MACMILLAN
CANCER SUPPORT

UNDERSTANDING NON-HODGKIN LYMPHOMA

> ‘It's been a rollercoaster year for my husband and me. I'm honestly feeling so much better though and would say I actually feel 100%. I'm just learning to adjust to my new normal as a lot of cancer survivors describe it!’

Christina, 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 is having tests or is diagnosed with NHL. There is also information for carers, family members and friends.

The booklet explains what the signs and symptoms of non-Hodgkin lymphoma are, how it is diagnosed, and the treatments you might have. It also has information about the feelings you might experience, and 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.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 144 to 154, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see pages 155 to 156).

Quotes

In this booklet, we have included quotes from people who have had non-Hodgkin lymphoma, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Christina, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

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**.

Contents

ABOUT NON-HODGKIN LYMPHOMA

The lymphatic system

What is the lymphatic system?

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

The lymphatic system includes:

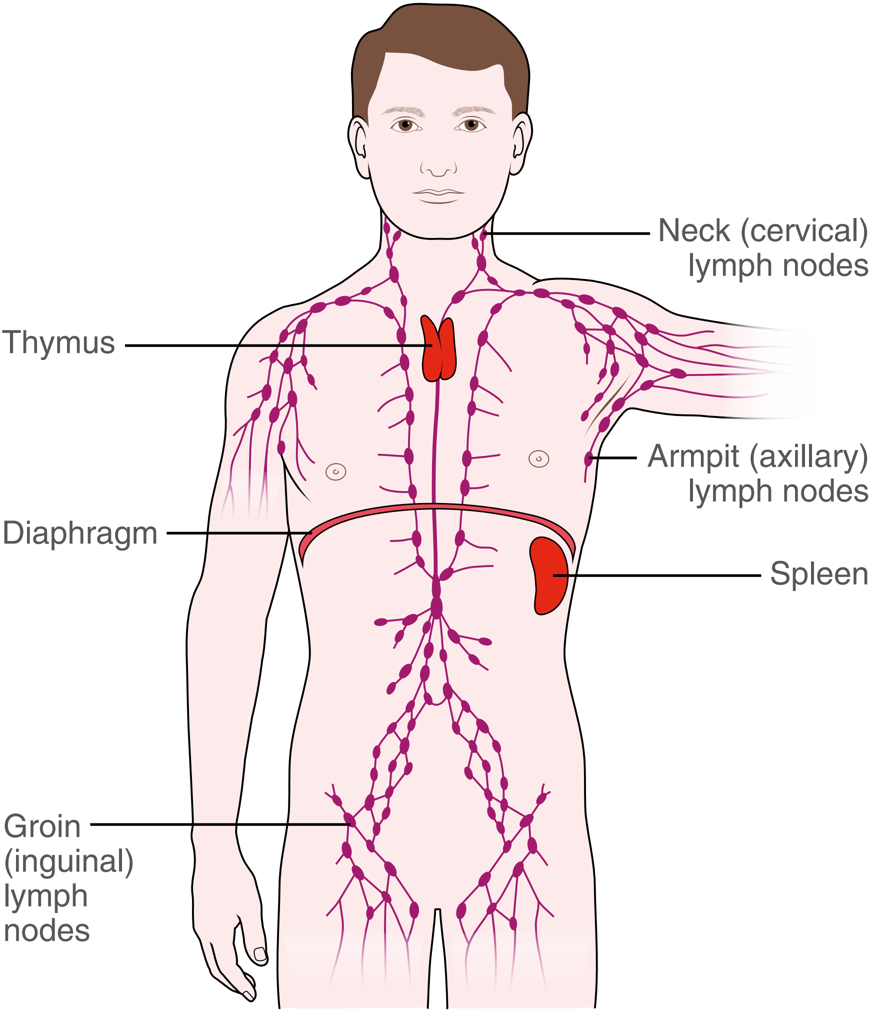
- lymph vessels
- lymph nodes (sometimes called lymph glands)
- lymphocytes (blood cells that fight infection)
- lymphatic organs
- other lymphatic tissue.

Lymphatic organs

Lymphatic organs include the following:

- The thymus – this helps some types of lymphocytes to mature.
- The spleen – this helps fight and filter out disease and germs.
- The tonsils – these help fight and filter out disease and germs.

The lymphatic system



Bone marrow

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 lymphoma?

Lymphoma is a cancer of the lymphatic system (see pages 6 to 7).

Cancer starts in the cells of our body. Cells are the tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and repair.

Sometimes the process of cell division can get out of control. Too many cells may be made and a cancer, such as lymphoma, can develop.

In lymphoma, blood cells called lymphocytes become abnormal. These are the lymphoma cells. Usually the body's immune system destroys abnormal cells. But lymphoma cells are often able to avoid the immune system. This means they can keep dividing and grow out of control. Over time, there are enough lymphoma cells to form a lump. The most common place for this to happen is in the lymph nodes (see page 6). But lymphoma can start growing in other parts of the body. Lymphoma that grows outside the lymph nodes is called extra-nodal lymphoma.

Lymphocytes travel around the body. This means that lymphoma can travel from where it first started. It can travel through the lymphatic system from lymph nodes in one part of the body to lymph nodes in another part of the body. Lymphoma cells can also travel in the bloodstream to organs such as the bone marrow, liver or lungs. The cells may then divide to form a new area of lymphoma.

Types of lymphoma

There are two main types of lymphoma. They develop and are treated in different ways.

They are:

- Hodgkin lymphoma (HL)
- non-Hodgkin lymphoma (NHL).

A doctor can only find out your lymphoma type by collecting a sample of lymphoma cells and testing them in a laboratory (see page 23).

If the sample contains a type of cell called Reed-Sternberg cells, the lymphoma is usually Hodgkin lymphoma. If there are no Reed-Sternberg cells, it is non-Hodgkin lymphoma.

Your doctors will also examine the sample of cells to identify what specific sub-type of lymphoma you have. There are many different sub-types of NHL.

> **‘Probably more than once a day, I visit the Macmillan website which I have found to be a goldmine of information.’**
>
> **Christina**

What is non-Hodgkin lymphoma?

NHL is the sixth most common cancer in the UK. Around 14,000 people are diagnosed with it each year. It can affect people at any age but is more common as people get older. Most people who are diagnosed with NHL are over 55. The highest rate of diagnosis is in people aged 80 to 84.

Types of non-Hodgkin lymphoma

NHL usually starts in the lymph nodes. Often several areas of lymph nodes around the body are affected.

