MACMILLAN
CANCER SUPPORT

UNDERSTANDING NON-HODGKIN LYMPHOMA

> It was quite difficult for the first few months, as I was living alone. My Macmillan nurse Pat was fantastic and really supported me.

Mario, diagnosed with non-Hodgkin lymphoma

About this booklet

This booklet is about a type of cancer called non-Hodgkin lymphoma (NHL). It is for anyone who has been diagnosed with NHL. There is also information for carers, family members and friends.

The booklet explains what the signs and symptoms of NHL are, how it is diagnosed, and what treatment you might have. It also has information about the feelings you might have, as well as practical information about how your relationships, work and finances might be affected.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

There are several different types of non-Hodgkin lymphoma. You can find more detailed information about them at **macmillan.org.uk/information-and-support/lymphoma/lymphoma-non-hodgkin/understanding-cancer/types-of-non-hodgkin-lymphoma**

There is another type of lymphoma called Hodgkin lymphoma. We have another booklet about this called **Understanding Hodgkin lymphoma**. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

How to use this booklet

To help you find the information you need, we have divided this booklet into sections. You can either read it from start to finish, or you can go straight to any section or chapter in the booklet and start reading from there. For example, if you are having tests to diagnose lymphoma, you may want to go straight to that section for the information you need. It is fine to skip bits of the booklet. You can always come back to them another time.

We have included quotes from people who have been diagnosed with non-Hodgkin lymphoma. We hope you will find these useful. Some are from **healthtalk.org** Others are from people who have shared their stories with us, like Mario, who is on the front cover. To share your experience, visit **macmillan.org.uk/shareyourstory**

Contents

ABOUT NON-HODGKIN LYMPHOMA

The lymphatic system

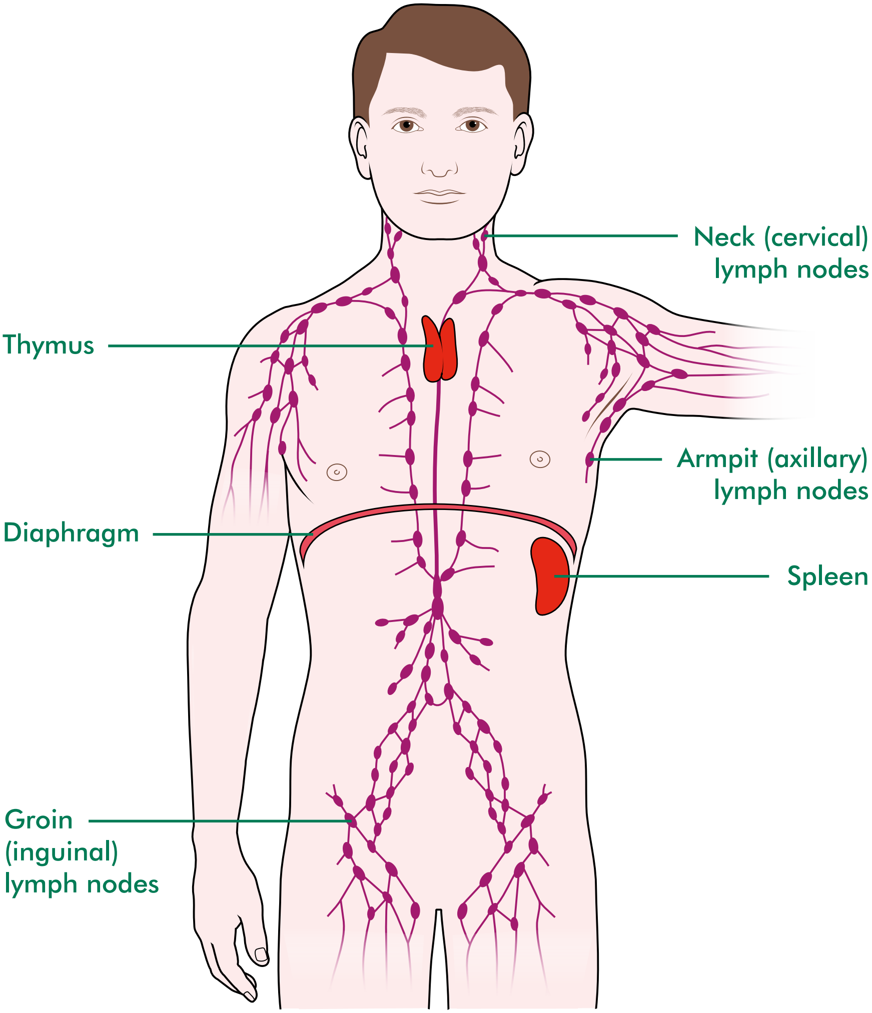
Non-Hodgkin lymphoma (NHL) is a cancer of the lymphatic system. To help you understand NHL, it is useful to know a little about this system and what it does.

The lymphatic system (see diagram on page 8) is part of the body's immune system, which helps to protect us from infection and disease. The lymphatic system also drains fluid from the body's tissues back into the blood.

The lymphatic system includes:

- lymph vessels
- lymph nodes (sometimes called lymph glands)
- lymphocytes (blood cells that fight infection)
- lymphatic organs
- other lymphatic tissue.

The lymphatic system



Lymph vessels are fine tubes that form a network inside the body. A clear fluid called lymph moves through the vessels and nodes and eventually returns to the bloodstream.

There are groups of lymph nodes around the network. As the lymph fluid passes through the nodes, they filter out disease and germs (bacteria and viruses). The lymph nodes contain infection-fighting white blood cells called lymphocytes. Lymph nodes often swell when they are fighting infection. If you have a throat infection, you may be able to feel swollen lymph nodes in your neck below your jaw.

Lymphatic organs include the thymus, which helps some types of lymphocytes to mature. They also include the spleen and the tonsils, both of which help fight or filter out disease and germs.

The bone marrow is the spongy material in the middle of bones. It makes:

- all the different types of white blood cell including lymphocytes
- red blood cells, which carry oxygen from your lungs to other cells in your body
- platelets, which help blood to clot and prevent bleeding and bruising.

There are also other areas of lymphatic tissue where lymphocytes and other infection-fighting cells collect. These areas are mostly found where disease or germs are more likely to enter the body – for example, in the lining of the bowel, lungs and nose.

What is non-Hodgkin lymphoma?

Non-Hodgkin lymphoma (NHL) is a cancer of the lymphatic system (see pages 7 to 9).

NHL is the fifth most common cancer in the UK. Around 13,500 people are diagnosed with it each year. There are many types of NHL. Some grow very slowly and may not need treatment for months or years. In some cases, they may never need treatment. Other types grow quickly and need treatment soon after diagnosis.

How does non-Hodgkin lymphoma develop?

NHL, like other types of cancer, is a disease of the cells in the body.

The body is made up of cells that need to be replaced as they age or are damaged. This happens by cell division, which is when a cell divides and makes new copies of itself.

Normally, cell division is carefully controlled. But sometimes this process can get out of control. Too many cells may be made and a cancer, such as lymphoma, can develop.

In NHL, blood cells called lymphocytes become abnormal. These abnormal lymphocytes are the lymphoma cells. They keep dividing and grow out of the body’s control. Over time, there are enough lymphoma cells to make a lump, called a tumour.

The most common place for this to happen is in the lymph nodes. But NHL can start in almost any part of the body, including the stomach, small bowel, skin, tonsils, thyroid or testicles. Lymphoma that grows outside the lymph nodes is called extra-nodal lymphoma.

Lymphocytes travel around the body. So NHL can spread from where it first started. The lymphoma cells can move through the lymphatic system from lymph nodes in one part of the body to lymph nodes elsewhere. Lymphoma cells can also travel in the bloodstream to organs such as the bone marrow, liver or lungs. They may then carry on dividing and make another tumour.

Risk factors and causes

In many cases, experts don’t know exactly what causes lymphoma. However, some things may increase the risk of developing it.

It is important to remember that having these risk factors does not mean you will get lymphoma. Many people affected by lymphoma do not have any risk factors.

Infections

Some viruses or bacteria can increase the risk of developing NHL.

An infection called helicobacter pylori can sometimes cause a type of NHL called MALT lymphoma. The Epstein Barr virus (EBV), which causes glandular fever, may slightly increase the risk of developing NHL.

Both infections are very common in the UK. But most people who have had these infections will not develop lymphoma.

Lymphoma is not infectious and cannot be passed on to other people.

A weakened immune system

If the body’s immune system is weak, the risk of developing lymphoma may be higher.

Conditions such as HIV can weaken the immune system. Drugs called immunosuppressants also cause this. Some people need this type of drug after an organ transplant or to treat autoimmune disease.

Autoimmune disease

Autoimmune diseases develop when the immune system attacks healthy body tissue by mistake. Several autoimmune diseases can increase the risk of lymphoma. These include conditions called:

- rheumatoid arthritis
- Sjogren's syndrome
- systemic lupus erythematosus.

Doctors do not fully understand why these diseases increase the risk of developing lymphoma. It may be because of the diseases themselves, or because of the treatments used to control them.

Previous cancer

NHL is slightly more common in people who have had cancer before. This may be because of the cancer or because of the cancer treatments. Treatment with radiotherapy, or with some chemotherapy drugs, can increase the risk of developing NHL many years later. But the risk is small compared to the benefit of having the treatment in the first place.

