epirubicin and etoposide
- mini-BEAM – carmustine, etoposide, cytarabine and melphalan
- GDP – gemcitabine, dexamethasone and cisplatin

## Stem cell transplants

For some people, a stem cell transplant using your own stem cells might be an option. This is known as an autologous stem cell transplant. You'll only be offered a stem cell transplant if you have relapsed or refractory high-grade NHL which has responded to second-line chemotherapy and if your doctors think you're fit enough. This is because a stem cell transplant will only work if your body has responded well to chemotherapy before.

If you have a second relapse, an allogeneic stem cell transplant (a transplant using donor cells) may be possible.

Your consultant will discuss all these treatment plans with you in detail if you're going to have a transplant.

## Palliative care

Occasionally treatment is unsuccessful. Palliative care is used when no further treatment options are available to cure or control the cancer.

Palliative care involves a range of health professionals working together to give people relief from their symptoms, including pain and distress. It includes physical, psychological, emotional, social and spiritual support for both the person with lymphoma and their family.

## Treatment for transformed NHL

Some people with low-grade NHL (most often, follicular lymphoma) will go on to develop high-grade NHL through a process called transformation. Low-grade NHL usually transforms into DLBCL, but rarely transforms completely. Your treatment will focus on the fast-growing DLBCL, but you will probably still have some low-grade disease as well.



For information about stem cell transplants, order or download our booklet, **Blood stem cell and bone marrow transplants: the seven steps**. See **page 106** for details.

- If you've been on 'watch and wait' (where you have been diagnosed with low-grade NHL and monitored, but not been treated with chemotherapy), your recommended treatment will usually be R-CHOP chemotherapy – see page 54.
- If you've had chemotherapy before, you might be offered an alternative chemotherapy treatment – see page 59 for potential treatment plans.
- You may receive an autologous stem cell transplant (using your own cells) at the end of your treatment, if you're fit enough and the lymphoma responds to chemotherapy.

If your treatment is successful, you'll be in complete remission from the high-grade NHL. While your treatment plan will also be effective against the low-grade NHL, it's likely that the low-grade disease may come back in the future. If this happens, then the disease will be controlled using treatments designed for low-grade NHL



See **page 106** for how to order or download our booklet **Low-grade non-Hodgkin lymphoma (NHL)**.



## **Treatment of high-grade NHL in the central nervous system**

Having lymphoma in parts of your body outside the lymphatic system (extranodal disease) can increase your risk of getting lymphoma in your central nervous system, for example, your brain or spinal cord.

If you have lymphoma in a breast, testicle, kidney or adrenal gland, then you are more likely to develop lymphoma in your central nervous system as well. Extra treatment may be directed at the central nervous system to reduce the risk of the lymphoma appearing here.

Doctors use two different terms to refer to high-grade NHL in your central nervous system:

- primary CNS lymphoma: the lymphoma is only in your central nervous system
- NHL with CNS involvement: the lymphoma is in your central nervous system as well as other parts of your body.

## Chemotherapy aimed at the central nervous system

Your brain has a natural protection to stop harmful chemicals (toxins) such as chemotherapy drugs from entering your central nervous system. This is called the blood-brain barrier. But if you have a high risk of the lymphoma affecting your central nervous system, or you already have lymphoma cells in your central nervous system, the chemotherapy drugs need to break through this barrier.

Certain drugs, like cytarabine or methotrexate are able to do this. These can be given into a vein (intravenously) or directly into the spinal fluid (intrathecally). You'll usually take these drugs in high doses and will need to stay in hospital while you have your treatment.

During intrathecal therapy, you'll have a lumbar puncture to inject a small amount of the chemotherapy drugs into your spinal cord. You may be advised to lie down for an hour or so after the treatment to try to reduce the chance of developing a headache.

## Supportive care

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

Supportive care could include:

- stopping you feeling sick
- avoiding or treating constipation
- preventing gout, which causes painful swelling in the feet
- mouth care
- blood transfusions
- pain management
- diet planning.



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For an explanation of lumbar punctures, see **page 42**.

For general information on managing side effects and symptoms, see our fact sheets **Managing sickness and vomiting**, **Sore mouth or gut (mucositis)** and **Understanding infection**. Turn to **page 106** for more details.

## Infections

While you're having treatment, you have more chance of developing an infection, and a minor infection could become more serious. Symptoms 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.

Symptoms of infection can be less obvious because of your NHL, or if you are taking paracetamol-based medicines. If you're in any doubt you should contact your healthcare team straight away.

## Follow-up

After your treatment, you'll have follow-up checks with your healthcare team. It's really important that you go to these appointments. Your team will monitor your condition and check for relapse, which is most common in the first two years after your treatment has finished. After two years in remission, the chance of relapse is lower.