NHL can also start outside the lymph nodes in almost any part of the body. Lymphoma that starts outside the lymph nodes is called primary extranodal lymphoma (see page 14).

There are many different types of NHL. Some grow very slowly and may not need treatment for months or years. These are low-grade lymphomas. Other types grow quickly and need treatment soon after diagnosis. These are high-grade lymphomas.

Doctors can find out which type you have by examining some lymphoma cells under a microscope. They need to know which type you have, so they can give you the best treatment.

B-cell and T-cell lymphomas

Lymphomas develop from white blood cells called lymphocytes. There are two types of lymphocyte:

- B-cell lymphocytes
- T-cell lymphocytes.

A lymphoma that develops from an abnormal B-cell lymphocyte is called a B-cell lymphoma. A lymphoma that develops from an abnormal T-cell lymphocyte 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 lymphoma are:

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

Other less common types include:

- mantle cell lymphoma
- Burkitt lymphoma
- primary mediastinal large B-cell lymphoma
- nodal marginal zone B-cell lymphoma
- extranodal marginal zone B-cell lymphoma (also called MALT lymphoma)
- splenic marginal zone lymphoma
- small lymphocytic lymphoma
- lymphoplasmacytic lymphoma (also called Waldentröm’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 (ACLC)
- angioimmunoblastic lymphoma
- lymphoblastic lymphoma (this is mainly T-cell but can be B-cell).

Lymphoma that starts outside the lymph nodes

Lymphomas that begin outside the lymph nodes are called primary extranodal lymphomas (pENL). The most common places for them to start are the stomach and small bowel (intestine). But they can begin in almost any part of the body. They are usually treated according to the type of lymphoma cells causing them. The most common types of pENL are:

- diffuse large B-cell lymphoma (DLBCL)
- extranodal marginal B-cell lymphoma (MALT lymphoma).

Lymphoma of the brain or spinal cord

Rarely, lymphoma may start in the brain or spinal cord. This is called primary central nervous system lymphoma (PCNSL). The most common type is a diffuse large B-cell lymphoma (DLBCL).

We have more information about all these different types of lymphoma and their treatment on our website (see page 140).

Causes and risk factors

The causes of non-Hodgkin lymphoma are mostly unknown. But some things may increase your risk of developing it. These are called risk factors.

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.

Age

NHL can affect people at any age. But it is more common in people who are over 50 years old.

Gender

Lymphoma is slightly more common in men than women.

Infections

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

- Helicobacter pylori infection sometimes causes a type of NHL called MALT lymphoma.
- Epstein Barr virus (EBV) infection, which causes glandular fever, may slightly increase the risk of developing some types of NHL.
- Hepatitis C virus (HCV) can slightly increase the risk of splenic marginal zone lymphoma (SMZL).
- Human T-lymphocytotrophic virus-1 (HTLV-1) is a rare infection that is linked with T-cell lymphoma in some people.

Most people who have had these infections will not develop lymphoma. Lymphoma is not infectious and cannot be passed on to other people.

We have more information about these risks on our website (see page 140).

A weakened immune system

If your immune system is weak, you have a higher risk of developing lymphoma.

Conditions such as HIV can weaken the immune system. We have more information about lymphoma and HIV on our website (see page 140). Drugs called immunosuppressants also weaken it. Some people need this type of drug after an organ transplant or to treat auto-immune disease.

Auto-immune disease

Auto-immune diseases develop when the immune system attacks healthy body tissue by mistake. Several auto-immune diseases can increase the risk of lymphoma. These include:

- coeliac disease
- Sjogren’s syndrome
- rheumatoid arthritis
- 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.

A 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. Radiotherapy and 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.

Having a close relative with non-Hodgkin lymphoma

People who have a parent, brother or sister with lymphoma have a higher risk of developing NHL. The reason for this is not known. It may be because there is a genetic change that runs in families. Or it could be because people within one family tend to have the same lifestyle factors.

This risk is still very small. Most people who have a close relative with lymphoma will not develop lymphoma.

Breast implants

Breast implants are linked with a lymphoma called breast implant-associated anaplastic large cell lymphoma (BIA-ALCL). This is a rare type of lymphoma. The risk of women with breast implants developing it is very small.

Signs and symptoms of lymphoma

The most common symptom of lymphoma is a painless swelling in the lymph nodes in the neck, armpit or groin.

Local symptoms

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

- If the lymphoma is in the chest area, symptoms include a cough, difficulty swallowing or breathlessness.
- If the lymphoma is in the stomach or bowel, symptoms include indigestion, tummy pain or weight loss.
- Pain caused by pressure from swollen lymph nodes. For example, pain in an area such as the tummy (abdomen). This is not common.

Other symptoms

Lymphoma can also cause symptoms which affect the whole body, including:

- heavy, drenching sweats, especially at night
- high temperatures over 38˚C (100.4 ˚F) that come and go without any obvious cause
- unexplained weight loss
- tiredness
- itching all over the body that does not go away.

Some people do not have any of these symptoms and the lymphoma is found during tests for other conditions.

If lymphoma is in the bone marrow

If the lymphoma is in the bone marrow (see page 9) it can reduce the number of blood cells in your body. 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 (platelets).

DIAGNOSING NON-HODGKIN LYMPHOMA

Diagnosing lymphoma

If you have symptoms (see page 17), you usually start by seeing your GP. If they think your symptoms could be caused by cancer, they may arrange for you to have blood tests or scans. Your doctor will refer you to hospital for tests and for specialist advice and treatment.

At the hospital, the doctor will ask about any symptoms, your general health and any illnesses you have had. They will also examine you.

If you think you may be pregnant, tell your doctor. Some tests and treatments for lymphoma can be harmful to a baby in the womb. Pregnant women can usually still have tests and treatment for lymphoma. But it is important to talk to your doctor so they can plan your care safely. We have more information about this in our booklet **Cancer and pregnancy** (see page 140).

> **'When you are diagnosed with cancer, there are so many thoughts, fears, worries and uncertainties swirling around your head. You have to find a way to cope with it, some mechanism as an outlet.'**
>
> **Christina**

Taking a tissue sample (biopsy)

The most important test for diagnosing lymphoma is a biopsy. A biopsy is the removal of a small piece of tissue or a sample of cells, to be looked at under a microscope.

