High-grade non-Hodgkin lymphoma (NHL)
**My details**

This is a place to put important information about you, your condition and key contacts.

<table>
<thead>
<tr>
<th>Name and hospital number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My NHS number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My condition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My consultant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My key worker (usually your CNS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Haematology ward</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Haematology clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Out of hours</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
As the weeks passed and having gathered copious quantities of information from charities, books and my healthcare team, I slowly began to understand my condition and with understanding came acceptance.

A team of people helped produce this booklet. We’d like to thank a member of our Medical Advisory Panel, Dr Kirit Ardeshna, for his help and support in developing the content and checking for clinical accuracy. The draft was also assessed at an early stage by clinical nurse specialist Claire Barton.

Bloodwise staff revised the text to make it easy to read, and a non-medical panel of patients checked it for understanding. A member of Bloodwise’s Medical Advisory Panel, Dr Kirit Ardeshna is responsible for the content overall.

Our information is for you and those close to you to use whenever, wherever and however you need it. You’ll probably have lots of questions; this booklet aims to help you answer as many of them as possible.

Our information is developed for and with patients. It’s written in line with national guidelines and created with health professionals from our dedicated Medical Advisory Panel, so you know it’s accurate and up to date.

This booklet is one of many we make – you can find a list of our other booklets on pages 94–95. For the very latest information, visit our website.

Our booklets contain general information. Always listen to the advice of your specialist about your individual treatment – because every person is different.

When you see the symbols below in the booklet, it’s a sign that we think the websites and other organisations mentioned will also give you good information and support.

A list of references used in this booklet is available on request. Please email us at patientinformation@bloodwise.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. Bloodwise 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 (February 2015).

Date of next review February 2017.

Bloodwise, 39–40 Eagle Street, London WC1R 4TH
T: 020 7504 2200  E: info@bloodwise.org.uk  W: bloodwise.org.uk

© All rights reserved. No part of this publication can be reproduced or transmitted without permission in writing from Bloodwise.

Registered charity 216032 (England & Wales) SC037529 (Scotland)
There are many different types of high-grade lymphoma that are briefly listed on page 13.

The most common type of high-grade NHL is diffuse large B-cell lymphoma (DLBCL). This booklet mainly talks about DLBCL but lots of the information is relevant to everyone with high-grade NHL. Where this information is different we’ll highlight this and direct you to another source.

Being told that you, or a loved one, have any type of cancer can be one of the hardest things you’ll ever have to hear.

There’s sure to be a lot of information to take in at this time. We hope this booklet will help you to understand your condition and feel in control throughout this time. We’ll answer as many of the questions you might have along the way as we can – from symptoms through to tests, treatment and living with high-grade NHL, and where you can get support.

Every person is different, with a different medical history. So when you’re deciding what’s right for you, discuss your situation with your specialist as well as getting information from this booklet and other places.
High-grade non-Hodgkin lymphoma at a glance

In most cases, we don’t know what causes high-grade non-Hodgkin lymphoma (NHL). Treatment is likely to be effective and many patients have a good long-term outlook, despite the chance of relapse (the cancer coming back).

What is high-grade NHL?
High-grade NHL is a blood cancer that affects a type of white blood cells called lymphocytes.

There are many different types of NHL, which are often grouped depending on how quickly the cancer grows and spreads: high-grade, which develops quickly; and low-grade, which develops more slowly.

If you have high-grade NHL, your cancer will also be defined based on your symptoms and on how much lymphoma there is in your body. This is called the ‘stage’ of the cancer and determines your treatment.

Who gets high-grade NHL?
In most cases we don’t know what causes high-grade NHL. Factors like age and gender can affect how likely you are to get high-grade NHL.

It’s more common in older people. Children rarely get the most common type of high-grade NHL, called diffuse large B-cell lymphoma (DLBCL), but in some other sub-types, like Burkitt lymphoma, it can be slightly more common in children. There are some factors which can slightly increase your change of getting high-grade NHL, such as some viral infections or having a weakened immune system.

If you’ve got 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 can involve chemotherapy, radiotherapy, chemo-immunotherapy and growth factor injections. The amount of chemotherapy you have will depend on the stage of the cancer. If you don’t respond to treatment or you relapse, you may have more treatment, which could involve more chemotherapy or a stem cell transplant.

What’s the outlook?
The outlook for people with high-grade NHL depends on the type of lymphoma you have, the stage of the disease, and how it responds to treatment.

In high-grade NHL it’s common for the disease to spread to more than one site (place) in your body, but it’s still possible to treat high-grade NHL if this happens.

Most people can expect to achieve a good first remission (where there is no sign of the lymphoma in your body). The chance of relapse (the high-grade NHL returning) is highest in the first two years after you’ve finished your treatment.
Knowing the basics about the immune system and your lymphatic system is useful.

Your lymphatic and immune system

It’s a good idea to know a bit about the immune system and your lymphatic system as your healthcare team will talk about them to you.

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.

Within your lymphatic system there’s a network of thin tubes called lymph vessels which run around your body. The vessels collect fluid called lymph and return it to your blood. Lymph bathes all the cells in your body. It contains lots of lymphocytes (a type of white blood cell that fights infection), which carry nutrients and remove bacteria from infected areas.

You can find out more about your lymphatic and immune system on our website > bloodwise.org.uk/NHLlinks
Along the lymph vessels are small lumps of tissue called lymph nodes or lymph glands. There are many of these in your body. It may be possible for you to feel normal lymph nodes in the neck and groin, particularly if you’re slim. If you get an infection when you’re healthy, these can swell and become tender, which people may refer to as 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. It also filters out old or damaged cells from the blood stream and helps to fight infection.

**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 lymphocytes play an important role in this. There are lots of different kinds of lymphocyte, including ones called T cells and B cells. These can be affected when you have lymphoma, which can increase the risk of infections. Your healthcare team can let you know about the ways to reduce your risk.