In the first year after your treatment you'll have regular check-ups, usually every three months. Then the check-ups will get less frequent, or you'll be able to book an unscheduled appointment as and when you need to. Your consultant will explain how often you'll have check-up appointments, as this will be different depending on which treatment centre you've been visiting.

Once you have completed your treatment, you should contact your hospital team if you get any new swellings. It's also a good idea to tell the hospital team of any changes in your general health or other new signs or symptoms you notice. This is because there are many different symptoms which might be related to your condition, depending on which sites in your body are affected.

If all goes well, you and your healthcare team will agree that you don't need to be seen by them any more (discharge). Once you are discharged, your GP will be your main point of contact.

It's rare, but there is a slightly increased risk of getting another type of cancer in the future, either because of the treatment someone has had, or because people who have had one cancer are more likely to get a second cancer, compared to people who have never had cancer. It's always best to contact your GP and let them decide whether your symptoms are significant.



Ann was initially treated for DLBCL with chemotherapy and radiotherapy, then had a stem cell transplant after the lymphoma came back.

We told the girls we needed to get through the treatment and everything would be fine. Which it was, even though there were lots of twists and turns along the way.

**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](mailto:support@bloodcancer.org.uk)**



# The outlook

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

Most people with DLBCL are cured with standard R-CHOP chemotherapy (see page 54). If the lymphoma responds well to the treatment you have and goes into remission (which means there's no sign of cancer left), then you may not need any further treatment. Depending on the amount and type of treatment you've had, it may take some time to get back to your normal health.

Around 10-15% of people with DLBCL have refractory disease, which means the DLBCL doesn't respond to standard treatment. And for between 20% and 30% of people, the DLBCL will come back after remission (it'll relapse), usually in the first two years. Refractory and relapsed DLBCL are more difficult to treat, but there are still many treatment options that can lead to remission.

### **If you want to find out more**

If you would like more detailed information on the general outlook for NHL, go to [cancerresearchuk.org](http://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](mailto: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](mailto:support@bloodcancer.org.uk)**

# Living with high-grade NHL

If you've been diagnosed with high-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 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 completed your treatment you may wonder whether there are any specific signs or symptoms you should look out for.

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

### **Keeping active**

You might feel tired a lot (fatigue). This could be caused by the high-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 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

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 healthcare team 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.



See **pages 25–27** for a list of symptoms to look out for.

You can talk to other people living with blood cancer or read about their experiences at **[forum.bloodcancer.org.uk](https://forum.bloodcancer.org.uk)**

We have more information and tips about coping with your emotions and keeping active at **[bloodcancer.org.uk/living-well](https://bloodcancer.org.uk/living-well)**

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.

## Smoking

People who've had chemotherapy treatment for high-grade NHL may have an increased risk of late effects (side effects which show up after treatment has finished), such as heart and lung problems. For example, the drug hydroxydaunorubicin (also called doxorubicin), which is used in treatments for NHL, has been linked to potentially toxic effects on the heart in later life.



Because smoking also raises your risk of heart and lung disease, if you smoke, your doctor will strongly recommend that you stop, and will advise on other things you can do to reduce your risk of developing heart and lung conditions.

## 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 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.



For dietary advice for people with blood cancer, see our booklet **Eating well with neutropenia**.

For guidance on managing the risk of infection, read our fact sheet **Understanding infection**.

See **page 106** for how to order or download our health information.

Symptoms of shingles 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.

## Vaccination

It's a good idea for all people with high-grade NHL to have the flu vaccine each year. Your GP might contact you about this, but if they don't then you can request the vaccine yourself. It might not work as well for people with high-grade NHL, but will still offer some protection. It is also sensible for the people you live with to be vaccinated against flu.

## 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 what they can recommend.

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.

## **Sex and pregnancy**

If you're a woman receiving chemotherapy, it's essential to take precautions to avoid becoming pregnant while you're having 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.

## Practical support

### Work, education and home life

If you work or are studying you might want to contact your employer or college about your condition, or ask someone to do it for you.

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 treatment. You may receive varying advice on this but it's entirely your decision, so discuss 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 cannot discriminate against you. 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 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

Your finances might be the last thing on your mind if you've just been diagnosed with cancer, but when you're ready, 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. These might be especially useful if you're on a low income or you're 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 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 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](mailto: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](http://bloodcancer.org.uk)
- 0808 2080 888 (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)
- [support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)
- [forum.bloodcancer.org.uk](http://forum.bloodcancer.org.uk)

## General information and support

### Macmillan Cancer Support

Offers practical, medical, financial advice and emotional support.

- 0808 808 0000
- [macmillan.org.uk](http://macmillan.org.uk)

### Lymphoma Action

Provides emotional support and information to people affected by lymphatic cancer.