There are different types of biopsy. We have more information about these on our website (see page 140). Your cancer doctor or specialist nurse will explain the type of biopsy that is best for you. Sometimes, they use a scan or x-ray to help them take the biopsy from the exact area. This is called image guide 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 the 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.

The tissue is examined under a microscope by a doctor called a pathologist. They look for lymphoma cells and do different tests on the cells.

You may have to wait up to 2 weeks for the results of the biopsy. This is because diagnosing lymphoma is complicated and several tests need to be done.

Further tests

You will have more tests before you start treatment for lymphoma. Some tests help to show the stage (see pages 34 to 40) of the lymphoma.

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.

For example, your doctor will do blood tests to check the levels of different blood cells in your blood. They may also talk to you about having blood tests to check for certain viruses, such as HIV and hepatitis.

Information from tests helps your doctors plan your treatment safely and effectively. You may have some of the following tests.

> ‘Initially I was just off work ill and having tests. I smiled when I finally got the cancer diagnosis, which might seem strange, but at least now I knew what was wrong. It was scary not knowing what was wrong with me.’

Leslie

CT scan

A CT scan makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

Having a CT scan

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.

Ultrasound

An ultrasound uses sound waves to build up a picture of internal organs. It can be used to guide a biopsy (see page 23). The scan helps to guide them to the exact area.

A small device called an ultrasound probe is used. The probe gives off sound waves. These bounce off different parts of the body and make echoes. A computer converts the echoes into a picture.

PET or PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body. It is sometimes given together with a CT scan. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans. PET scans are not suitable for everyone. Your doctor or specialist nurse can tell you whether they might be helpful for you.

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

About an hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in the arm. This is called a tracer. While you wait to have the scan, you will be encouraged to drink. Drinking water helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The person who works the scanner is called a radiographer. The scan takes about 30 to 60 minutes. You will lie on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner. You can usually go home after the scan. The amount of radioactive substance used is very small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

MRI

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

Bone marrow biopsy

Bone marrow is spongy material found in your bones. Blood cells are made in the bone marrow.

A biopsy is the removal of a small piece of tissue or a sample of cells, to be looked at under a microscope. For a bone marrow biopsy, a small sample of bone marrow is taken from the back of the hip bone (pelvis).

Rarely, the sample is taken from the breastbone (sternum). A bone marrow biopsy is done at the hospital. If you are taking medicine to thin the blood, tell the doctor or nurse before the test.

The doctor or nurse will give you a local anaesthetic to numb the area. You may also have a sedative. If you are having the biopsy from your hip, you lie on your side and a doctor uses a biopsy needle to get the sample. They put the needle into the hip bone and draw a small sample of liquid or core of bone marrow into a syringe. It can feel uncomfortable for a few seconds. Some people may have a pain in their leg.

After the biopsy, a dressing will be put over the area to keep it clean. You can remove this after 24 hours. If you have had a sedative, you will need someone to take you home and stay with you overnight. You may ache or feel bruised. Taking painkillers can help.

Lumbar puncture

A doctor or specialist nurse may do a lumbar puncture to take a sample of the fluid that surrounds the brain and spinal cord. This fluid is called cerebrospinal fluid (CSF). The sample will be examined under a microscope in a laboratory. In some types of non-Hodgkin lymphoma, the lymphoma cells may get into this fluid.

You may have a lumbar puncture on the ward or in the outpatient department. If you are taking any medicines to thin your blood, you should tell your doctor before the test.

You will usually have a local anaesthetic to numb the area. To take the sample of CSF, a doctor or specialist nurse puts a hollow needle between the bones of the lower back. The needle goes into the fluid around the lower part of the spinal cord. They collect a few drops of the fluid into a pot.

Having a lumbar puncture should not be painful, but you may feel some pressure as the needle is put in.

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, family or a close friend. Your specialist nurse or a support organisation (see pages 144 to 154) can also provide support. You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. 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. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

> ‘I felt like I was falling from a great height, but Pat, my Macmillan nurse, was there to catch me.’
>
> **Mario**

Staging and grading

Knowing the extent of the lymphoma helps your doctor plan the right treatment. This is called staging. Lymphomas are also grouped as either low grade or high grade. The grade of the lymphoma is also an important factor in your treatment plan.

The stage of a lymphoma describes how many areas of the body are affected by lymphoma and where these areas are. Your doctor will also ask you about any symptoms you have. All this information helps doctors plan the right treatment for you.

Staging of lymphoma can sometimes be complicated. Your doctor or specialist nurse will explain what stage you have.

Number staging

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

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

In some situations, a stage 2 lymphoma that is large (bulky) is treated as advanced disease (see page 40).

Stage 1

The lymphoma is either:

- in a single lymph node, one group of lymph nodes, or in one organ of the lymphatic system, such as the tonsils
- or in another part of the body outside the lymph system (extra-nodal) – see page 40.

Stage 2

The lymphoma is either:

- in two or more groups of lymph nodes
- in another part of the body (extra-nodal) and in one group of lymph nodes.

For both these, the sites of lymphoma are on the same side of the diaphragm – either above or below it. The diaphragm is the sheet of muscle underneath the lungs that separates the chest from the tummy (abdomen).