Having a close relative with NHL

Having a parent, brother or sister with NHL may increase your risk of developing it. But the risk of developing NHL is still low, with a lifetime risk of about 3 in 100 (3%). The lifetime risk for people who do not have a close relative with NHL is about 2 in 100 (2%).

Types of non-Hodgkin lymphoma

There are many different types of NHL. Your doctors need to know which type you have so they can give you the best treatment.

B-cell and T-cell lymphomas

Lymphomas develop from abnormal lymphocytes (see page 9). There are two main types of lymphocyte: B-cell lymphocytes and T-cell lymphocytes. If a lymphoma developed from abnormal B-cell lymphocytes, it is called a B-cell lymphoma. If it developed from abnormal T-cell lymphocytes, it is called a T-cell lymphoma.

Types of B-cell lymphoma

B-cell lymphomas are more common than T-cell lymphomas. About 9 out of 10 people diagnosed with NHL (90%) have a B-cell lymphoma.

The most common types of B-cell lymphoma are:

- diffuse large B-cell lymphoma (DLBCL)
- follicular lymphoma (FL).

Other less common types include:

- extranodal marginal zone B-cell lymphoma (also called MALT lymphoma)
- mantle cell lymphoma
- Burkitt lymphoma
- primary mediastinal large B-cell lymphoma
- nodal marginal zone B-cell lymphoma
- splenic marginal zone lymphoma
- small lymphocytic lymphoma
- lymphoplasmacytic lymphoma (also called Waldenström's macroglobulinaemia).

Types of T-cell lymphoma

T-cell lymphomas are much less common than B-cell lymphomas. There are a number of different types of T-cell lymphoma. They include:

- peripheral T-cell lymphoma
- skin (cutaneous) lymphomas – including mycosis fungoides and Sézary syndrome
- anaplastic large cell lymphoma
- angioimmunoblastic lymphoma
- lymphoblastic lymphoma (this is mainly T-cell but can be B-cell).

We have more detailed information about all these different types of lymphoma and their treatment. For other rare types of lymphoma, call us on **0808 808 00 00**. We can give you more information about your illness and its treatment.

Signs and symptoms

The most common early symptom of NHL is a painless swelling in the lymph nodes in one area of the body, such as the neck, armpit or groin.

Some people have other symptoms, depending on where the lymphoma is in their body. Symptoms may include:

- a cough, difficulty swallowing or breathlessness, if the lymphoma is in the chest area
- indigestion, tummy pain or weight loss, if the lymphoma is in the stomach or bowel
- pain – this isn’t common but may be caused by swollen lymph nodes pressing on tissue in a part of the body such as the back or tummy (abdomen).

If NHL spreads to the bone marrow (see page 9), it can reduce the number of blood cells. This can cause:

- tiredness, if you do not have enough red blood cells
- difficulty fighting infections, if you do not have enough white blood cells
- bruising or bleeding, if you do not have enough blood-clotting cells, called platelets.

NHL can also cause general symptoms, including:

- repeated heavy, drenching sweats at night
- high temperatures that come and go without any obvious cause
- unexplained weight loss
- tiredness
- itching of the skin that doesn’t go away.

DIAGNOSING NON-HODGKIN LYMPHOMA

How lymphoma is diagnosed

Usually, you begin by seeing your doctor (GP), who will examine you. They may arrange for you to have blood tests or scans. Your doctor will refer you to hospital for these tests and for specialist advice and treatment. At the hospital, the doctor will ask you about any symptoms, your general health and any illnesses you have had. They will also examine you.

If you think you may be pregnant, let your doctor know. Some tests and treatments for lymphoma can be harmful to a baby in the womb. Pregnant women can often still have tests and treatment for lymphoma. But it is important to talk to your doctor so they can plan your care safely.

Taking a tissue sample (biopsy)

The most important test for diagnosing lymphoma is a biopsy. A doctor or nurse will take a sample of tissue from the affected area. They may use a scan such as an ultrasound or CT scan (see page 22) to guide them to the area. This is called image guided biopsy.

They send the tissue sample to a laboratory to be examined under a microscope and for further tests.

You may have to wait up to two weeks for the results of the biopsy. This is because diagnosing lymphoma is complicated and several tests need to be done.

Lymph node biopsy

Most lymphomas involve the lymph nodes, so the most common place to take a biopsy from is an enlarged lymph node. You may have all or part of the lymph node removed. This may be done using a local anaesthetic to numb the area, or under a general anaesthetic while you are asleep.

For a few days after any biopsy, you may feel sore and bruised around the area. Taking mild painkillers will help. The bruising will go away in a couple of weeks.

Further tests

You will have more tests before you start treatment for lymphoma. Some tests help to show the stage of the lymphoma (see pages 28 to 30). You may have other tests, such as blood tests or x-rays, to check your general health and how well your heart, lungs, liver and kidneys are working.

Information from these tests help your doctors plan your treatment safely and effectively.

You may have some of the tests listed on the following pages.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

PET/CT scan

This is a combination of a CT scan (see above), which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You can't eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

MRI scan

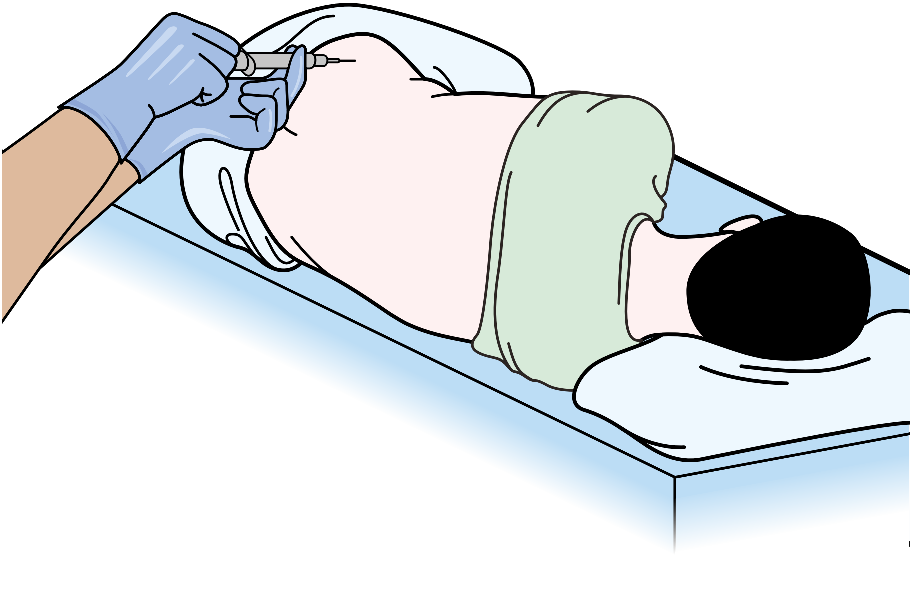
This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc. You should also tell your doctor if you've ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Bone marrow sample

A doctor or nurse takes a small sample of bone marrow from the back of the hip bone (pelvis). The sample is sent to a laboratory to be checked for abnormal cells.

A sample of bone marrow is usually taken from the back of the hip bone



You may have this test on a ward or outpatient clinic. It takes about 20 to 30 minutes and you can usually go home shortly afterwards.

Before the bone marrow sample is taken, you have local anaesthetic injections around the area to numb it. You may also be offered a sedative to relax you. Or, you may be given gas and air (Entonox®) to breathe in through a mouth piece or mask. This helps reduce any discomfort during the test.

The doctor or nurse passes a needle through the skin into the bone (see diagram on the opposite page). They then draw a small sample of liquid from inside the bone marrow into a syringe. This is called a bone marrow aspirate. It can feel uncomfortable for a few seconds when the marrow is drawn into the syringe.

They may also take a small sample of the spongy bone marrow tissue (a trephine biopsy). To do this, the doctor or nurse passes a thicker hollow needle through the skin into the bone marrow. When they take the needle out, it contains a small strip of bone marrow tissue.

You may feel bruised and achy for a few days after this test. Mild painkillers can help. If the pain gets worse, or you notice any bleeding from the area, let your doctor know.

Lumbar puncture

The spinal cord and the brain are surrounded by a fluid called cerebrospinal fluid (CSF). In some types of lymphoma, the lymphoma cells may get into this fluid. Some people may have a lumbar puncture test to check for lymphoma in the CSF.

The test is done on the ward or in the day unit. The doctor numbs the area of skin over the lower spine with a local anaesthetic. They then feel for a space between two bones (vertebrae) in the lower spine and put a thin needle into the space to collect a sample of CSF. After this, they take the needle out and put a small dressing over the skin. The sample of CSF is sent to the laboratory so it can be tested for lymphoma cells.

Most people have no problems with this test, although when the needle is put in, it may cause tingling down the back of your legs. This is harmless, but it can be worrying if you are not expecting it. Some people have a headache for a few days afterwards and may need to take painkillers.

It will probably take several days for the results of your tests to be ready and a follow-up appointment will be arranged for you before you go home.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, a family member or a close friend. Your specialist nurse or one of the organisations listed on our database can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**. To find details about the cancer registry in your area, see pages 126 to 127.

Staging NHL

The stage of a lymphoma describes how many areas of the body are affected by lymphoma and where these areas are. This information helps doctors plan the right treatment for you.