You can also find more information about how to manage infections in our booklet > Supportive care
There are many different types of lymphoma. Make sure to check with your specialist that this is the right booklet for you.

**What is high-grade NHL?**

Lymphoma is a cancer of the lymphatic system. Non-Hodgkin lymphoma is a type of lymphoma that usually affects B cells. There are different types of non-Hodgkin lymphoma, which are grouped depending on how fast the lymphoma grows and spreads.

**Lymphoma**

Lymphoma is a cancer of the lymphatic system. When you have lymphoma some of your lymphocytes don’t work properly. For about 85% of NHL cases, and almost all high-grade NHL cases, it’s a type of lymphocyte called B cell lymphocytes that are affected.

Sometimes these lymphocytes aren’t developed fully (they’re immature), they divide in an abnormal way, or don’t die when they should. These abnormal lymphocytes can build up in your lymph nodes, causing them to swell and form a lump. Swollen lymph nodes can be in a place where they can be easily felt (such as your armpits, neck or groin) or deep inside your chest and abdomen. Lymphoma can occur anywhere in the body where lymphocytes collect.

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

- 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 refers to lymphoma that usually develops quickly and needs treatment.

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

However, there are other types of high-grade lymphoma which behave differently, and are treated very differently to DLBCL. These types are listed on the opposite page. For example, there can be differences in treatment between the types of NHL which affect B cells and those which affect T cells.

WHO Classification of high-grade NHL

The classification of types of non-Hodgkin lymphoma is based on the World Health Organisation (WHO) classification system. This system is very important to your treatment, but it can be very complicated, and there can often be overlap between different types.

As each individual case is so different, particularly in non-Hodgkin lymphoma, your consultant is the best person to ask about your type of lymphoma and your treatment.

Types of B-cell high-grade NHL (besides DLBCL) include:

- Burkitt lymphoma
- lymphoblastic lymphoma
- mediastinal large B-cell lymphoma.

Types of T-cell high-grade NHL types include:

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

For more information on low-grade non-Hodgkin lymphoma, see our booklet > Low-grade non-Hodgkin lymphoma

For more information on Burkitt lymphoma, please see our factsheet > Burkitt lymphoma

For information on the treatment and outlook of T-cell lymphomas, please visit the Lymphoma Association website > go to lymphomas.org.uk and search for 'high-grade NHL'
Who gets 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 NHL. There are some factors that could make you more likely to develop high-grade NHL.

How common is NHL?

Around 10,000 people are diagnosed with NHL every year in the UK.

About two-thirds of people diagnosed with NHL will get the high-grade type of the disease. DLBCL makes up about one-third of all cases of NHL.

In most cases, we can't say what causes high-grade NHL.
Age
You can get high-grade NHL at any age, but it’s more common in over 65s. Children rarely get DLBCL, but some other types of high-grade NHL can be slightly more common in children.

Gender
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. Most people who get NHL don’t have a relative who has it, so the risk is small.

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. This virus is common, but only a very small number of people who get the virus go on to develop NHL.

It’s important to remember that although these viruses can be passed from person to person, you can’t catch lymphoma from someone else. A lot of things have to happen after you get the virus for you to develop NHL.

Radiation
If you’ve been exposed to high levels of radiation, you may have a higher chance of getting NHL.

It’s very unlikely that anyone in the UK would be exposed to the amount of radiation needed to be linked to NHL.

Transformation of low-grade NHL
In some patients, low-grade NHL can change in nature to become a faster-growing high-grade NHL.

This is called transformation. This happens in around a third of people with low-grade NHL.

When I was first diagnosed ‘why me?’ was one of the first things that went through my head. Then I wanted to know what caused it, but with high-grade NHL it’s not something you can point to.
It's important to remember that not everyone will get all, or even any, of the symptoms listed – each person is different.

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. You might have heard this being called '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 are swollen.
Once I’d been diagnosed, I realised that I’d had a lot of the common symptoms of NHL, but I hadn’t joined the dots before.

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:

› chest or abdominal (stomach area) pain
› 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 (greater 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:

› fatigue – a feeling of extreme tiredness that doesn’t go away after rest or sleep
› itching – either widespread or in one place.

You can find out more about symptoms of NHL on our website > bloodwise.org.uk/NHLlinks
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.

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 quite often, like blood tests. Some other tests you'll only have 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 might include fasting (having nothing to eat or drink except water). 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 people have symptoms that don’t clearly point towards a diagnosis of high-grade NHL. Many people will go to the GP about a lump; sometimes your doctor will ask you to wait to see if it goes down. If it doesn’t, you’ll be referred to a hospital for a biopsy. 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 analyse the results and your healthcare team will want to check that it is lymphoma, and that you have the right treatment.

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

**Diagnostic tests**

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 give them more information about the type of high-grade NHL you have. That information comes from the lymph node biopsy and bone marrow tests.

**Lymph node biopsy**

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

This test may be done under general anaesthetic. You’ll often have one whole lymph node removed – you might hear this being called an excision biopsy. Increasingly a core of lymph node is removed under local anaesthetic with the help of ultrasound or CT. This is called a core biopsy or incisional biopsy.

This is the test that will confirm your diagnosis of lymphoma. After this test, your lymphoma will be ‘staged’ to understand the extent of the cancer.

“When I was diagnosed I asked my consultant to write it down and I’m really glad I did. I could then go away and do my own research and also tell people accurate information about my condition.”
Staging

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

It’s very important that your doctor takes the time to understand what stage of NHL you have. This will make sure that you have the treatment that’s right for you. Any delay at this point won’t change the result of your treatment.

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.