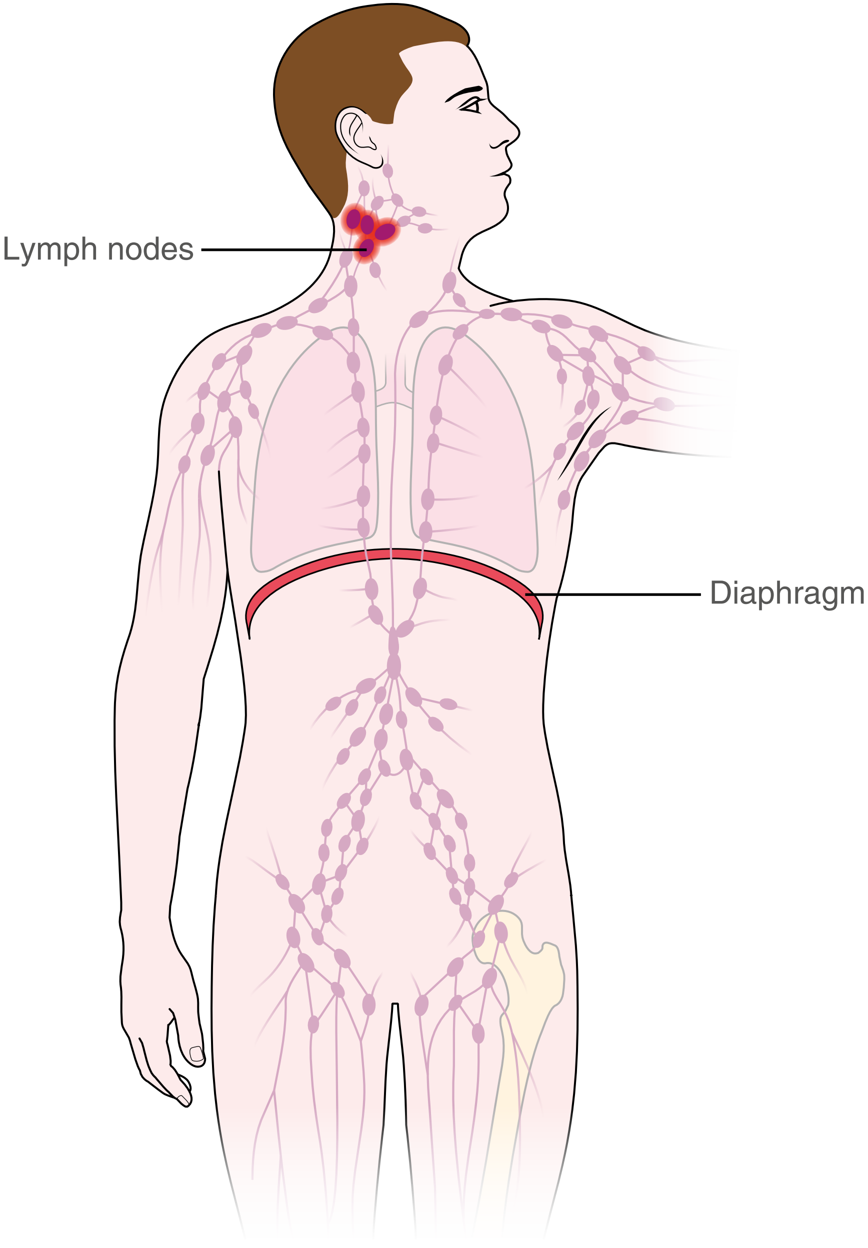
Stage 3

There are areas of lymphoma above and below the diaphragm.

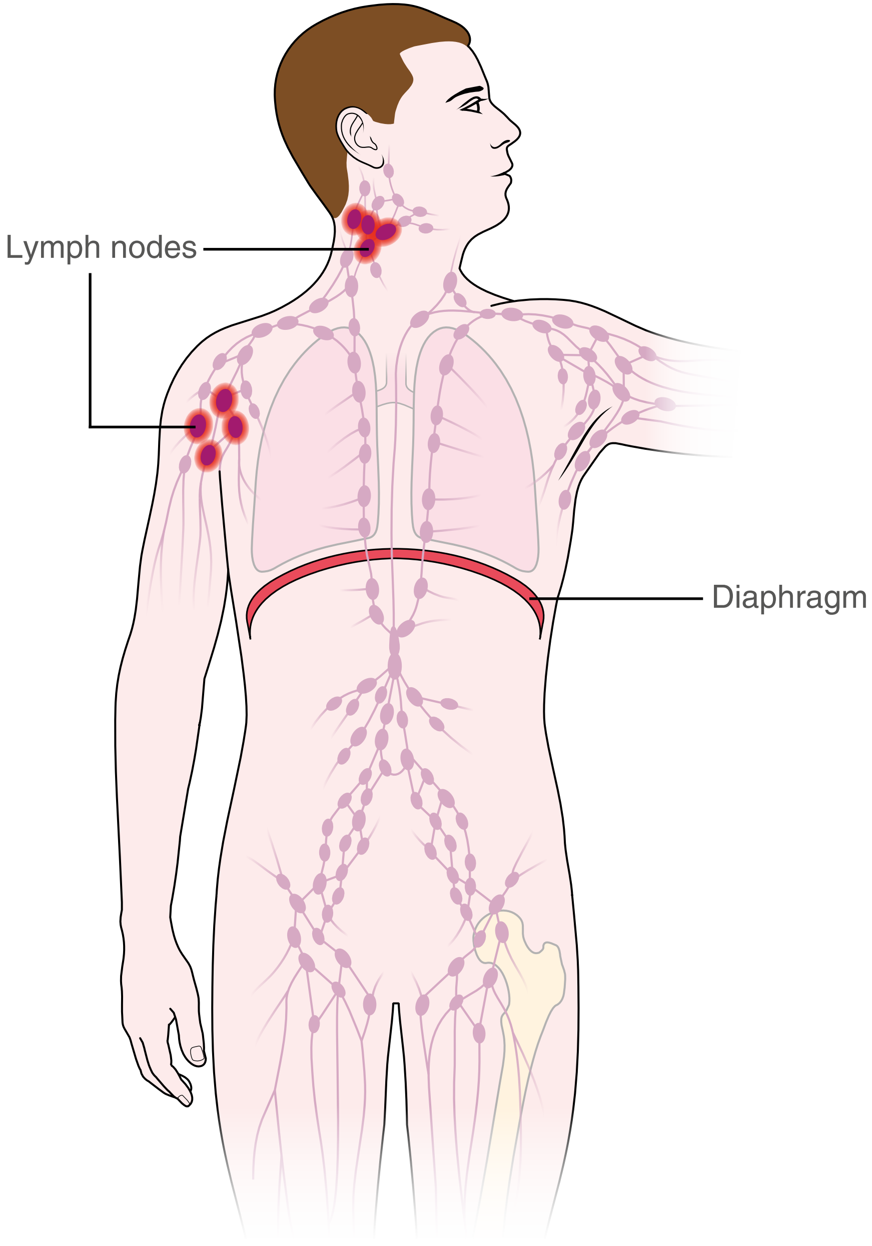
Stage 4

The lymphoma is more widespread and may also affect organs such as the bone marrow, lungs or liver.