The stage of a lymphoma is usually described using numbers from 1 to 4:

- Stage 1 – there is only one area of lymphoma. This may be one group of lymph nodes, or a different part of the body (called extra-nodal lymphoma).
- Stage 2 – there are two or more areas of lymphoma on the same side of the diaphragm (the sheet of muscle underneath the lungs – see diagram on page 8).
- Stage 3 – there are areas of lymphoma above and below the diaphragm.
- Stage 4 – the lymphoma is more widespread and may also affect organs such as the bone marrow, liver or lungs.

Stages 1 and 2 are also called early-stage, limited or localised lymphoma. Stages 3 and 4 are also called advanced lymphoma.

B symptoms

If you have any B symptoms, the letter B is added after the stage number, for example stage 1B. B symptoms are:

- heavy, drenching night sweats
- unexplained high temperatures
- unexplained weight loss.

If you do not have any of these symptoms, the letter A is used instead, for example stage 1A.

Bulky disease

If an area of lymphoma is 10cm (4 inches) or more in diameter, this is called ‘bulky’ disease. The letter X may be added after the stage number, for example stage 3X.

Extra-nodal lymphoma

Sometimes lymphoma is found in parts of the body outside the lymph nodes. This is called extra-nodal lymphoma.

It's described by adding the letter E (for extra-nodal) after the stage number.

The staging of extra-nodal lymphoma depends on whether the lymphoma:

- started in an organ outside the lymph nodes (this is called primary extra-nodal NHL)
- started in the lymph nodes and then spread somewhere else.

If you have extra-nodal lymphoma, your doctor can explain to you how this affects the stage.

Low-grade and high-grade lymphomas

Lymphomas are also often grouped as either low-grade or high-grade.

Low-grade lymphomas (sometimes called indolent lymphomas)

These grow very slowly and may need little or no treatment for months or possibly years. Some people will never need treatment. Follicular lymphoma (FL) is the most common type of low-grade NHL.

High-grade lymphomas (sometimes called aggressive lymphomas)

These grow more quickly. They usually cause symptoms and need immediate treatment. Diffuse large B-cell lymphoma (DLBCL) is the most common type of high-grade lymphoma.

TREATING NON-HODGKIN LYMPHOMA

Treatment overview

There are several types of treatment for NHL. You may need just one type of treatment or a combination of different types.

Chemotherapy (see pages 46 to 65) is the most common treatment and is usually given with steroids (see pages 66 to 67). Monoclonal antibody therapy (see pages 68 to 70) is also often given with chemotherapy. Together, this is called chemoimmunotherapy. Other treatments that may be used include radiotherapy (see pages 72 to 75), targeted therapy (see pages 68 to 71) and stem cell transplant (see pages 76 to 78).

The treatment you have will depend on:

- the type of lymphoma you have (see pages 14 to 15)
- the stage of your lymphoma (see pages 28 to 30)
- whether the lymphoma is high-grade or low-grade (see page 31)
- which part(s) of your body are affected
- your general health
- your preferences.

How treatment is planned

Usually, a team of specialists called a multidisciplinary team (MDT) meets to plan your treatment.

The MDT may include:

- haematologists and oncologists – these are doctors who specialise in treating lymphoma
- a radiologist – this is a doctor who analyses scans and x-rays
- a clinical nurse specialist, who will make sure you get help and support throughout your treatment.

It may also include other specialists, such as a pharmacist, dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

> ‘Having the right information was very important to me. When I went to my first appointment, I felt the consultant was more open with me because I had informed myself about my cancer.’
>
> **Kewcha**

Talking about your treatment options

Your lymphoma doctor will talk to you about your treatment options. You might find it useful to write down a list of your questions before you meet with them. You can use the space on page 129 to do this. It's also a good idea to have a family member or friend with you at the meeting. They can help you remember what was said and talk it over with you afterwards.

Your doctor will explain what your treatment involves and what its main aims are. This may be to:

- try to cure the lymphoma
- control it for as long as possible
- relieve symptoms.

They will also explain the side effects of treatment. People often worry about these, but most side effects can be controlled or managed.

If you do not understand something, ask your doctor or nurse to explain it again. If you feel worried about anything, it is important to discuss this with your doctor.

Deciding about treatment

You decide on your treatment plan with your lymphoma doctor. Your doctor is an expert in lymphoma and treatments. But you know best about what you want and what you believe is right for you.

You may find it easy to make your decision, especially if you are told that treatment has a good chance of curing the lymphoma or putting it into remission. But sometimes the decision is more complicated. You may find it harder to decide to have treatment if you are told that it has a smaller chance of working or a high risk of side effects.

Some people are offered a choice of treatment plans. Before you decide which one is right for you, make sure you have enough information about the different options. Check that you understand what each treatment will be like, and the possible advantages and disadvantages of each one. You may have more than one meeting with your doctor to discuss your treatment plan.

Second opinion

Your multidisciplinary team (MDT) uses local and national treatment guidelines to decide on the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your lymphoma doctor or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

Giving your consent

Before you have any treatment, your doctor will usually ask you to sign a form. This form gives permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent. Before your doctor asks you to sign the form, they should give you full information about:

- the aims of the treatment
- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

You are free to choose not to have the treatment. If you decide not to have treatment for the lymphoma, you can still have treatment to help control any symptoms. A doctor will record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to let the staff know your concerns. This will help them give you the information you need.

Treating low-grade lymphoma

Early-stage low-grade lymphoma

Up to 1 in 5 people with low-grade lymphoma (20%) have early-stage or localised disease (stage 1 to 2) when they are diagnosed.

The most common treatment is radiotherapy to the affected lymph nodes. This usually makes the lymphoma disappear completely, and many people are cured after having it.

If radiotherapy is not suitable for you, you will be offered the same treatment options as the ones used for advanced lymphoma (see below). The treatment options will depend on whether you have symptoms or not.

Advanced-stage low-grade lymphoma

Most people with low-grade NHL have advanced-stage lymphoma (stage 3 or 4) when they are diagnosed. Because low-grade lymphoma is often very slow-growing, some people do not need to start treatment straight away.

If you do not have any symptoms

If you are not having problems with symptoms, your specialist may offer you a choice between:

- delaying treatment until symptoms develop (this is called watch and wait – see pages 43 to 45)
- having treatment with rituximab (see page 69).

If you have symptoms

When low-grade NHL causes symptoms, the most commonly used treatments are:

- chemotherapy
- rituximab
- a combination of both chemotherapy and rituximab.

These treatments are often very successful at shrinking the lymphoma so you feel well and do not have any symptoms. This is called remission.

When the lymphoma is in remission, some people have a further course of treatment with rituximab. This is called maintenance treatment.

After a period of remission, which may last for years, low-grade lymphoma eventually comes back. But with more treatment, it often shrinks back down again, giving another period of remission. In this way, lymphoma may be controlled for years, even decades, and most people have a good quality of life.

Transformation of lymphoma

Over time, about 1 in 3 low-grade lymphomas become high-grade (33%). If this happens, the transformed lymphoma is treated as a high-grade lymphoma.

Sometimes both low-grade and high-grade NHL are diagnosed in the same person, at the same time. If this happens, the NHL is treated as a high-grade lymphoma.

Treating high-grade lymphoma

High-grade lymphoma is usually fast-growing and needs treatment soon after it is diagnosed. The aim is to make the lymphoma disappear completely. This is called complete remission.

The most common treatment is chemotherapy given into a vein. This is often given in combination with a monoclonal antibody (see pages 68 to 70). Most people have their treatment as an outpatient. Chemotherapy can often shrink high-grade lymphoma very quickly.

Sometimes, radiotherapy is used after chemotherapy. It is most likely to be used if the lymphoma was in just one area of the body. It may also be used if the lymph nodes were very enlarged (bulky) before chemotherapy was given.

Some types of high-grade lymphoma may spread to the brain. If there is lymphoma in your brain or a high risk of it spreading there, you may be given additional treatments. This may include having chemotherapy directly into the fluid in the spine. This is called intrathecal chemotherapy.

Many people with high-grade NHL are cured. But in some people, the lymphoma will come back. If this happens, the lymphoma can sometimes be put back into remission with further treatment. Some people are offered more intensive treatment than their first. The aim is to try to cure the lymphoma. This treatment may involve high-dose chemotherapy with stem cell support (autologous stem cell transplant) or using another person’s stem cells (donor or allogeneic stem cell transplant). See pages 76 to 78 for more about stem cell transplants.

Watch and wait

Your doctor may suggest that you don’t need to start treatment straight away. Instead you have regular tests and appointments to monitor the lymphoma and check for signs that you need to start treatment. This is called watch and wait. It is a way of delaying treatment until it is needed.

Watch and wait is an option for some people with low-grade lymphoma. It is not suitable for high-grade lymphoma.

Watch and wait is most likely to be offered to people who have low-grade lymphoma but who do not have symptoms.

A watch and wait treatment plan lasts an average of about three years. For some people, it is shorter than this, and for others it can be much longer.

Sometimes people worry about not having treatment immediately. But there can be advantages to delaying treatment.

Advantages of watch and wait

- Studies have shown that people who decide to put off having treatment until it is needed live as long as people who start their treatment immediately. They also respond just as well to treatment.
- You will not experience side effects from treatment until it is absolutely necessary.
- Effective treatments can be kept in reserve for you until they are needed.
- Low-grade lymphoma can go through periods when it is more active and others when it is stable or even shrinks. In some people, the lymphoma may shrink without any treatment. This is called spontaneous regression.