The staging groups and their features are:

<table>
<thead>
<tr>
<th>STAGE</th>
<th>FEATURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>I (1)</td>
<td>Only one group of lymph nodes is affected, in one place in your body.</td>
</tr>
<tr>
<td>II (2)</td>
<td>More than one group of nodes is affected but all affected sites are on the same side of the diaphragm – either above or below. The diaphragm is a sheet of muscle separating your chest from your abdomen (stomach area) and pelvis (hip area).</td>
</tr>
<tr>
<td>III (3)</td>
<td>Lymph nodes on both sides of the diaphragm are affected, or the lymphoma has spread from lymph nodes into organs close to the affected node, or nodes.</td>
</tr>
<tr>
<td>IV (4)</td>
<td>The lymphoma has spread to other organs, such as the lungs, liver or bone marrow.</td>
</tr>
</tbody>
</table>

Staging is also based on which symptoms you have when you’re diagnosed. This is shown by a letter ‘A’ or ‘B’ – any letter can apply to any of the numbered stages on the opposite page.

<table>
<thead>
<tr>
<th>A</th>
<th>No B symptoms (see below)</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>symptoms are present:</td>
</tr>
<tr>
<td></td>
<td>› fever (greater than 38°C)</td>
</tr>
<tr>
<td></td>
<td>› drenching night sweats which soak your nightclothes and bedding</td>
</tr>
<tr>
<td></td>
<td>› unexplained weight loss in the last six months (10% or more of your previous weight).</td>
</tr>
</tbody>
</table>

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 when 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 long, and you have a mass in your chest which is bigger than 1/3 of your chest diameter.
Early stage and advanced stage NHL

Early stage disease usually refers to stage I and II disease without bulk or B symptoms. Some patients with early stage disease, especially those with stage I, may be treated differently from those with advanced stage disease.

Advanced stage disease refers to stage III or IV disease, or stage I or II disease with bulk or B symptoms.

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.

Performance status

Your ‘performance status’ is based on how well you are when you’re diagnosed with high-grade NHL.

The most commonly used scale for rating your performance status is called the ECOG guide:

› 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, determine if you’re well enough to take part in a clinical trial.

Staging tests

Bone marrow aspirate and trephine

Most patients will have a bone marrow biopsy (sample) 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; you can have it as an outpatient using local anaesthetic.

Some patients 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 instead using a larger needle. No sedation is usually needed.

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

For more information on clinical trials > see page 46
Further tests

You’ll have a series of tests which will help doctors to further 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 scans 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 to help take the scan. 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.

You can find out more about the diagnosis of high-grade NHL, and other topics covered in this booklet, on our website > bloodwise.org.uk/NHLlinks
Diagnosis

32 Diagnosis

33 CT scan

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

You may have a full body CT scan to help with your staging. The scan gives a detailed picture of your internal organs to help stage the cancer. The procedure won’t cause any pain.

You’ll lie on a table that moves into a cylindrical tunnel 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 often need to have a dye injected into one of your veins to help get a better image.
Diagnosis

Magnetic resonance imaging (MRI)
Not everyone will have an MRI scan. You might have this scan to see if your central nervous system (brain and spinal cord) has been affected by the cancer. The scan will focus on your head and neck, or your spine.

However, you’ll have this scan again at the end of your treatment to see if it’s been successful.

Ultrasound scans
Ultrasound scans can be used to give more information on your condition. For example, it could be used to measure the size of the spleen which is often enlarged in lymphoma patients. Ultrasound is also used to help see lymph nodes when performing a biopsy.

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 radioactive sugar. This small amount of radioactivity is safe, and your doctors will discuss it with you before your scan. Like with CT scans, you’ll lie on a table as you move through a cylindrical tunnel.

As the cancerous cells take up more of the radioactive sugar than non-cancerous cells, doctors will be able to see more clearly where the lymphoma is in your body.

However, you’ll have this scan again at the end of your treatment to see if it’s been successful.

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

I did feel from time to time that I couldn't keep track of all the tests and what they were for. I often wrote down basic details, and just kept checking in with my key worker on the specifics for each one.

For more information about how PET scans are used at the end of your treatment > see page 51

Magnetic resonance imaging (MRI)

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.

Ultrasound scans

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.
Diagnosis

Blood tests
You’ll be given a series of blood tests which are routinely carried out on initial admission to hospital. This gives your healthcare team a full picture of your general health before beginning 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 patients might have one when they’re in hospital for something else.

The FBC will help doctors spot if you develop anaemia (low haemoglobin in your red blood cells), either because of your illness or your treatment. If you have bone marrow involvement, your blood counts may be low.

Liver function test
This test checks if your liver is working normally. This is important to know when you’re having chemotherapy. This is because lots of drugs are broken down in the liver. If your liver isn’t working normally you might need to adjust the doses of your treatment drugs.

Urea and electrolytes test
This test checks how well your kidneys are working. This may help to decide the doses of the drugs you’ll need in your treatment.

You’ll usually have your kidney function checked every time you visit hospital during your treatment. This is done to check if you’re ready to have your next course of treatment and to see whether any of the doses of the chemotherapy needs to be altered.

Liver function test
This test checks if your liver is working normally. This is important to know when you’re having chemotherapy. This is because lots of drugs are broken down in the liver. If your liver isn’t working normally you might need to adjust the doses of your treatment drugs.

Urea and electrolytes test
This test checks how well your kidneys are working. This may help to decide the doses of the drugs you’ll need in your treatment.

You’ll usually have your kidney function checked every time you visit hospital during your treatment. This is done to check if you’re ready to have your next course of treatment and to see whether any of the doses of the chemotherapy needs to be altered.

Lumbar puncture
You might need a lumbar puncture if your lymphoma is at a high risk of spreading to your central nervous system (CNS).

During a lumbar puncture, the doctor will take a small sample of cerebrospinal fluid (CSF). A very fine needle is very carefully inserted between the bones of the lower spine (backbone) under local anaesthetic.
Diagnosis 39

If you’re diagnosed with high-grade NHL, your hospital will give you the names and contact details of your consultant, clinical nurse specialist 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 consultant
Most patients with a blood cancer are treated by a haematologist – a doctor who specialises in treating patients with blood diseases like blood cancer.