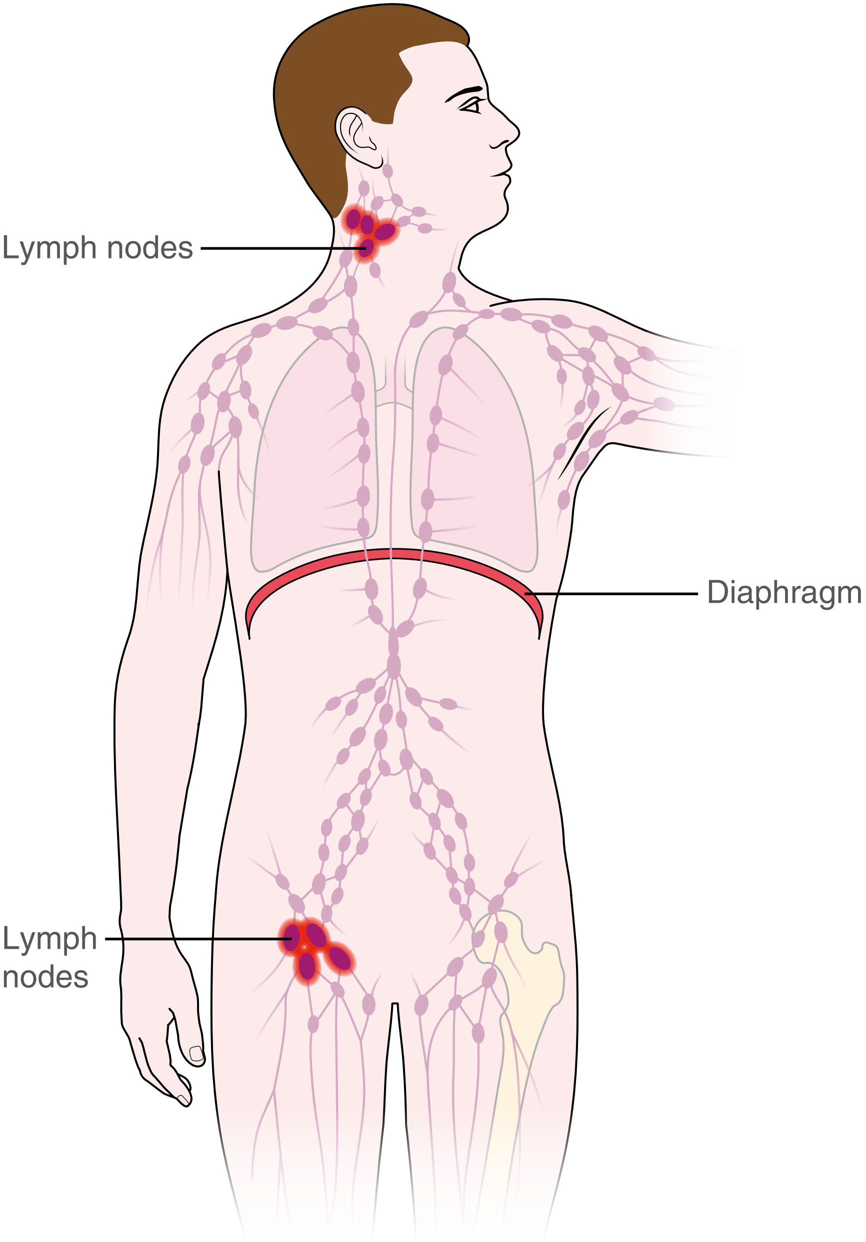
Stage 1 – Lymphoma in a single group of lymph nodes



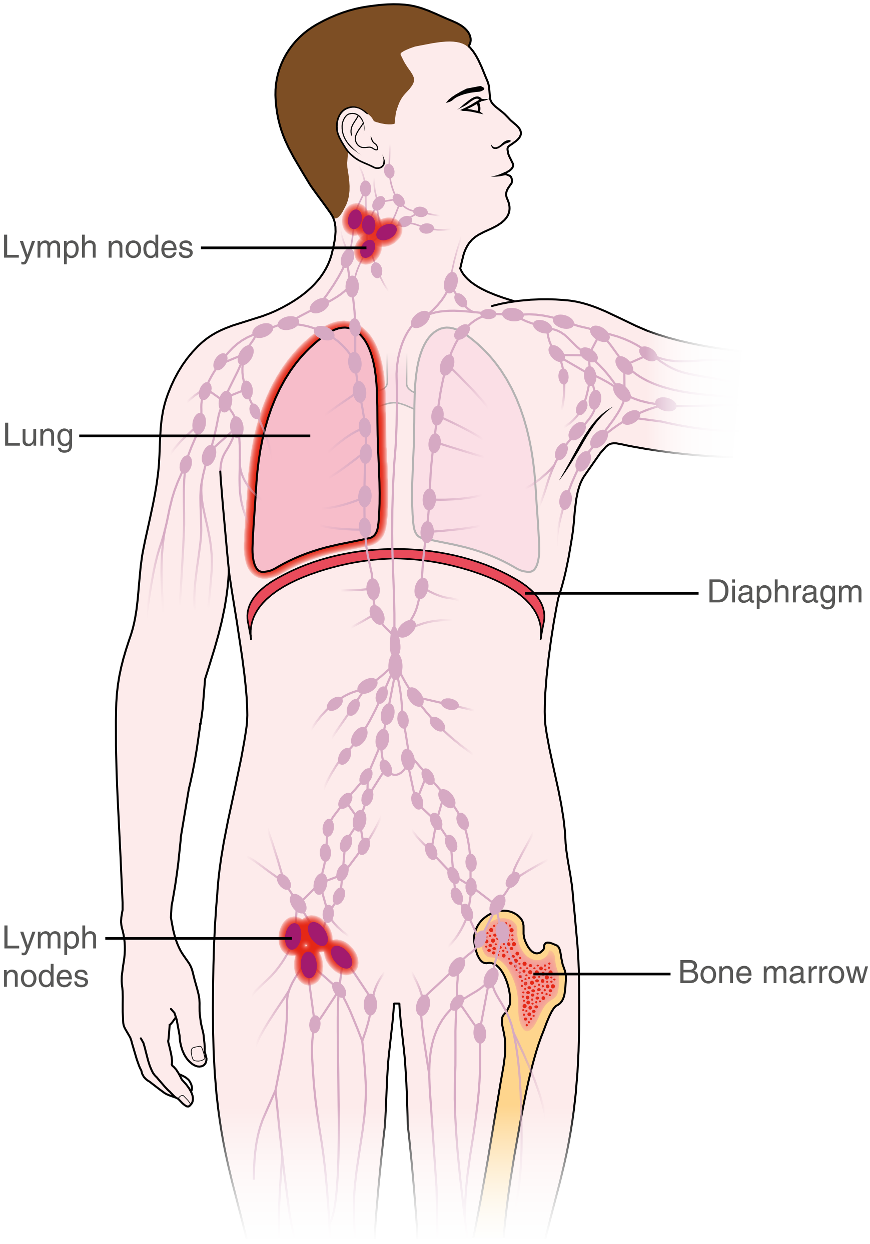
Stage 2 – Lymphoma in two groups of lymph nodes



Stage 3 – Lymphoma in two groups of lymph nodes, above and below the diaphragm



Stage 4 – Lymphoma has also spread to the lung and bone marrow



Extra-nodal lymphoma

Lymphoma is sometimes found in parts of the body outside the lymph nodes. This is called extra-nodal lymphoma. Extra-nodal sites include the liver, lungs, spinal cord and bone marrow.