Monitoring

Even when you are not having any treatment for lymphoma, you will still see your lymphoma doctor regularly. At each appointment, they will check you for signs that you may need to start treatment. These signs might include:

- unexplained weight loss, severe night sweats or unexplained fever (B symptoms – see page 29)
- a lower than normal number of red blood cells (anaemia), white blood cells or platelets in your blood
- the lymphoma starting to grow quickly
- the lymphoma starting to affect an important organ, such as a kidney
- the lymph nodes getting bigger and bulky
- a build-up of fluid in the tummy area (ascites) or in the lining of the lungs (pleural effusion).

Coping with watch and wait

If you are worried about delaying treatment, here are some helpful tips from people who have experienced watch and wait:

- Make sure you understand why watch and wait is recommended and what other treatment options there may be (see page 34). If you have any concerns, talk to your doctor.
- Think of your time without treatment as an opportunity to make the most of your quality of life. Use it to do things you enjoy, and to get as fit and healthy as you can.
- Try to focus on the present rather than what might happen in the future.
- Express your feelings – you can do this by talking to family and friends, joining a support group or online forum (see pages 82 to 83), or by keeping a journal.

Although watch and wait can be difficult to adjust to at first, many people find it gets easier as time goes on.

Chemotherapy

Chemotherapy is often used to treat lymphoma. It uses anti-cancer (cytotoxic) drugs to destroy lymphoma cells. Cytotoxic means the drugs are toxic to cells.

Most people have chemotherapy as an outpatient. Usually you have a combination of two or more chemotherapy drugs. The drugs are usually given as liquids into a vein (intravenously) or as tablets.

You have the chemotherapy drugs over one or a few days. Then you have a break of a few weeks without chemotherapy. The treatment and break is called a cycle of treatment. The break allows your body to recover from any side effects before you start the next cycle.

Your whole course of chemotherapy treatment may last several months. During this time, you have regular check-ups at the hospital. You usually have a scan before starting chemotherapy and then again at the end. You may also have a scan part of the way through your course of treatment. These scans help check how the treatment has worked in shrinking the lymphoma.

Chemotherapy drugs for NHL

There are several chemotherapy treatments that work well for NHL. The most commonly used treatments include the following.

- CHOP – this is a combination of the chemotherapy drugs cyclophosphamide, doxorubicin (hydroxydaunorubicin) and vincristine (Oncovin®) given into a vein, and steroid tablets called prednisolone (see pages 66 to 67).
- CVP – this is a combination of the chemotherapy drugs cyclophosphamide and vincristine given into a vein, and prednisolone tablets. Sometimes a drug called gemcitabine is added to CVP, to make a treatment combination called GCVP.
- Bendamustine – this is a chemotherapy drug given into a vein.
- Chlorambucil – this is a chemotherapy drug taken as tablets.
- Fludarabine – this is a chemotherapy drug often given in combination with other drugs. It can be given into a vein or taken as tablets.

Chemotherapy may be given in combination with a targeted therapy (see pages 68 to 71). The most commonly used targeted therapy is a monoclonal antibody called rituximab. This is often used to treat B-cell lymphomas (see pages 14 to 15). When chemotherapy and rituximab are given together, the letter R is added to the treatment name, for example R-CHOP or R-CVP. The combination of chemotherapy and rituximab is sometimes called chemoimmunotherapy.

We have more information about different chemotherapy drugs and their side effects. Call us on **0808 808 00 00** or visit **macmillan.org.uk/chemotherapy** to find out more.

How chemotherapy is given

Chemotherapy into a vein

Chemotherapy given into a vein (intravenously) goes directly into your blood and is carried to all areas of your body.

It can be given through:

- a cannula
- a central line
- a PICC (peripherally inserted central venous catheter) line
- an implantable port (portacath)

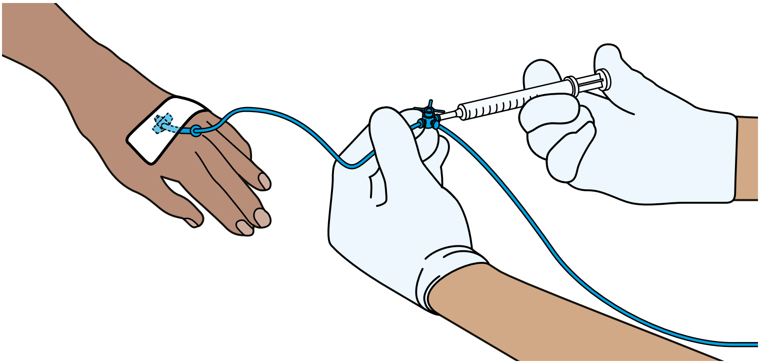
Chemotherapy drugs can be given into a cannula, line or port by injection, as a drip or through a pump. Your nurse will check that the cannula, line or port is working properly before giving you chemotherapy.

Cannula

A cannula is a thin tube which is put into a vein in the back of your hand or lower arm. Your nurse will place a see-through dressing over it to make sure it stays in place. Having a cannula put in can be a bit uncomfortable or painful, but it shouldn't take long and any pain soon wears off.

The cannula is removed before you go home.

Having chemotherapy through a cannula

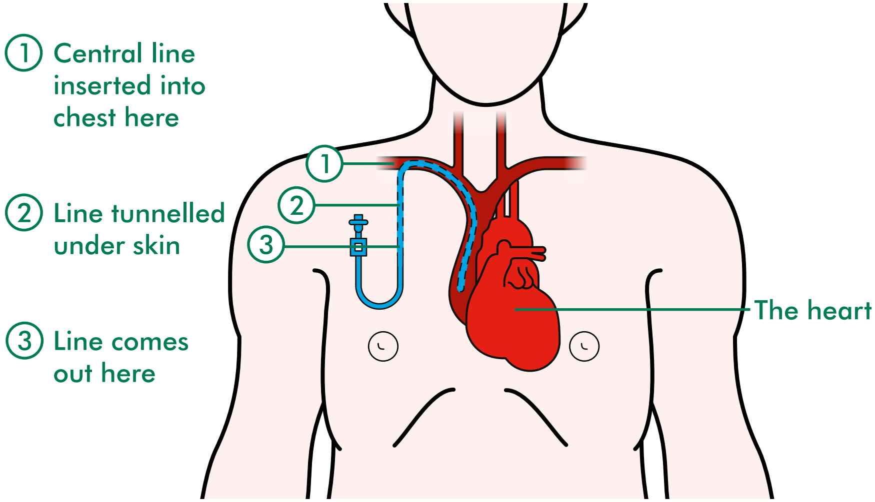


Central line

A central line is a long, thin, hollow tube that is inserted into a vein in your chest. They're sometimes called skin-tunnelled central venous catheters. But you may hear them called by brand names, such as Hickman® or Groshong® lines.

The line is put in under a general or local anaesthetic. It should be completely painless, but you might have a stiff shoulder for a couple of days. Once it's in place, the central line is either stitched or taped firmly to your chest to prevent it from being pulled out of the vein.

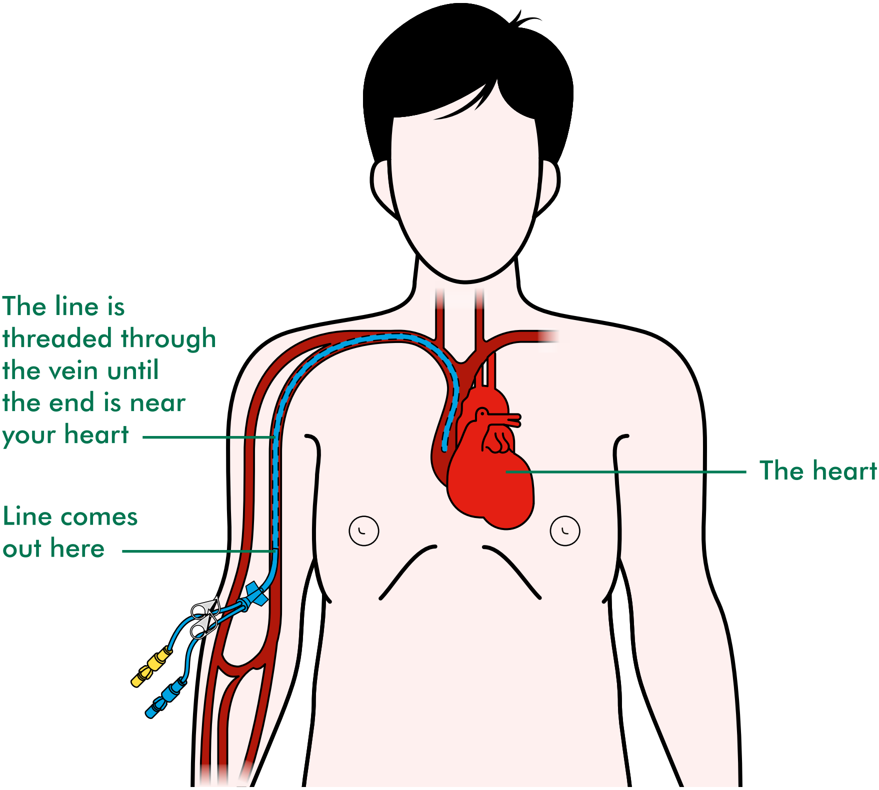
A central line



PICC (peripherally inserted central catheter) line

A PICC line is a long, thin, hollow tube that is inserted into a vein near the bend in your elbow. You'll be given a local anaesthetic to numb the area before the line is put in. The line is gently threaded along the vein until the tip sits in a large vein in your chest. The end of the line comes out just below the crook of your elbow. Once it's in place, the PICC line is taped firmly to your arm to prevent it being pulled out of the vein.