Some patients 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
All cancer patients are normally given a key worker, usually a clinical nurse specialist. They are your point of contact with the rest of your healthcare team. You may like to have a meeting with your clinical nurse specialist when you’re first diagnosed, to discuss your condition. Really make use of your clinical nurse specialist as they’ll be with you right through your cancer journey.

Your multidisciplinary team
When you’re diagnosed with something like high-grade NHL, your condition is discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses and any other specialist staff who will be looking after you. This includes histopathologists and radiologists, who are experts in the diagnosis of lymphoma under the microscope and radiological diagnosis (when doctors use the results of any scans you have to help with your diagnosis).

A senior consultant usually leads the meetings, which are held regularly. They’ll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

Talking to other patients
You might want to ask your key worker 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 patients have side effects from a drug and other patients don’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.

For a list of support organisations > see page 73

We also produce a diary which you can order online. It’s yours to use however you like – for practical information or to record thoughts or sketches > bloodwise.org.uk/patient-diary
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 clinical nurse specialist 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 clinical nurse specialist questions rather than your consultant, but do whatever works for you.

› Most patients say they find it useful taking someone with them to consultations. If 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 might be useful to ask in advance what time the consultant is likely to speak to 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.

You can find a list of questions you might want to ask on page 79 and room to write more questions on page 83
I didn’t know whether to tell people I had cancer and at first only told people on a need-to-know basis.

Telling people

Many patients 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 different people can post information on it that everyone can read.

You might not want to tell many people – or anyone at all – about your condition. This is ok too, whatever works for you.

Telling your GP

Your team at the hospital will keep your GP informed about your condition and any treatment you’re having. They’ll usually send your GP a letter with this information. As the patient, you’ll often be sent a copy too. These letters can have a lot of medical terms in them which you might not have heard before, or there might be something in it which worries you. If this is the case, let your hospital or GP know – a quick chat with them might help to reassure you.

Cancer and work

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

There’s more information about cancer and how it can affect your work or study on page 66.
The treatment you decide on with your healthcare team will depend on your health, your individual condition and your wishes.

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.

“Throughout my treatment, no matter if it was a good day or a bad day, my healthcare team were amazing. They supported me throughout and were always there to answer any questions that I might have had.”
Clinical trials

If there’s a clinical trial (study) available that’s suitable for you, your consultant may recommend that you consider this.

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

In a clinical trial, the best current treatment is compared to one that could be better. You’ll still get normal treatment while you’re taking part in the trial, and your safety and well-being is always the first priority.

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

Types of treatment

If you have high-grade NHL, you might have a range of different types of treatment.

Chemotherapy
During chemotherapy treatment, you’ll take drugs that stop the cancer cells growing and dividing.

Radiotherapy
Radiotherapy is a treatment that uses radiation, usually x-rays, to kill the cancer cells by damaging the genetic material.

Biological therapies
It’s likely that your treatment plan will include a biological therapy called rituximab. This identifies a protein on the surface of the affected B cells and kills them. Rituximab is given as an infusion (a drip into the vein).

Whilst you’re taking the drug, you might have some immediate side effects, like a temperature, 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. Most patients 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 anti-hypertensive drugs (drugs to lower your blood pressure) let your treatment team know – they might ask you not to take your normal dose on the day you’re having rituximab.

For more information, read our booklet > Clinical trials

You can find out more about clinical trials in the UK Clinical Trials Gateway > www.ukctg.nihr.ac.uk
Initial treatment
Your initial treatment may involve a combination of chemotherapy, radiotherapy or immunotherapy.

Treatment regimens
There are many different treatment 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 plan.

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

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

› rituximab
› cyclophosphamide
› hydroxydaunorubicin
› Oncovin™, which is the trade name for a drug called vincristine
› prednisone, a steroid tablet.

If you’re not fit enough to have R-CHOP, you might be given a modified version of these drugs. You’ll be given this as an outpatient as an infusion (through a drip).

Staging and your treatment
The stage of your high-grade NHL will affect the initial treatment you have.

Stage I high-grade NHL
Because high-grade lymphomas tend to be fast growing, only a small number of patients are at Stage I when they start their treatment. If you are, you’ll usually receive three courses of R-CHOP chemotherapy and radiotherapy treatment 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.

Steroids
Steroids are very effective in killing lymphoma cells and are often included in treatment regimes, alongside chemotherapy and biological therapies, but can sometimes be used alone to shrink down the lymphoma. They’re also used to prevent sickness and to help improve 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’re at a high risk of developing infections

Macmillan Cancer Support has a guide to R-CHOP > go to macmillan.org.uk then search for ‘R-CHOP chemotherapy’
Side effects of treatment

You’re unlikely to have all of these 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-nausea drugs.

Side effects of chemotherapy
Some of the possible side effects of chemotherapy include:

› achy feeling
› alopecia (hair loss)
› diarrhoea or constipation
› fatigue (extreme tiredness)
› infections
› loss of appetite
› bruising
› risk of bleeding
› shortness of breath
› mouth sores
› nausea (feeling sick) and vomiting.

There is also a risk that having chemotherapy can give you an increased risk of getting a new, second cancer. Your healthcare team will be able to discuss this with you.

Side effects of Oncavin™ (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 Oncavin™ or stop taking it entirely
› constipation – your healthcare team might give you some laxative medication to help with this.

Side effects of steroids

› mood changes such as hyperactivity, or feeling emotional, elated, low or listless
› increase in appetite
› insomnia – to help with this, try taking your tablets in the morning rather than the evening
› changes in blood sugar, causing you to pass water often, have an unexplained thirst or feel dizzy and light-headed. If this happens, contact your healthcare team.

Once you’ve finished your treatment, you’ll have an FDG PET/CT scan to see if all the lymphoma cells have been destroyed. This scan can tell the difference between residual scar tissue 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 mention the term ‘complete metabolic response’.