Extra-nodal lymphoma is described by adding the letter E (for extra-nodal) after the stage number. For example, the lymphoma may be described as 1E.

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 (see page 14)
- or started in the lymph nodes and then spread somewhere else.

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

Bulky disease

If an area of lymphoma is large, it is often called bulky disease. The letter X may be added after the stage number. For example, the lymphoma may be described as 1X.

B symptoms

Sometimes the letter B is added after the stage number. For example, the lymphoma may be described as stage 1B. This is used to show if you have any symptoms that doctors call B symptoms. The B symptoms are:

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

If you have any B symptoms, it usually means the lymphoma is more advanced. If you do not have any of these symptoms, the letter A is used instead, for example stage 1A.

Grade

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

Low-grade lymphomas

These grow very slowly and are sometimes called indolent lymphomas. They 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

These grow more quickly and are sometimes called aggressive lymphomas. 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

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include:

- Oncologist – a doctor who treats people who have cancer.
- Haematologist – a doctor who diagnoses and treats blood disorders and cancers.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

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

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects (see pages 101 to 107) and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

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.

It can help to talk to your family or friends about your treatment options. Your doctor or nurse can help you with your decision. You do not usually need to decide straight away.

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

You could write a list of benefits and disadvantages for each treatment. When choosing a treatment, you may want to think about:

- how long you need to have it for
- how it may affect your everyday life
- how much time you will need to spend in hospital
- the different side effects and how they are likely to affect you.

We have more information about making treatment decisions and about coping with treatment in our booklets **Making treatment decisions** (see page 140).

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (see page 45).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website (see page 140).

> At my pre-chemo meeting with my NHS clinical nurse specialist, she gave me lots of Macmillan literature, which I found very helpful. When you are diagnosed it is impossible to have too much information.

Christina

Treating non-Hodgkin lymphoma

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

The treatment you have will depend on:

- the type and stage of the lymphoma
- if it is high grade or low grade
- the symptoms you have
- which parts of your body are affected
- your general health
- your preferences.

Low-grade non-Hodgkin lymphoma

Early stage low-grade lymphoma (stage 1 or 2)

If you have low-grade NHL you do not always need to start treatment straight away. This is because it usually grows slowly. Instead, you will be monitored for signs that you need to start treatment. This is called watch and wait (see pages 56 to 59).

The most common treatment for early stage or localised disease (stage 1 or 2), low-grade NHL is radiotherapy (see pages 81 to 87). It is given to the affected lymph nodes and can usually make the lymphoma disappear completely. Some people are cured after radiotherapy alone.

If radiotherapy is not suitable for you, your treatment options will be the same as those used for advanced lymphoma.

Advanced stage low-grade lymphoma (stage 3 or 4)

Most people with low-grade NHL have advanced stage lymphoma (stage 3 or 4). Your treatment will depend on whether you have symptoms or not. Some people with stage 1 or 2 lymphoma may be treated as advanced stage.

Treatment aims to control the lymphoma rather than cure it. It is often very successful at shrinking the lymphoma. You will feel well and will not have any symptoms. This is called remission.

Remission may last years. After a period of remission, the lymphoma eventually comes back. But with more treatment, it often shrinks back down again. Then you have another period of remission. This means the lymphoma can be controlled for a long time. Most people have a good quality of life between courses of treatment.

If you do not have any symptoms

If you are not having problems with symptoms, your doctor may ask you to choose between either:

- delaying treatment until symptoms develop – called watch and wait (see pages 56 to 59)
- or having treatment with rituximab or a similar drug (see pages 76 to 80).

If you have symptoms

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

- chemotherapy (see pages 60 to 73)
- rituximab or a similar targeted drug (see page 76)
- a combination of chemotherapy and a targeted drug (chemoimmunotherapy).

These treatments are often very successful at getting the lymphoma into remission. When the lymphoma is in remission, some people continue to have further treatment with rituximab. This is called maintenance treatment. You may have this for up to 2 years.

Sometimes radiotherapy may be used to shrink the lymphoma in an area and reduce symptoms.

If low-grade lymphoma becomes high grade

Over time, some low-grade lymphomas change (transform) and become high grade. If this happens, the lymphoma is treated as a high-grade lymphoma. Treatment is often successful in shrinking the lymphoma.

Some people are diagnosed with both low-grade and high-grade NHL at the same time. If this happens, the NHL is treated as a high-grade lymphoma.

Although the high-grade lymphoma does not usually come back, the low-grade lymphoma usually comes back eventually.

High-grade non-Hodgkin lymphoma

High-grade lymphoma is usually fast-growing and needs to be treated straight away. The aim is to make the lymphoma disappear completely. This is called complete remission.

The most commonly used treatments are:

- chemotherapy (see pages 60 to 73) and steroids (see pages 74 to 75)
- a combination of chemotherapy and a targeted therapy drug such as rituximab (see page 76) and steroids.

Treatment can often shrink high-grade lymphoma very quickly. Sometimes, radiotherapy (see pages 81 to 87) is given after chemotherapy. This is usually if the lymphoma was only in one area of the body. It may also be used if the lymph nodes were very enlarged (bulky) before you had chemotherapy (see page 40).

Many people with high-grade NHL are cured. But if the lymphoma does not completely respond to treatment your doctor may talk to you about having more intensive treatment. This may involve high-dose chemotherapy with stem cell support (autologous stem cell transplant) or a donor's stem cells (donor or allogeneic stem cell transplant) – see pages 88 to 91.

If non-Hodgkin lymphoma comes back

Treatment can often cure high-grade NHL. But, in some people, the lymphoma comes back. If this happens, it may be possible to have more treatment to try to cure it. You usually have a more intensive treatment than your first treatment. This is to try to get the lymphoma into remission.

Low-grade NHL cannot usually be cured. It nearly always comes back or starts to grow again at some point after treatment. You can have further treatment to control the lymphoma. This can often keep people feeling well for long periods of time.