A PICC line



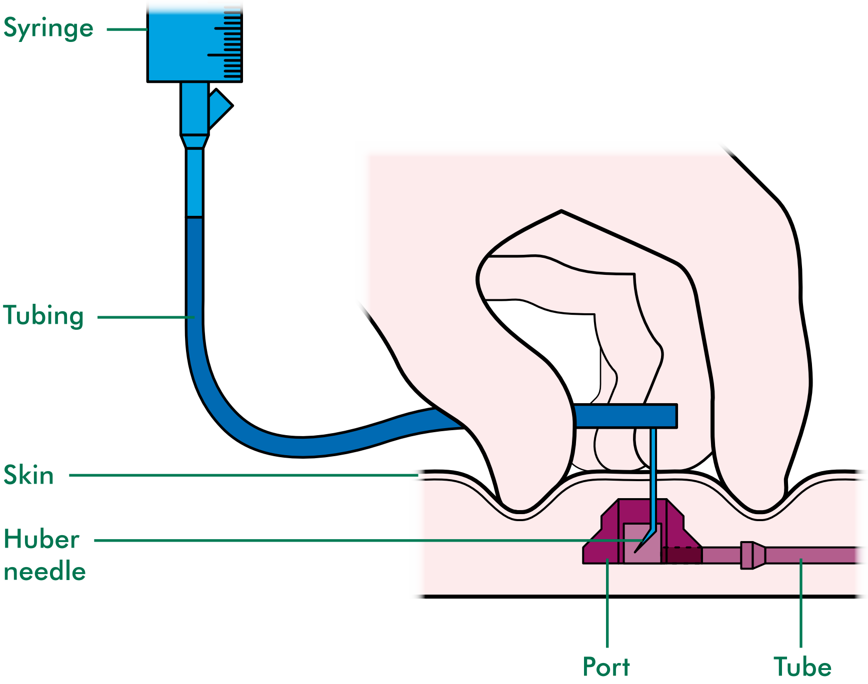
Implantable port (portacath)

An implantable port is a thin, soft plastic tube with a rubber disc (port) at the end. It can be put in under a general or local anaesthetic. The tube is inserted into a vein until its tip sits just above your heart and the port lies under the skin on your upper chest. Once it's in place, you can feel and see the port as a small bump underneath the skin of your chest, but nothing shows on the outside of your body.

To use the portacath, a special needle called a Huber needle is passed through your skin into the port. Your nurse can give medicines into the vein or take blood. The skin over the port can be numbed with an anaesthetic cream first so you don't feel any discomfort.

> 'I have a portacath. It has been wonderful. It was inserted by a surgeon under a local anaesthetic. Instead of loads of needles, I just have one needle and blood is taken that way. All the chemo was administered through it too.'
>
> **Sandra**

An implantable port



Your line or port after chemotherapy

If you have a line or port, it can be left in until your whole course of chemotherapy is over. This means you won't need a cannula or needles put into the veins in your arm every time you have treatment. You can also have blood tests taken from your line or port. Antibiotics, fluids or a blood transfusion can be given through it too.

When your course of treatment is over, the line or port will be taken out. A doctor or nurse will do this for you, usually in the outpatient department.

We have more information about central lines, PICC lines, and implantable ports. Call us on **0808 808 00 00** or visit **macmillan.org.uk**

Chemotherapy tablets

Some chemotherapy drugs are taken as tablets or capsules. This is just as effective as other types of chemotherapy. The drug is absorbed into your blood and carried around your body just like intravenous chemotherapy.

Your cancer specialist will tell you when to take your chemotherapy tablets or capsules. They will also give you other instructions, such as whether or not to take them with food.

It's very important to follow the guidelines below.

- Read the labels on the boxes before you leave the hospital. If instructions are unclear, ask your nurse, doctor or pharmacist.
- Take your drugs exactly as prescribed. Not taking them at the right times can affect how well the treatment works.
- Contact your nurse or doctor at the hospital immediately for advice if you can't take your medicines for any reason or are sick after taking them.

Chemotherapy by mouth can cause side effects, just like chemotherapy into a vein. It is important to know what those side effects are. You also need to know how to store your drugs safely.

Chemotherapy into the spinal fluid (intrathecal chemotherapy)

With some types of NHL, there's a higher risk of lymphoma cells getting into the brain. This can happen with some types of high-grade NHL or when lymphoma is in certain areas of the body.

Doctors use extra treatment to treat or prevent lymphoma in the brain. The doctor puts a small amount of liquid chemotherapy into the spinal fluid. This is called intrathecal chemotherapy. It's done in a similar way to a lumbar puncture. The chemotherapy drug most commonly used is methotrexate. Most people have intrathecal chemotherapy treatment as an outpatient.

Another way to treat or prevent lymphoma in the brain is to give high doses of methotrexate into a vein. In this situation, intrathecal chemotherapy may not be needed.

We have more information about methotrexate and intrathecal chemotherapy on our website – visit **macmillan.org.uk**

Side effects of chemotherapy

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines and they will usually go away once treatment has finished. Not all drugs cause the same side effects, and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that is planned for you. We explain the main side effects here, as well as some ways to reduce or control them.

Risk of infection

Chemotherapy can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more chemotherapy. If your white blood cell count is low, your doctor may delay your treatment for a short time.

Anaemia (reduced number of red blood cells)

Chemotherapy may reduce the number of red bloods cells (haemoglobin) in your blood. A low level of red blood cells is known as anaemia, which can make you feel very tired and lethargic. You may also become breathless.

Anaemia can be treated with blood transfusions. This should help you to feel more energetic and ease the breathlessness. People treated with the chemotherapy drugs fludarabine or bendamustine should only have blood that has been treated with x-rays (irradiated).

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you can’t explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Feeling sick

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

Constipation

This treatment can cause constipation. Here are some tips that may help:

- Drink at least two litres (three and a half pints) of fluids each day.
- Eat high-fibre foods, such as fruit, vegetables and wholemeal bread.
- Do regular gentle exercise, like going for short walks.

If you have constipation, contact the hospital for advice. Your doctor can give you drugs called laxatives to help.

Taste changes

You may find that your sense of taste changes, or that the texture of food seems different. This may be due to the lymphoma, or it can be a temporary change following cancer treatment. You may no longer enjoy certain foods, or find that all foods taste the same. Some people having chemotherapy notice a metallic taste in their mouth. Others find that food has no taste at all.

Sore mouth

You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. It depends on what chemotherapy drugs you are having (your doctor or nurse can tell you more about what to expect). If you do experience hair loss your hair should start to grow back within about 3 to 6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Effects on the heart

Some of the drugs used to treat lymphoma can affect the heart. It can depend on the type of drug and how much you are given. Your doctor will plan your treatment carefully and monitor the doses you are given.

You may have tests to check your heart health before, during and after treatment.

Effects on the lungs

Before you start treatment, you may have tests to check how well your lungs are working. This is because some drugs used to treat lymphoma can affect the lungs. If you become more breathless or develop a cough, it is important to tell your doctor or nurse specialist immediately.

If you are a smoker, it is a good idea to stop smoking before having treatment.

We have more information about giving up smoking that may help. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment affects the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes, but for some people they may never go away. Talk to your doctor if you are worried about this.

More information

We can send you more information on many of these side effects. Visit **macmillan.org.uk** or call us on **0808 808 00 00**.

Sex and chemotherapy

Sex

It is not known if chemotherapy drugs pass into semen or vaginal fluids. Because of this, it is advisable to use condoms for a few days after chemotherapy, to protect your partner.

Remember that cancer cannot be passed on to your partner, and sex will not make the cancer worse.

Contraception

It is not advisable to become pregnant or father a child while having chemotherapy drugs used to treat lymphoma. This is because they may harm the developing baby.

It is also important to use effective contraception for a period of time after treatment ends. You can discuss this with your doctor or specialist nurse.

Our booklets **Cancer and your sex life – information for men** and **Cancer and your sex life – information for women** have more information and helpful advice. Call us on **0808 808 00 00** to order a free copy.

Possible effects on fertility

Unfortunately, some chemotherapy drugs can cause infertility. Infertility is the inability to become pregnant or to father a child. This may be temporary or permanent, depending on the treatment that you have.

It's important to discuss your infertility risk with your cancer doctor before you start chemotherapy. If you have a partner, it's a good idea to include them at this discussion.

Women

Some, but not all, chemotherapy drugs may temporarily or permanently stop your ovaries producing eggs.

Chemotherapy may cause your periods to become irregular or stop for a while (temporary infertility). But after treatment stops, the ovaries can start producing eggs again and your periods may return to normal. It can take between a few months and two years for them to come back again. The younger you are, the more likely you are to have periods again and still be fertile after chemotherapy.

If your periods don't come back you won't be able to become pregnant and will have your menopause.

It's important to know if your fertility is likely to be affected before chemotherapy starts. Speak to your cancer doctor or nurse about it. You can then decide if you want to be referred to a fertility specialist. A fertility specialist can discuss possible options to help preserve your fertility, such as storing embryos (fertilised eggs) or eggs, with you.