Partial remission
Partial remission is when the amount of lymphoma in your body has gone down by more than 50%. However, there’ll still be some lymphoma cells in your body.

Refractory high-grade NHL
Occasionally, the high-grade NHL won’t respond to initial treatment. This means that a remission hasn’t been achieved. This is called refractory high-grade NHL, and you’ll need to have more treatment. If there’s a clinical trial available, you may also be asked if you’d consider taking part.

For information about the side effects of chemotherapy see our booklet > Chemotherapy: what do I need to know?
Relapse, refractory NHL and further treatment

If your initial treatment hasn’t worked, or you have a relapse (the high-grade NHL returns after you’ve been in remission) you’ll need to have more treatment. Relapse is most likely to happen in the first two or three years after finishing treatment, but it could happen later.

You might hear doctors using some different names for the cancer in these cases. These are usually defined as:

› refractory high-grade NHL: you haven’t responded to initial treatment, or the NHL has come back within three months of finishing treatment

› relapsed high-grade NHL: you’ve relapsed three months after the end of treatment.

Further treatment

Chemotherapy
You’ll have a different type of chemotherapy to the one you had in your initial 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 ones below are commonly used for second- or third-line treatment and are drugs that you might take before stem-cell transplant:

› ESHAP
› ICE
› IVE
› mini-beam.

Stem cell transplants
For some patients, an autologous stem cell transplant might be an option. This is a stem cell transplant using your own stem cells.

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 curative treatment options are available. It involves a multi-disciplinary holistic approach to care. Patients are provided relief from their symptoms, pain and distress. Palliative care includes physical, psychological, emotional, social and spiritual support both for the patient and their family.

For information about autologous stem cell transplants see our booklet > Undergoing high dose therapy and autologous stem cell transplant
Treatment of transformed low-grade NHL

About a third of people with low-grade NHL will go on to develop high-grade NHL. In these cases, the low-grade NHL will usually transform into DLBCL.

Even if the low-grade NHL has transformed, it’s unlikely that the high-grade NHL will completely replace all of the low-grade disease.

Your treatment will be focused on treating the high-grade NHL:

› You may receive an autologous (own cell) stem cell transplant at the end of your treatment, if you’re fit enough and your lymphoma responds to the chemotherapy.

If your treatment is successful, you’ll be in complete remission of the high-grade NHL. Whilst 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 your disease will be controlled using treatments designed for low-grade NHL.

› If you’ve had chemotherapy before, you might be offered an alternative chemotherapy treatment, like ESHAP, ICE, IVE or mini-beam (used with or without antibodies).

Treatment of high-grade NHL in the central nervous system

Having lymphoma in extranodal parts of your body (parts of your body outside the lymphatic system) can increase your risk of getting lymphoma in your central nervous system (CNS).

The risk of CNS involvement is higher if lymphoma is found in the breast or testicle.

Doctors use two different terms to refer to high-grade NHL which is in your CNS:

› primary CNS lymphoma: the lymphoma is only in your CNS

› NHL with CNS involvement: the lymphoma is in your body and in your CNS.

Chemotherapy aimed at the CNS

Your brain has a natural protection to stop toxins (such as chemotherapy drugs) from entering your CNS – this is called the ‘blood brain barrier’. But if you have a high risk of the lymphoma affecting your CNS or if you have lymphoma cells in your CNS, the chemotherapy drugs need to break through this barrier. Certain drugs, like cytarabine (or AraC) or methotrexate are able to do this. These can be given intravenously (into a vein) or intrathecally (directly into the spinal fluid). You’ll usually take these drugs in high doses as an inpatient in the hospital.

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.

For more information on lumbar punctures > see page 37
Supportive care
You might need supportive care alongside your other treatment.

Supportive care involves dealing with complications of your illness or your treatment. This includes things such as dealing with nausea, preventing gout, avoiding/treating constipation, mouth care, blood transfusions, pain management and diet planning.

Infections
Whilst 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
› fast heartbeat and breathing
› difficulty in passing urine or not producing urine
› suddenly increasing pain
› shivering or shaking and feeling cold
› quickly becoming more ill.

Symptoms of infection can be less obvious because of your illness, 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 the end of your treatment. After two years in remission, the chance of relapse decreases.

In the first year after your treatment you’ll have regular check-ups. Then they’ll 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.

You and your healthcare team will discuss at which point you can be discharged and your GP will be your main point of contact.

When you have completed your treatment, there are some specific signs or symptoms you should look out for. If you get any new swellings you should contact the hospital team.

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, depending on which sites in your body are affected, there are many different symptoms which might be related to your condition. It is always advisable to contact the experts and let them decide whether they are significant.

For more information on supportive care > see our booklet Supportive Care

For more information on signs and symptoms to look out for after your treatment > see page 62
Every person is different, so your consultant and healthcare team are the best people to ask about your likely outlook (your prognosis).

The outlook

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

For the majority of people with high-grade NHL, the cancer responds well to treatment. Most people can expect to achieve remission with initial treatment, and you may not need more treatment after this. Depending on the amount and type of treatment you’ve had, it may take some time for you to get back to your normal health.

Unfortunately, it’s more difficult to treat patients with either refractory or relapsed DLBCL. However, there are still many further treatments that can still lead to a full remission.
Everyday life and 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. This section will guide you through both aspects.

Looking after yourself emotionally

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

Your healthcare team should look at your emotional, as well as 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 emotional 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 see – 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.

A list of signs of infection can be found on page 57.

Keeping active
You might feel tired a lot (fatigue). This might be caused by your treatment or condition 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 make your symptoms less severe.

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

Smoking
People who’ve had chemotherapy treatment for high-grade NHL may have an increased risk of late effects, such as heart and lung problems.