If lymphoma comes back (see page 100), it might be in the same area where it was before. Or it could affect another part of the body. If it causes symptoms, they may be the same as before or different.

You may have one, or a combination, of the following treatments:

- Chemotherapy – with different drugs, that are usually stronger than ones you had before.
- Targeted therapies and immunotherapy drugs – you may have a different drug than you have had before.
- Radiotherapy – may be used if lymphoma comes back in one group of lymph nodes or to relieve symptoms.
- A stem cell transplant – with your own cells or a donor's stem cells. You have this transplant after having intensive chemotherapy that put the lymphoma into remission.
- CAR-T therapy (see page 80) – this is a new treatment. It is not commonly used. It changes some of your immune cells to make them better at fighting cancer cells. It may be used if you have diffuse large B-cell lymphoma or primary mediastinal large B-cell lymphoma that is still growing after 2 or more courses of treatment.

For some people with low-grade lymphoma, the doctor may suggest monitoring the lymphoma with regular tests rather than starting more treatment straight away. This is called watch and wait (see pages 56 to 59).

Watch and wait

If you have low-grade lymphoma (see pages 51 to 53), your doctor may suggest you do not 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 may also be called active surveillance or active monitoring. It is a way of delaying treatment until it is needed.

Your doctor may suggest watch and wait if:

- you have low-grade lymphoma and do not have symptoms
- low-grade lymphoma has come back after treatment, but is not causing problems.

Low-grade lymphoma often develops slowly and you may not need treatment for a long time. Sometimes people worry about not having treatment straight away. But there can be advantages to delaying treatment.

Advantages of watch and wait

- Studies have shown that people who delay treatment until it is needed often live as long as people who start treatment straight away. They also respond just as well to treatment.
- You will avoid the risk of treatment side effects, for as long as possible.
- 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 shrinks without any treatment. This is called spontaneous regression.

Monitoring lymphoma

Even when you are not having any treatment for lymphoma, you will see your cancer 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)
- 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 (see page 7) getting bigger and bulky
- a build-up of fluid in the tummy area (ascites) or in the lining of lungs (pleural effusion) – we have information about these on our website (see page 140).

Coping with watch and wait

If you are worried about delaying treatment, here are some helpful tips:

- Make sure you understand why watch and wait is recommended and what other treatment options there may be. If you have any concerns, talk to your doctor.
- Think of your time without treatment as an opportunity to make the most of a good 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 page 127), or by keeping a journal.

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

We have more information about keeping fit and healthy in our **Healthy eating** and **Physical activity and cancer** booklets (see page 140).

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.

Your doctor and nurse will talk to you about the chemotherapy that is best for your situation. This depends on the type of lymphoma you have and whether it is low grade or high grade.

Chemotherapy is often given along with a targeted therapy drug (see pages 76 to 80). This is commonly used to treat B-cell lymphomas. Some people may have chemotherapy on its own or with radiotherapy.

Targeted drugs work on the immune system, so they are sometimes described as immunotherapy drugs. When you have them with chemotherapy it is sometimes called chemoimmunotherapy.

Chemotherapy drugs for non-Hodgkin lymphoma

Combinations of different drugs are named after the initials of the drugs used. These are the most common chemotherapy and chemoimmunotherapy treatments for NHL.

CHOP

This is a combination of the chemotherapy drugs cyclophosphamide, doxorubicin (hydroxydaunorubicin) and vincristine (Oncovin®) which are given into a vein, and steroid tablets called prednisolone. This treatment is called:

- R-CHOP when it is given with rituximab
- O-CHOP when given with obinutuzumab (Gazyvaro®).

CVP

This is a combination of the chemotherapy drugs cyclophosphamide and vincristine given into a vein, and steroid tablets called prednisolone. This treatment is called:

- R-CVP when CVP is given with rituximab
- O-CVP when it is given with obintuzumab.

GCVP

This is when the chemotherapy drug gemcitabine is added to CVP.

Other drugs

Other chemotherapy drugs that may also be used to treat NHL are:

- bendamustine
- chlorambucil
- fludarabine.

If the lymphoma does not completely respond to chemotherapy your doctor may advise different or stronger drugs than you had before. If this happens the lymphoma can still be treated successfully.

Sometimes your doctor may talk to you about having intensive chemotherapy and a stem cell transplant (see pages 88 to 91).

How chemotherapy is given

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

Your course of treatment is usually given over a few days. But sometimes you it all in one day. After your first treatment, you have a break of a few weeks without treatment. This 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 treatment may last several months. During this time, you have regular check-ups at the hospital. You usually have a scan before starting treatment and then again at the end. You may also have a scan part way through your course of treatment. These scans show your doctors if the treatment has shrunk the lymphoma.

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 short, thin tube put into a vein in the arm or the back of the hand
- a central line – a long, thin tube put into a vein in the chest
- a PICC (peripherally inserted central venous catheter) – a line put into a vein in the arm and threaded through to a vein in the chest
- a portacath – an implantable line (catheter) put into a vein, with an opening (port) under the skin on the chest or arm.

When your cannula, line or port is in place, the chemotherapy drugs can be given into it:

- by injection
- as a drip
- through a pump.

Your nurse will check that the cannula, line or port is working before giving you the chemotherapy.

We have more information about central lines, PICC lines, and implantable ports on our website.

Your line or port

If you have a line or port, it can be left in until your whole course of chemotherapy is over. This means you will not need a cannula or needles put into the arm every time you have treatment. Your doctor or nurse can take blood tests from your line or port. You can have antibiotics, fluids and blood transfusions 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.

Chemotherapy tablets

Some chemotherapy drugs you take as tablets or capsules. These work just as well as other types of chemotherapy. The tablet is absorbed into your blood and carried around your body – just like intravenous chemotherapy. Your doctor, nurse or pharmacist will tell you when to take your chemotherapy tablets or capsules. Take them exactly as they tell you to.

Chemotherapy into the spinal fluid (intrathecal chemotherapy)

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

You may have a type of chemotherapy to treat or prevent lymphoma in the brain. This is called intrathecal chemotherapy. A doctor puts a small amount of liquid chemotherapy into the spinal fluid. This is done in a similar way to a lumbar puncture (see page 31).

You usually have intrathecal chemotherapy as an outpatient. The chemotherapy drug most commonly used is methotrexate.

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

We have more information on intrathecal chemotherapy on our website (see page 140).