You can read more information in our booklet **Cancer treatment and fertility – information for women**.

Men

Some chemotherapy drugs have no effect on fertility. But others can slow down or stop you producing sperm. For most men, this will be temporary. Any problems with sperm production won't stop you from getting an erection or enjoying sex.

Even if your chances of becoming infertile are low, you may still be advised to store sperm for use in the future. This has to be done before you start chemotherapy. Teenage boys at risk of infertility should also, if possible, have their sperm stored for later years.

You will usually be asked to produce several sperm samples over one or two weeks. These will be frozen and stored so they can be used later to try to fertilise an egg and make your partner pregnant.

It can take a few years for your sperm count to go back to normal after chemotherapy. Unfortunately, in some men infertility is permanent. Your doctor can check your sperm count after your treatment is over.

You can read more information in our booklet **Cancer treatment and fertility – information for men**. For a free copy call **0808 808 00 00** or visit **be.macmillan.org.uk**

Steroid therapy

Steroids are drugs that are often given with chemotherapy (see pages 46 to 65) to help treat lymphoma. They may also help you feel better and feel less sick during chemotherapy. The steroids most commonly used to treat lymphoma are called prednisolone and dexamethasone.

Side effects of steroids

Your treatment for lymphoma may involve taking steroids for a few days at a time during every cycle of chemotherapy.

Possible side effects include:

- indigestion
- increased appetite
- weight gain
- swollen ankles
- having more energy or feeling restless
- difficulty sleeping
- skin rash or acne.

Tell your doctor if you have any side effects that are causing you trouble.

If you have indigestion, it can help to take your steroids with food. Your doctor may also prescribe drugs to prevent indigestion. Tell your doctor if you have stomach pains while taking steroids.

Taking your steroids in the morning may help reduce sleeping problems.

Sometimes, steroids may cause a temporary increase in your blood sugar level. You may have regular blood or urine tests to check this. During treatment, tell your doctor if you get very thirsty or if you are passing more urine than usual. If you have diabetes, tell your doctor before you start taking steroids.

Side effects usually get better when you finish taking steroids. But some people feel tired, have aches and pains, or have low moods when they stop taking them. This usually gets better within 2 to 3 days as your body adjusts to the change in steroid levels.

Targeted therapy

Targeted therapies (also called biological therapies) are drugs that use unique features of the cancer to find and destroy cancer cells. These drugs mainly ‘target’ the cancer cells, so they have less effect on healthy cells.

The main type of targeted therapy used to treat NHL is a monoclonal antibody called rituximab. This works by encouraging the body’s immune system to attack and destroy the lymphoma cells.

Monoclonal antibody therapy

Antibodies are part of the body’s natural defence against infection. They recognise harmful cells and destroy them.

Monoclonal antibodies are man-made drugs designed to target certain types of cell. Monoclonal antibody treatments for NHL are designed to target and destroy lymphocytes. The treatment is given as a drip into a vein (intravenous infusion) and can usually be given to you as an outpatient.

The monoclonal antibody most commonly used to treat NHL is rituximab. See the next page for details.

Rituximab

Rituximab is used to treat some types of B-cell NHL, including the two most common types: follicular lymphoma and diffuse large B-cell lymphoma (see page 14). Rituximab may be given on its own or in combination with chemotherapy (see pages 46 to 65).

Rituximab attaches to a protein called CD20 on the surface of B-cell lymphocytes. This stimulates the body's natural defence (the immune system) to attack and destroy the lymphocytes. Because of this, doctors sometimes call it immunotherapy.

Treatment with rituximab reduces the number of healthy B-cells, as well as destroying lymphoma cells. But once the treatment has finished, the level of healthy B-cells in the blood will usually gradually return to normal.

Rituximab can be used in different ways. We have more information about rituximab that we can send you.

Maintenance treatment

For some types of NHL, rituximab treatment continues after the lymphoma is in remission. The aim is to keep the lymphoma away for as long as possible. It may be given every 2 to 3 months for up to 3 years, or for as long as it is keeping the lymphoma in remission. This is called maintenance treatment.

Other monoclonal antibodies

Several other monoclonal antibodies are also being developed. You may be offered these as part of a research trial – see pages 79 to 80.

Possible side effects

Infusion reaction

Sometimes, people have a reaction while being given a monoclonal antibody, or soon after.

The symptoms of a reaction may include:

- a high temperature (fever)
- shakes (rigors)
- a rash
- low blood pressure
- feeling sick (nausea).

A reaction is most likely to happen the first time you have the treatment, so you will be given your first infusion slowly to reduce the chance of one occurring. You will also be given medicines to help reduce any reaction that does happen. Reactions are usually milder with a second infusion, and any more after that.

Lowered numbers of blood cells

Monoclonal antibodies can temporarily reduce the number of normal white blood cells in your blood. During this time, you are more likely to get an infection and you may get tired easily. If you have any signs of infection during chemotherapy, it is very important to contact the hospital for advice immediately.

See pages 57 to 58 for more information about the side effects that can be caused by a reduced number of blood cells.

Other targeted therapies

People with some rarer types of NHL may have other types of targeted therapy as part of their treatment.

A targeted therapy drug called bortezomib (Velcade®) is sometimes used as part of the treatment for mantle cell lymphoma. It is given as an injection into a vein or as an injection under the skin (subcutaneously).

Other types of targeted therapy are being developed. They may be used to treat lymphoma as part of a clinical trial (see pages 79 to 80).

We have more information about targeted therapy drugs and their side effects. Visit **macmillan.org.uk** to find out more.

Radiotherapy

Radiotherapy treats cancer by using high-energy rays that destroy cancer cells, while doing as little harm as possible to normal cells. It only treats the area of the body that the beams are aimed at.

Radiotherapy is given in the hospital radiotherapy department, usually as daily sessions from Monday to Friday, with a rest at the weekend. The length of your treatment will depend on the type and stage of the lymphoma. But it is normally no more than three weeks.

We have more information about having radiotherapy. Call us on **0808 808 00 00** or visit **macmillan.org.uk**

When is radiotherapy used?

Radiotherapy can be used to treat groups of lymph nodes (see pages 7 to 9) that are affected by lymphoma.

For some people with low-grade NHL in just one group of lymph nodes, radiotherapy may be the only treatment needed. Sometimes radiotherapy is used after chemotherapy to treat low-grade or high-grade NHL.

If low-grade NHL returns in just one area of the body, radiotherapy may be used instead of chemotherapy.

Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it's as effective as possible. Treatment is planned by a cancer specialist (clinical or radiation oncologist). This may take a few visits.

On your first visit to the radiotherapy department, you will be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

You may need some small marks made on your skin to help the radiographer (who gives you your treatment) position you accurately. These marks will show where the rays will be directed. They must stay visible throughout your treatment, and permanent marks (like tiny tattoos) are usually used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

If you are having radiotherapy to your neck, you may need to wear a mask during treatment sessions. This is made for you before you have treatment.

We have more information about radiotherapy masks. Call us on **0808 808 00 00** or visit **macmillan.org.uk**

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you'll be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Possible side effects of radiotherapy

Radiotherapy often causes tiredness. You will also lose hair in the treated area. Other side effects will depend on the part of your body being treated. Treatment to the tummy area (abdomen) can make you feel sick or be sick, and can cause diarrhoea. If you have radiotherapy to the neck, it can make your mouth or throat dry and sore.

Side effects can be mild or they might cause you more trouble, depending on how much treatment you have. Your cancer doctor will tell you what to expect. Most side effects disappear gradually once your radiotherapy treatment is over.

Always tell your cancer doctor and specialist nurse about your side effects during and after radiotherapy. They can prescribe drugs to control them and give you advice on how to manage them.

Radiotherapy can have long-term side effects. These are rare and will vary depending on the part of the body treated. Your cancer doctor can tell you more.

> ‘I am almost recovered now, ten days on from radiotherapy. And I’m sure I will be fine in another couple of days.’
>
> **Raquel**

Tiredness

Tiredness usually begins towards the end of treatment and can continue for several weeks after treatment finishes.

Feeling sick (nausea)

If you feel sick, your doctor can prescribe anti-sickness (anti-emetic) drugs. If you don't feel like eating, you can replace meals with nutritious high-calorie drinks. These are available from most chemists or they can be prescribed by your doctor.

Skin reaction

During your treatment, avoid using soaps, perfumes and lotions on your skin, other than the ones advised by the radiotherapy staff.

After a few treatments, skin around the area being treated may become red or darker. It may also feel sore or itchy. If you develop a skin reaction, tell the radiotherapy staff as soon as possible. They will advise you on the best way to manage it.

Hair loss

Although radiotherapy can cause hair loss, this only happens in the area being treated. For example, if you have radiotherapy to the lymph nodes in your neck, you may lose the hair on the back of the neck. Radiotherapy to the lymph nodes in the chest may make the hair on your chest fall out.

Hair usually grows back after treatment.

Radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, throughout your treatment.

Most side effects should gradually disappear once your treatment finishes, but tell your doctor if they continue. We can send you more information about all the side effects listed here.

Stem cell transplant

Stem cells are early blood cells, which can make all the different types of blood cell you need. There are two types of stem cell transplant. One uses your own stem cells. The other uses stem cells from someone else (a donor).