The drug doxorubicin used in combination treatment against NHL, for example, has been linked to potentially toxic effects on the heart in later life. If you smoke, your doctor will strongly recommend that you should stop, and will advise on other things you can do to reduce your risk of heart disease.

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 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.

Symptoms include:

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

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.

I had good days and bad days during treatment. I found it helpful to record these ups and downs in a journal, to spot patterns and remind myself of the good days when I wasn’t feeling so well.
Diet
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.

If you have high-grade NHL, there's a myth that eating a sugar-free diet will help during your treatment. Some people think that sugar should be avoided because lymphoma cells take up sugar. But all cells in the body need sugar to work properly – so there is no need to cut sugar from your diet.

You'll need to take extra care to avoid infections that you might get from food. Your body won't be able to destroy germs and resist infection as easily, so be careful about food 'use by' dates and things like keeping cooked and raw meat separate in the fridge.

Vaccination
It's a good idea for all high-grade NHL patients 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.

Babies who have received the oral (by mouth) polio vaccine will pass live virus in their stools (faeces). Because of this, avoid contact with their nappies and the contents – as well as the risk of general infection from their stools, there's a risk of getting polio.

Alternative and complementary therapies
There's an important difference between alternative therapies, which are offered in place of medical treatment, and complementary therapies, which are used alongside standard treatment.

Extensive research has shown no evidence that any alternative therapy has any benefit in treating any form of cancer. We don't recommend that you use any alternative therapy in place of proven medical care.

Always let your healthcare team know about any complementary therapies you're using or thinking of using. They may advise you to avoid certain therapies because of specific risks to do with your NHL or the treatments you're receiving. In other cases they may say a therapy is OK as long as you take specific precautions.

Herbal medicines
Herbal medicines may be safe for a healthy person but they could be dangerous when combined with your chemotherapy. Make sure you talk to your doctor before you consider taking herbal medicines.

Acupuncture
If you're considering acupuncture, you should look for a medically qualified acupuncturist who's likely to follow safe practices to avoid infection. It's likely that your healthcare team will advise against acupuncture, especially when you're not in remission, so it's a good idea to discuss it with your doctor before you go ahead.

This is because acupuncture could cause bleeding if your blood count isn't normal and this can sometimes lead to infection if you're neutropenic (if you have a low amount of neutrophils, a type of white blood cell that helps fight off infections, in your blood).
Practical support
Your work, education and domestic arrangements
If you work or are studying you might want to contact your employer or college about your condition, or you could ask someone to do it for you. Most will do everything they can to help.

You might need to make a short-term arrangement with your employer or college at the time 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 might need to bring in written proof of your diagnosis from your healthcare team, which make clear the effect NHL could have on your ability to work or study.

You may need to consider taking time out from work during your treatment and afterwards. You might hear different advice about this but it’s entirely your decision and it depends on what job you do. If you’re studying at college or university, your doctor might suggest you delay your course for a time.

If you’re a parent or a carer, you might 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 arrangements for ‘people with disabilities’ and cannot discriminate against you. An example of a reasonable arrangement would be if you need time off to go to hospital for treatment. Your employer or college has to allow this and isn’t allowed to reduce your pay or make you take the time as unpaid leave.

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

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

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. 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 with an advisor as soon as possible after your diagnosis.

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

Macmillan Cancer Support has lots of information on financial support > go to page 73 for their contact details
Each year we invest a large part of the money we raise in research which aims to stop people dying from blood cancer; make patients’ lives better; and stop people getting blood cancer in the first place. We have a number of NHL research projects going on. Here’s an overview of some of the things our researchers are looking into.

Researchers in Manchester and London are developing ways to harness the power of the immune system to target various non-Hodgkin lymphomas.

This new approach works by taking a patient’s white blood cells and re-programming them in the laboratory to recognise cancer-specific molecules. These are then given back to the patient so the white blood cells can find and destroy lymphoma cells, like diffuse large B-cell lymphoma (DLBCL).
Relapsed DLBCL can be more resistant to treatment. A protein called mTOR is involved in the growth and survival of cancer cells, but drugs which stop mTOR from doing this don’t work for every person with NHL. Our national Trials Acceleration Programme is running a clinical trial to look at this protein. The trial is testing a new drug to see if it’s better at stopping mTOR from working. The trial is also looking at whether it’s safe to combine this new drug with rituximab, which is often used in NHL treatment.

Studies in Cambridge are finding new biological factors that might help doctors better predict how people with NHL will respond to therapy, and how this new information could help guide decisions about a person’s treatment.

Other work in Leeds and Birmingham is focusing on understanding the biology of DLBCL to find new targets to hit with drugs.

“\n
The research that’s going on is truly amazing. It really gives me and my family hope to know that so much time, energy and wisdom is being devoted to finding new and better treatments.\n
“

Rare forms of non-Hodgkin lymphoma, called T-cell lymphomas, affect the white blood cells known as T lymphocytes (or T cells). A nationwide clinical trial is looking at the treatment drugs used in peripheral T-cell lymphoma, anaplastic large cell lymphoma and angio-immunoblastic T-cell lymphoma. The trial is testing if a different combination of chemotherapy drugs works better than the combination that patients take at the moment.

Another trial in the Trials Acceleration Programme is testing a combination of two drugs that block the growth of peripheral T-cell lymphoma cells, to see if this new treatment option is safe and effective.

Work in Cambridge is also seeking out the ‘master’ cells in anaplastic large cell lymphoma, so that future treatments can be targeted at the root of this cancer.

You can find more information about the latest NHL research on the Cancer Research UK website > go to cancerresearchuk.org and search for ‘NHL research’
Places you can get help and support

Many people affected by blood cancer find it useful to call on the expert information, advice and support offered by a variety of organisations, including ourselves. Here are some we recommend.