- 0808 808 5555
- [lymphoma-action.org.uk](http://lymphoma-action.org.uk)

### Cancer Research UK

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

- 0808 800 4040
- [cancerresearchuk.org](http://cancerresearchuk.org)

### Leukaemia Care

Offers information, a support line and support groups for people affected by leukaemia, lymphoma, myeloma and other blood disorders.

- 08088 010 444
- [support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)
- [leukaemiacare.org.uk](http://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](mailto:info@aclt.org)
- [aclt.org](http://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](http://anthonymolan.org)

## Maggie's

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

- 0300 123 1801
- [enquiries@maggies.org](mailto:enquiries@maggies.org)
- [maggies.org](http://maggies.org)

## Marie Curie

Runs nine 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](http://mariecurie.org.uk)

## MedicAlert

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

- 01908 951045
- [info@medicalert.org.uk](mailto:info@medicalert.org.uk)
- [medicalert.org.uk](http://medicalert.org.uk)

## Tenovus (Wales)

Provides an information service on all aspects of cancer, plus practical and emotional support for people with cancer and their families living in Wales.

- 0808 808 1010
- [tenovuscancercare.org.uk](http://tenovuscancercare.org.uk)

## Financial advice

### Citizens Advice

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

- 03444 111 444 (England), 0344477 20 20 (Wales)
- in Scotland or Northern Ireland, contact your local Citizens Advice
- [citizensadvice.org.uk](http://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](http://gov.uk/government/organisations/department-for-work-pensions)

## **Travel insurance**

### **Macmillan Cancer Support**

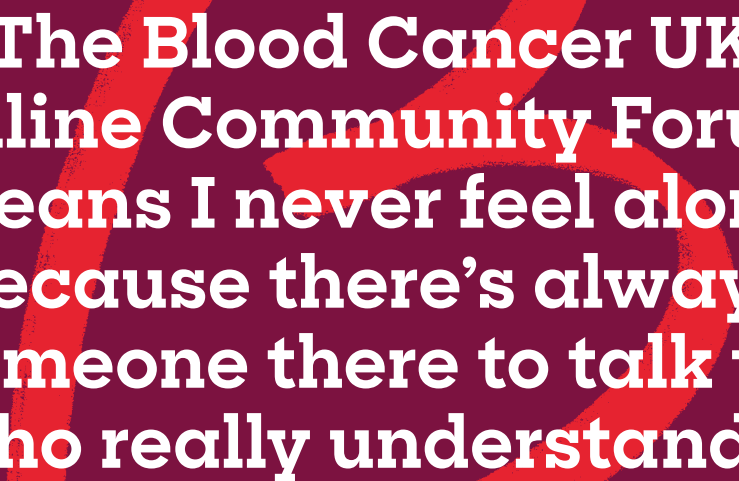
Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

- 0808 808 0000
- [macmillan.org.uk](http://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](mailto:enquiries@biba.org.uk)
- [biba.org.uk](http://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's my exact diagnosis and what stage is the high-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?

## 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)?

Will my treatment be continuous or in blocks of treatment with a break 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 address the risks?

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

## Stem cell transplant

Is a transplant an option for me?

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?



**A large part of my job is  
listening and talking to  
patients about their fears  
and other emotions.  
It's as important as the  
clinical care.**

Darren, Clinical Nurse Specialist

# 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.

## Biological therapies

Treatments that use natural substances in the body to change the way cells signal to each other. The aim is to get the body itself to attack cancer cells or control their growth. Rituximab is an example of a biological therapy, which is an important part of nearly all treatments for NHL.

### **Blood count, full blood count or FBC**

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

### **Bone marrow**

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

### **Central nervous system**

Part of the body's nervous system, consisting of the brain and spinal cord.

### **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, 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 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 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.

## 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. It contains white blood cells that fight infection.

### Lymph vessels

Small tubes which make up a network which runs 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.

### Performance status

A range of factors which determine how well your body will cope with different treatments, which is based on your health when you are diagnosed with NHL.

### 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 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.

## T lymphocyte or T cell

A type of white blood cell normally involved in controlling the reaction of the immune system and fighting viral infection.

## Transformation

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



**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 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://bloodcancer.org.uk/information)**

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

Email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

Or use the order form on **page 116**



**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](https://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](https://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](https://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](https://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](https://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 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 106)

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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](http://bloodcancer.org.uk)**

**0808 2080 888**

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

**[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

**[forum.bloodcancer.org.uk](http://forum.bloodcancer.org.uk)**

Your feedback on this booklet can help us improve – please send any comments to **[information@bloodcancer.org.uk](mailto:information@bloodcancer.org.uk)**



**Blood  
cancer  
UK**

Blood Cancer UK is a trading name of Bloodwise, 39-40 Eagle Street, London, WC1R 4TH. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland) © 2020 NHLHIGHGRADE/0618.2