Most people who have NHL will not need a stem cell transplant. But it may be used to treat types of NHL that don't respond well to the most commonly used chemotherapy treatments. It is also sometimes used to treat people who have NHL that has come back (relapsed) after treatment.

A stem cell transplant is an intensive treatment. It is only suitable for people who are fit enough to cope with the side effects. If your doctor recommends it as part of your treatment, they will discuss the possible benefits and disadvantages with you.

Because stem cell transplants are complicated treatments and carry some risk, they are done in specialist hospitals. This means you may have to be treated in a hospital some distance from your home.

Research is being done to find the best ways to use stem cell transplants to treat NHL. Your specialist may talk to you about having a stem cell transplant as part of a research trial (see pages 79 to 80).

Having a stem cell transplant

A stem cell transplant works best if you are in remission at the time that you have it. For this reason, you will have chemotherapy (see pages 46 to 65) to put the lymphoma into remission before having a stem cell transplant.

Once you are in remission, stem cells are collected from either your own blood or the donor's blood and they are stored. This is done as an outpatient. You will then be admitted to hospital, usually a few weeks later, to have more chemotherapy. This is called conditioning treatment. Sometimes radiotherapy is also given as part of conditioning. The aim is to remove any remaining lymphoma cells and to prepare your bone marrow for the transplant. Bone marrow is where blood cells are made.

A day or two after this, you are given the stem cells into your blood through a drip. The stem cells travel to your bone marrow. After a few weeks, your bone marrow starts to make blood cells again. Until your bone marrow recovers, you are at a high risk of getting an infection and will need to stay in hospital.

High-dose treatment with stem cell support (autologous stem cell transplant)

This involves being given your own stem cells. The main benefit is that it allows you to have more intensive doses of chemotherapy to treat the lymphoma. Most people having an autologous stem cell transplant need to be in hospital for 3 to 5 weeks. Then they take 3 to 6 months at home to fully recover.

Donor (allogeneic) stem cell transplant

In this type of transplant, you are given stem cells from another person (a donor). The donor's stem cells help your bone marrow recover from chemotherapy and give you a new immune system that can fight any remaining lymphoma.

This kind of transplant can have more risks than an autologous transplant. It may be used for people with lymphomas that are difficult to treat using less intensive therapies.

We can send you more information about high-dose treatment with stem cell support, and donor stem cell transplants. To order free copies, call **0808 808 00 00** or visit **be.macmillan.org.uk**

Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail. We can send you a copy.

Coping with treatment

Treatment for lymphoma usually takes several months. During this time, you may find you have to make changes to your home or work life. You may have practical or emotional challenges. Or you may need extra support to help you cope.

Who can help?

During your treatment, someone from your healthcare team will be your main contact person. This is often a clinical nurse specialist. (In England, this person is called a key worker.) Their name and contact details should be recorded in your case notes and given to you. If you have questions or need advice about your treatment, they will be able to help.

The hospital social worker can give you information about social services, such as:

- meals on wheels
- a home helper
- travel costs
- childcare.

You may find you have lots of strong emotions during your treatment. If you need help to cope with these feelings, your hospital doctor, clinical nurse specialist or GP may be able to help. They can arrange for you to see a doctor or counsellor who specialises in supporting people with cancer and their families. Or call us free on **0808 808 00 00** for advice about counselling and services in your area.

Sharing your experience

Many people find it helps to talk about what they are going through. You may want to talk to someone you know well. This could be a parent, sibling, partner or friend. Or you may decide to talk to someone outside your family and friends. This could be your GP or nurse specialist, or a religious leader. If you would like to talk to other people affected by cancer, there are several ways to do this.

Support groups

Self-help or support groups offer a chance to talk to other people in a similar situation. Joining a group can be helpful if you live alone, or don't feel able to talk about your feelings with people you know. Not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group is like before you decide whether to join.

Online support

Many people now get support on the internet through:

- online support groups
- social networking sites
- forums
- chatrooms
- blogs for people affected by cancer.

You can use these to ask questions and share your experience.

Our Online Community is a social networking site where you can talk to people in our forums, blog your journey, make friends and join support groups. Visit **macmillan.org.uk/community**

Complementary therapies

Some people use complementary therapies to help them feel better, such as massage and relaxation techniques. Many hospitals and hospices offer these therapies.

If you would like to try a complementary therapy, check with your cancer specialist or GP before using it. This is important because some complementary therapies should be avoided during, and for a short time after, cancer treatments.

AFTER YOUR TREATMENT

Follow-up

At the end of your treatment, you will have a meeting with your lymphoma doctor or specialist nurse. They will explain:

- how often you will have follow-up appointments
- possible signs of the lymphoma returning that you should be aware of
- any possible late effects of treatment.

Your cancer doctor or nurse may give you and your GP a letter with this information and a list of the treatments you have had. This is called a treatment summary.

To begin with, your follow-up appointments may be every three months or so. After the first two years, you may have fewer appointments or you may be discharged. This depends on the type of lymphoma you had. Your cancer doctor or specialist nurse will explain what to expect.

At your follow-up appointments

Your doctor may examine you, check your weight and take blood tests. You won't usually have scans, unless you develop symptoms that need to be checked. Your doctor will want to know how you are feeling. They will also want to check that you are recovering from any side effects. Appointments are a good time for you to talk to your doctor or nurse about any concerns you have.

Many people find they get anxious for a while before a check-up. This is natural. It can help to get support from family or friends. You can also contact the Macmillan Support Line by calling **0808 808 00 00**.

Our booklet **Life after cancer treatment** gives useful advice for people whose treatment is over apart from regular check-ups. Visit **be.macmillan.org.uk** to order a free copy.

Signs of lymphoma coming back

Sometimes lymphoma can come back. This is called a relapse or recurrence. If lymphoma comes back, it is usually discovered when symptoms develop. Your lymphoma doctor or specialist nurse will tell you what to be aware of.

Possible signs and symptoms include:

- new lumps or swellings
- heavy drenching sweats at night
- unexplained high temperatures over 38°C (100.4°F)
- unexplained weight loss
- extreme tiredness
- general itching or a rash that doesn't go away
- a cough or breathlessness that doesn't get better
- any other new symptoms that are worrying you.

If you notice any symptoms, it is important to have them checked. Contact your lymphoma doctor or specialist nurse for advice. They can arrange for you to have an earlier appointment if needed. Lymphoma that comes back can often be treated again.

If NHL comes back

Treatment can often cure high-grade lymphoma. But, in some people, high-grade lymphoma comes back. If this happens, it may be possible to have more treatment to try to cure it.

Low-grade NHL cannot usually be cured. It will nearly always come back or start to grow again at some point after treatment. When this happens, further treatment can be used to control the lymphoma. This can often keep people well for long periods of time.

If lymphoma comes back, it might be where it was before. Or it could affect another part of the body. If it causes symptoms, these may be the same as you had before or they may be different.

You may have chemotherapy, targeted therapy, radiotherapy, a stem cell transplant or a combination of these treatments. For some people with low-grade lymphoma, the doctor may suggest monitoring the lymphoma with regular tests rather than starting more treatment straightaway. This is called watch and wait.

Effects after treatment

Some people have side effects during their lymphoma treatment and for a few weeks after. Usually, these effects reduce and eventually disappear.

But some people may have side effects that continue for months after treatment and that sometimes become long-term. Other people may have late side effects that develop months or years after treatment.

Not everyone has long-term or late effects. And many side effects get better over time. This can depend on different factors such as the type of treatment. Your lymphoma doctor or nurse can give you more information.

> ‘It did take time to build up the courage to go out myself. I started with small targets: end of the drive, end of the street, round the block and down to the shop.’
>
> **Mike**

Tiredness

Recovering from chemotherapy can take time. You may feel tired for many months after treatment is over. Occasionally, tiredness may last for a year or two.

Physical activity can help improve energy levels and reduce tiredness. Short walks are a good way to start. Being active also helps you sleep better and can improve anxiety and depression.

Sometimes tiredness is a sign of depression, sleep problems, pain, or changes in the thyroid gland. These are problems that can be treated. If tiredness is not going away, talk to your doctor.

Immune system

Your immune system protects you against infection. After treatment, the number of lymphocytes in your blood (see page 11) may be lower than normal for a few months. This can make you less able to fight infections. If you were treated with fludarabine, your doctor will ask you to take tablets such as co-trimoxazole (Septrin®) to help prevent infection. You usually take them for about three months. They reduce your risk of getting chest and other infections until the number of lymphocytes in your blood returns to normal.

Your lymphoma doctor may advise you to have vaccinations to protect you against common infections such as flu. They will give you advice about when you should have any vaccinations.

Some vaccines have small amounts of a live virus or bacteria in them. They are called live vaccines. You should not have live vaccines for 6 to 12 months after treatment, or until your immune system has recovered. Your doctor will tell you which vaccinations are safe for you to have and which you should avoid.

Peripheral neuropathy

If the feeling in your hands or feet (see page 62) was affected by chemotherapy, you will usually find this slowly gets better after treatment ends. This may take up to two years. Sometimes nerves do not fully recover and you may continue to have difficulty with fiddly tasks, such as picking up very small objects or doing up small buttons. People generally find these kinds of changes become less noticeable over time as they adapt and find ways of coping with them.