Bloodwise
We offer patient information online and in free printed booklets, and have an online community you may like to join.
› 020 7504 2200 › patientinformation@bloodwise.org.uk
› bloodwise.org.uk
We can help with practical and emotional support and signpost you to other available services.
› 0808 2080 888 › patientservices@bloodwise.org.uk

Macmillan Cancer Support
Offers practical, medical, financial and emotional support.
› 0808 808 0000 › macmillan.org.uk

Lymphoma Association
Provides emotional support and information to anyone with lymphatic cancer and their families, carers and friends.
› 0808 808 5555 › lymphomas.org.uk
CancerHelp UK
(Cancer Research UK’s patient support service)
Offers information about different conditions, current research and practical support.

› 0808 800 4040 › cancerresearchuk.org/cancer-help

Leukaemia Care
Offers patient information, a 24 hour care line and support groups for people affected by leukaemia, lymphoma, myeloma, myelodysplastic syndromes, myeloproliferative neoplasms and aplastic anaemia.

› 01905 755 977 (general enquiries) or 08088 010 444 (Care Line)
› care@leukaemiacare.org.uk › leukaemiacare.org.uk

African Caribbean Leukaemia Trust (ACLT)
The ACLT aims to increase the number of black, mixed race and ethnic minority people on the UK Bone Marrow Register by raising awareness and running donor recruitment drives.

› 020 8240 4480 › info@aclt.org › aclt.org

Anthony Nolan
Runs the UK’s largest stem cell register, matching donors to patients with leukaemia and other blood related disorders who need a stem cell transplant.

› 0303 303 0303 › anthonynolan.org

Maggie's Cancer Caring Centres
Centres across the UK, run by specialist staff who provide information, benefits advice and psychological support.

› 0300 123 1801 › enquiries@maggiescentres.org
› maggiescentres.org

Marie Curie Cancer Care
Nine hospices throughout the UK and offers end of life support to patients in their own homes, free of charge.

› 0800 716 146 › supporter.services@mariecurie.org.uk
› mariecurie.org.uk

MedicAlert Foundation
Provides an identification system for individuals with hidden medical conditions and allergies, in the form of emblems you wear on your body and necklaces or wrist bands.

› 0800 581 420 › info@medicalert.org.uk
› medicalert.org.uk
**Financial advice**

Citizens Advice Bureau (CAB)
Offers advice on benefits and help with filling out benefits forms.

› 08444 111 444 (England) or 0844 477 2020 (Wales)  
› adviceguide.org.uk

Department for Work & Pensions (DWP)
Responsible for social security benefits. Provides information and advice about financial support, rights and employment.

› gov.uk

**Travel insurance**

Macmillan Cancer Support
Provides information about what to consider when looking for travel insurance. It also has a list of insurance companies recommended by people affected by cancer.

› 0808 808 0000  → macmillan.org.uk

Association of British Insurers (ABI)
Provides information about getting travel insurance and contact details for specialist travel companies.

› 020 7600 3333  → abi.org.uk

British Insurance Broker's Association (BIBA)
Offers advice on finding an appropriate BIBA-registered insurance broker.

› 0870 950 1790  → enquiries@biba.org.uk  → biba.org.uk
It can be a good idea to write down the questions you want to ask before each appointment.

Questions to ask
It’s easy to forget the questions you wanted to ask when you’re sitting with your healthcare team and trying to take in lots of new information. Some patients find it useful to write down the questions they want to ask before they get there. Here are some questions you might like to ask at different times.

Tests
› What tests will I have?
› What will these tests show?
› Where will I have the tests 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 high-grade NHL at?
Treatment

› 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 recommended?
› If I don’t need to start treatment straight away, how will I know when I need to start it?
› Who do I contact if I take a turn for the worse?
› Who can I contact if I have any questions?
› Is there any written information available or any recommended websites?

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 regimen 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 me 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?

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 prognosis likely to change with more treatment?
If you’re diagnosed with blood cancer you need to know that there are people who can help. You want to know what it means, what’s going to happen, what the treatment is like and what your chances of living a normal life are. You need to know someone is there for you.

Blood cancers represent one in 10 of all new cancer diagnoses – this means that each year 38,000 people are diagnosed with blood cancers and closely related conditions.

We play a vital role, working in collaboration with health professionals, the NHS, government, pharmaceutical companies and other charities to ensure that the needs of blood cancer patients are addressed. We take a leading role in research into blood cancers; we ensure patients have access to innovative clinical trials where possible; we provide information; and we’re a voice of influence when it really counts.

Bloodwise is one of the UK’s leading blood cancer charities, we feel both the responsibility and the opportunity that we have to make patients’ lives better.
Our patient services

We put the patient at the heart of everything we do. We strive to help everyone affected by a blood cancer to live the best possible quality of life, for life. Alongside our ongoing commitment to support vital medical research into the cause and cure of blood cancers, we’re developing and delivering quality support and services for patients, their family, friends and carers to help with the emotional and practical impact of blood cancer.

Through our dedicated Patient Support area on our website, people can share their experiences of blood cancer, connect with each other and access our wide range of patient information. We provide support, information and advice over the phone and online, and we’re constantly developing new ways to support our patients based on what they tell us they want and need.

How we raise money

We don’t get any government funding: it’s the money raised by our incredible supporters that lets us continue our life-saving work.

It’s because of them that we can offer our patient information free of charge to blood cancer patients, so we’d like to say a big thank you to everyone who gives so generously to us.

If you – or anyone close to you – ever feels able to make any kind of donation, large or small, it will help us continue our life-saving work > bloodwise.org.uk/give

Our patient information is available to download, order or read online. You can also blog about your journey there and read about other people’s blood cancer experiences > bloodwise.org.uk/patient-support
How you can get involved

There's lots of other ways you can get involved that will help us achieve our vision of beating blood cancer.