Early menopause or menopausal symptoms in women

Most women reach the menopause between the ages of 47 and 53. But after treatment for lymphoma, some women may have an earlier menopause. Your lymphoma doctor can tell you if this is likely.

Symptoms of the menopause can include hot flushes, night sweats, joint pain, reduced sex drive, vaginal dryness, and disturbed sleep. It can also cause mood swings and feelings of anxiety. If you have any of these symptoms, tell your doctor. You may have blood tests to check for signs of the menopause. Some women have hormone replacement therapy (HRT) to reduce menopausal symptoms. Your doctor will explain any possible benefits and risks of HRT.

Thyroid changes

The thyroid is a small gland in the front of your neck. It makes hormones that help to control and influence the way your body functions.

Some people who have radiotherapy to the neck develop changes in their thyroid gland a few years after treatment. The thyroid stops producing enough hormones. This is called an underactive thyroid or hypothyroidism. It can cause symptoms such as weight gain, tiredness and constipation.

Your lymphoma doctor will explain if your treatment could cause thyroid changes. You will have a blood test once a year to check how your thyroid is working. You may need daily tablets if your thyroid is underactive.

Second cancer

Chemotherapy and radiotherapy can lead to a slightly increased risk of developing a second cancer later in life. But treatments are designed to limit these risks as much as possible.

Women under the age of 30 who have had radiotherapy to the chest area have a higher risk of breast cancer. They should have screening for breast cancer at an earlier age than usual. Screening usually involves a physical check-up and an x-ray (mammogram) or MRI scan of each breast. Your doctor or nurse will explain what to expect.

We can send you more information on breast screening. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk**

Effects on the heart

Some lymphoma treatments may cause heart problems later in life. This includes some types of chemotherapy and, rarely, radiotherapy to the chest area.

Your doctor will explain if there is a risk your treatment may cause heart problems. You may have heart tests before and during chemotherapy to check how well your heart is working. After treatment, you may have regular heart tests to check for signs of heart changes.

Our booklet **Heart health and cancer treatment** has more information. Visit **be.macmillan.org.uk** to order a free copy.

Effects on the lungs

The chemotherapy drug bleomycin can cause changes to the lungs that may affect your breathing. These changes may happen during treatment and usually get better over several months or years after treatment ends. Sometimes bleomycin causes permanent damage to the lungs. Lung changes are more likely if:

- you also have radiotherapy to the chest area
- you are over the age of 60
- you have other lung problems.

If you smoke, quitting will improve your lung health and reduce the risk of breathing problems.

High doses of oxygen can make breathing problems worse in people who have had bleomycin. If you need oxygen treatment or an operation, always let your doctor or nurse know that you have had bleomycin.

Well-being and recovery

It takes time to recover from treatment for lymphoma. You may still have some side effects and you are likely to feel tired. Or you may find you are struggling with difficult feelings and you are not sure how to cope.

Some people choose to make lifestyle changes after treatment. This can be a way of moving on and taking back control of your life. These changes can also help your body recover, improve your sense of well-being, and lower your risk of getting other illnesses.

You might find some of the suggestions on the next pages helpful. But it is also important to remember that although your treatment has finished, you may still need support. This might come from family or friends, or from your healthcare team. If you are finding it difficult to cope, you can call our cancer support specialists free on **0808 808 00 00**.

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases your risk of bone thinning (osteoporosis) and is a major risk factor for smoking-related cancers and heart disease.

Eat well and keep to a healthy weight

After treatment, some people may find they have put on weight. This can happen with chemotherapy and steroid therapy. When you feel ready, you can check with your GP if your weight is within the normal range for your height.

Eating well and keeping to a healthy weight reduces the risk of heart and lung problems, diabetes and developing some other cancers. Try to:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less saturated fat and sugar.

Stick to sensible drinking

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over three or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Get physically active

Being physically active helps to keep your weight healthy and can reduce stress and tiredness. This can be an important part of your recovery after treatment. It can help you cope with stress, build up your energy levels and feel better in yourself. It also helps to keep your bones strong and reduces the risk of heart disease, stroke and diabetes. Talk to your cancer specialist or GP before you start exercising. Start slowly and increase your activity over time.

Take care in the sun

Radiotherapy and some chemotherapy drugs can make your skin sensitive to sunlight and more likely to burn in the sun. This effect can last for several months after treatment. During this time, take extra care in the sun. Protect your skin by covering areas that have been treated with radiotherapy. If you are out in the sun, you should also wear a suncream with a sun protection factor (SPF) of at least 30.

Try to deal with stress

Finding ways to relax can help you cope with stress and anxiety. Try to build things into your routine that help you relax. These may include going for walks, listening to relaxing music or spending time with friends.

You may want to learn specific techniques to help you, such as:

- deep breathing
- muscle relaxation exercises
- yoga
- meditation.

Hospitals or support groups sometimes offer classes in relaxation techniques.

> ‘The new Macmillan centre was looking for volunteers. I get a huge amount of satisfaction from doing something to help people. It has also really helped me get my confidence back.’
>
> **Mario**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It’s common to feel overwhelmed by different feelings when you’re told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You’ll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

> ‘My partner did what she could but she was also dealing with my diagnosis and its impact on our life and relationship.’
>
> **Helena**

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

> 'I went to a lymphoma meeting. It was really good and I felt as though we'd all been through the same experience. I didn't feel quite as alone, and my experience wasn't such a solitary experience that nobody else had gone through. It was comforting.'
>
> **Tim**

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet **Talking to someone who has cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

> 'I was referred to a Macmillan cancer counsellor who I had a few sessions with and found very helpful. I also find researching helps me understand, though everyone is different and some people don't like that.'
>
> **Sally**

‘My employer agreed to a job share. That way I still enjoyed work, but I didn’t get so tired. I think my health gradually improved because of this. Working every morning then resting in the afternoons was a better work-life balance for me.’

Hilary

WORK AND FINANCIAL SUPPORT

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled. There are two different types of ESA:

- contribution-based (contributory) – you can get this if you have paid enough national insurance
- income-related (means tested) – you can get this if you don't qualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called Universal Credit. This benefit is for people below retirement age who are out of work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least three months and expect them to last for at least nine months. PIP replaces an older benefit called Disability Living Allowance (DLA) for adults.

Attendance Allowance (AA) is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least six months. If you are terminally ill, and may be expected to live for less than six months, you can apply for PIP, DLA or AA under the special rules. It does not have to be certain and it does not matter if you live longer than six months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

We've just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 128).

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 128.

Our booklets **Insurance** and **Travel and cancer** may also be helpful.

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also lots more information at **macmillan.org.uk/work**


HOUSING COSTS
HOUSING COSTS
THE CANCER GUIDE FOR YOUNG PEOPLE
CANCER AND OLDER PEOPLE

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand.

Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things.

You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Lymphoma support organisations

Anthony Nolan Trust
Tel 0303 303 0303
www.anthonynolan.org
Runs the UK's largest register of volunteer donors.

Bloodwise
Tel 0808 2080 888
(Mon to Fri, 10am to 4pm)
www.bloodwise.org.uk
Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Provides information about blood cancers and treatments.

Children's Cancer and Leukaemia Group (CCLG)
Tel 0116 252 5858
Email info@cclg.org.uk
www.cclg.org.uk
Provides information for children, young people and families affected by cancer.

Lymphoma Action
Tel 0808 808 5555
(Mon to Fri, 10am to 3pm)
Email information@lymphomas.org.uk
www.lymphomas.org.uk
Provides information and support to anyone affected by lymphoma. Has a helpline, newsletter and network of support groups. Also loans videos and other materials.

General cancer support

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncr.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777
Email nss.csd@nhs.net
www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Financial or legal advice and information

Carer’s Allowance Unit

Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Thu, 8.30am to 5pm, Fri, 8.30am to 4.30pm)
www.gov.uk/carers-allowance-unit

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 028 9023 1120
www.citizensadvice.co.uk

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0800 121 4433
Textphone 0800 121 4493
(Mon to Fri, 8am to 6pm)

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

You can search for more organisations on our website at **macmillan.org.uk/organisations** or call us on **0808 808 00 00**.

YOUR NOTES AND QUESTIONS

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Anne Parker, Consultant Haematologist.

With thanks to: Dr Kirit Ardeshna, Consultant Haematologist; Dr Di Gilson, Consultant Clinical Oncologist; Dr Jon Lambert, Consultant Haemato-oncologist; and Karen Stanley, Macmillan Lymphoma Nurse Specialist. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

National Institute for Health and Care Excellence (NICE). Guideline NG46. Haematological cancers: improving outcomes. 2016.
National Institute for Health and Care Excellence (NICE). Guideline NG52. Non-Hodgkin's lymphoma: diagnosis and management. 2016.
Treleaven et al. Guidelines on the use of irradiated blood components prepared by the British Committee for Standards in Haematology blood transfusion task force. British Journal of Haematology. 2011.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don’t let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

Registered with FUNDRAISING REGULATOR

If you’d rather donate online go to **macmillan.org.uk/donate**

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about non-Hodgkin lymphoma. It is for anyone who has been diagnosed with non-Hodgkin lymphoma.

The booklet explains what the signs and symptoms are, how it is diagnosed, and what treatment you might have. It also has information about the feelings you might have, and how relationships, work and finances might be affected.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00,** or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

MAC11635_E15_N. Next planned review 2020.
Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).
Also operating in Northern Ireland. Printed on sustainable material. Please recycle.