Patient Support
Patient Support is your space to find information, share knowledge and experiences and connect with others affected by blood cancer.

bloodwise.org.uk/patient-support

Patient focus groups
Patients are at the heart of everything we do. That's why we consult patients at every opportunity to get their views about the services we provide. Check our website for upcoming events.

bloodwise.org.uk/focus-groups

Cycling
We like to think we're the UK's premier cycling charity! From short family rides through to our flagship London and Birmingham Bikeathons and epic London | Paris challenge, if you've got a bike you can cycle with us to beat blood cancer.

bloodwise.org.uk/cycling

Running
All around the country, right throughout the year, our unstoppable runners take to the streets to help us beat blood cancer. Whether it's at the London Marathon, one of the Great Run series or a junior run, it's a case of every step counts.

bloodwise.org.uk/running

Triathlons
You won't know what you can do until you tri! Triathlons are ever popular with sporty types who want to conquer swimming, cycling and running, all on the same day! We're the proud title sponsor of the wonderful Blenheim Palace Triathlon but there are so many more on offer.

bloodwise.org.uk/triathlon

Challenges
And then there are some who want to climb mountains, trek through jungles and canoe rivers for us! Get in touch to tell us about your challenge and we'll support you all the way.

bloodwise.org.uk/challenges
How you can get involved

Corporate fundraising
We’re always looking for companies who share our vision of a future without blood cancer and we recognise the benefits that partnering with us can bring your business. We know we can achieve more together than we ever could alone and our dedicated corporate team will work with you to build an innovative, mutually beneficial partnership.

localfundraising

Local fundraising
We were formed back in 1960 by some brave parents in Middlesbrough whose daughter sadly died from leukaemia. Fast forward all these years and our local fundraisers are still right at the heart of our organisation. Our friendly regional teams can support you in every aspect of your fundraising and are always on hand for a chat.

localfundraising

Special events
Meet the likes of Billy Connolly and Miranda Hart at our annual ‘Audience with’ events or flock up for our star-studded ‘Christmas with the Stars’ concert at the Royal Albert Hall. To see our very latest events check out our website.

special-events

Being part of our online community
Short on time? Join our Facebook and Twitter communities. Every quick share could mean a new supporter, a new donation or a new patient finding out about our support services.

facebook.com/bloodwise.uk
twitter.com/bloodwise_uk

Shop with us
To give gifts that give back, visit our online shop. We have a great range of ethically sourced products and 100% of profits go towards beating blood cancer.

shop
Your feedback

We're always looking for ways to improve the information we provide for people with blood cancer.

We welcome your feedback on this booklet and our other patient information. Any improvements you suggest mean we can make better information for other blood cancer patients and people close to them.

To fill in a short survey about our patient information online, please go to > bloodwise.org.uk/bookletsurvey

Other booklets

Leukaemia
› Acute lymphoblastic leukaemia (ALL) in children up to 16 years
› Adult acute lymphoblastic leukaemia (ALL) in children and young adults up to 16 years
› Acute myeloid leukaemia (AML) in children and young adults up to 16 years
› Adult acute myeloid leukaemia (AML)
› Childhood acute myeloid leukaemia (AML)
› Chronic lymphocytic leukaemia (CLL)
› Chronic myeloid leukaemia (CML)

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

Myeloma
› Myeloma

Related conditions
› Myelodysplastic syndromes (MDS)
› Myeloproliferative neoplasms (MPN)

Treatment
› Bone marrow and stem cell transplantation – for children and adults
› Chemotherapy
› Clinical trials
› Donating stem cells
› Donor lymphocyte infusion
› The seven steps – blood & bone marrow transplantation
› Treatment decisions
› Undergoing high dose therapy and autologous stem cell transplant

General
› Complementary and alternative medicine
› Dietary advice for patients with neutropenia
› Newly diagnosed with a blood cancer
› Supportive care
› Watch and wait

For children and young adults
› Jack’s diary
› Wiggly’s world
› Young adults with a blood cancer – what do I need to know?
Cancer can sometimes feel like it has its own language. Here are some of the most common words you might hear:

Glossary

**Anaemia**
Having a reduced amount of oxygen in your bloodstream. This can be caused if you have fewer red blood cells than normal, or if you your red blood cells have less haemoglobin (the protein which carries oxygen) in them.

**B lymphocyte or B cell**
A type of lymphocyte normally involved in producing antibodies to fight infection.

**Blood count, full blood count or FBC**
A blood test that counts the different types of cells in your blood.

**Bone marrow**
A spongy material inside long bones, which 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 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.

**Clinical nurse specialist**
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 nurse specialist can provide information and expert advice about your condition and treatment.

**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’ll always be told if your treatment is part of a trial.

**Fatigue**
Fatigue is a feeling of extreme tiredness which doesn’t go away after rest or sleep. It may be caused by the NHL itself or might be a side effect of treatment. It’s one of the most common problems that patients with cancer have.

**Lymphoma**
The word lymphoma covers several different cancers which affect blood cells called lymphocytes and lymphocyte-producing cells.
Lymphocytes are one type of white blood cell and are part of the immune system, which defends the body against infection. The abnormal lymphocytes are found in lymph nodes (‘glands’) or other lymphoid tissues, so patients 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 foreign materials. It contains white blood cells that fight infection.

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

**Neutropenia / neutropenic**
If you have an abnormally low amount 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 before you were 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 such as lymphoma and myeloma.

**Spleen**
An organ that filters the blood. It sits under your ribs on the left hand side of your body. The spleen has two main jobs: to remove old red blood cells and to help protect your body from infections.

**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 are able to develop into other cell types. Stem cells act as a repair system for your body and replenish other cells. They’re found in embryos and some organs in adults.

**T lymphocyte or T cell**
A type of lymphocyte normally involved in controlling the reaction of the immune system and fighting viral infection.

**Transformation**
The process by which low-grade lymphoma changes in nature to become a faster-growing high-grade lymphoma.
Bloodwise
For adults and children with blood cancer

39-40 Eagle Street, London WC1R 4TH
bloodwise.org.uk
020 7504 2200 (Reception); 0808 2080 888 (Helpline)