Side effects

Chemotherapy drugs cause different side effects. These can usually be well controlled with medicines. Most side effects usually go away once treatment has finished. Your doctor or nurse will tell you about the most likely side effects and how they can be controlled or managed. They will also talk to you about the risk of possible late effects (see pages 101 to 107).

Risk of infection

This treatment 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 (99.5°F)
- 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 treatment. 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)

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

People treated with the chemotherapy drugs fludarabine or bendamustine should only have blood that has been treated with x-rays (irradiated).

Bruising and bleeding

This treatment 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 cannot 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

You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Constipation

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

- Drink at least 2 litres (3½ 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.

Changes to your taste

You may get a bitter or metal taste in your mouth. Sucking sugar-free sweets may help with this. Some foods may taste different or have no taste. Try different foods to find out what tastes best to you. Taste changes usually get better after treatment finishes. Your nurse can give you more advice.

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

Your hair will get thinner or you may lose all the hair from your head. You may also lose your eyelashes, eyebrows or other body hair. Hair loss usually starts after your first or second treatment.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary and your hair will usually grow back after treatment ends.

Effects on the heart

Chemotherapy can affect the way the heart works. You may have tests to see how well your heart is working. These may be done before, during, and sometimes after treatment. If the treatment is causing heart problems, your doctor can change the type of chemotherapy you are having.

Contact a doctor straight away if you:

- have pain or tightness in your chest
- feel breathless or dizzy
- feel your heart is beating too fast or too slowly.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor.

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, tell your doctor or nurse straight away.

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

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.

> **'The Macmillan Online Community has proved invaluable with practical advice on coping with the day-to-day living with cancer, such as hair loss and side effects.'**
>
> **Christina**

Early menopause

In some people, treatment causes an early menopause. This can cause menopausal symptoms.

Your periods will stop and you will start the menopause. Doctors usually say early menopause is before 45.

We have more information about managing menopausal symptoms on our website (see page 140).

Sex and chemotherapy

Sex

It is not known if chemotherapy drugs pass into semen or vaginal fluids. Because of this, you should 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

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

Possible effects on fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. This is called infertility. It may be temporary or permanent, depending on the treatment that you have.

If you are worried about fertility, it is important to talk with your doctor before you start treatment. If you have a partner, it is a good idea to include them at this discussion. You can then decide if you want to be referred to a fertility specialist.

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. This is called 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 2 years for them to start again.

The younger you are, the more likely you are to have periods again and still be fertile after chemotherapy. If your periods do not come back, you will not be able to become pregnant. If this happens, you will have your menopause.

A fertility specialist can discuss possible options to help preserve your fertility with you. These could include storing embryos (fertilised eggs) or eggs.

We have more information in our booklet **Cancer and fertility – information for women** (see page 140).

Men

Some, but not all, chemotherapy drugs may slow down or stop your body producing sperm. For most men this will be temporary. Any problems with sperm production will not 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.

If you store sperm, you will usually be asked to produce several sperm samples. These will be frozen and stored so they can be used later to try to fertilise an egg and make your partner pregnant.

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

We have more information in our booklet **Cancer and fertility – information for men** (see page 140).

Steroid therapy

What are steroids?

Steroids are substances that are naturally produced in the body. They help to control many of the different ways our bodies work. Steroids can also be made in a laboratory as drugs for use in cancer treatment. Steroids are often given with chemotherapy to help treat lymphoma. They may also help you feel better during chemotherapy (see pages 60 to 73). The steroids most commonly used to treat lymphoma are called prednisolone and dexamethasone.

Side effects

You might take steroids for a few days during each cycle of chemotherapy for lymphoma.

Possible side effects of steroids include:

- indigestion
- increased appetite and weight gain
- swollen ankles
- having more energy or feeling restless
- changes in your mood
- difficulty sleeping
- skin rash or acne
- increased sugar levels in the blood.

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

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

If you have difficulty sleeping, it may help to take steroids in the morning.

Sometimes, steroids 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 urine (peeing) more 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 you may feel tired, have aches and pains, or have low moods for 2 to 3 days after you stop taking them. This is because your body is adjusting to the change in steroid levels.

We have more information about managing side effects in our booklet **Side effects and cancer treatment** (see page 140).

Targeted therapies and immunotherapies

The main targeted therapies drug used to treat non-Hodgkin lymphoma are called rituximab and obinutuzumab. Both drugs are targeted therapies called monoclonal antibodies. They work by recognising and targeting specific proteins on cells. They also encourage the body's immune system to attack and destroy lymphoma cells. Because of this, doctors may also call them immunotherapy treatment.

You may have rituximab or obinutuzumab on their own. But it is more common to have them in combination with chemotherapy (see pages 60 to 73). This is called chemoimmunotherapy.

If you have a rarer type of NHL, you may have other types of targeted therapy as part of your treatment.

New types of targeted therapy and immunotherapy drugs are being developed. They may be used to treat lymphoma as part of a clinical trial (see pages 92 to 94).

Rituximab and obinutuzumab

Rituximab is used to treat some types of B-cell NHL, including the two most common types. These are follicular lymphoma (FL) and diffuse large B-cell lymphoma (DLBCL). Instead of rituximab, some people may be given a similar drug called obinutuzumab. It may not be available everywhere in the UK. Some people may have it in a clinical trial.

Both drugs attach to a protein called CD20 on the surface of B-cell lymphocytes. This encourages the immune system to attack and destroy the lymphocytes.

The nurse will give you rituximab into a vein as a drip (intravenous infusion). It may be given as an injection under the skin after you have had at least one treatment into a vein. If obinutuzumab is given, you have it as an injection into a vein.

Biosimilars

Newer CD20 drugs are becoming available. They work in the same way as rituximab and obinutuzumab. They are just as effective. These drugs are called biosimilars. Your doctor or nurse will explain if you are having one of these drugs.

Maintenance treatment

For some types of NHL, targeted therapy treatment continues after the lymphoma is in remission. This is to keep the lymphoma in remission for as long as possible. This is called maintenance treatment.

You may have maintenance treatment for up to 2 years, or for as long as you need.

Other targeted therapy drugs for non-Hodgkin lymphoma

If you have a rarer type of NHL, you may have other types of targeted therapy that work in different ways.

Mantle cell lymphoma

You may have a drug called bortezomib (Velcade®) to treat mantle cell lymphoma (MCL). It is usually given as an injection into a vein (intravenous) or sometimes as an injection under the skin (subcutaneous).

Ibrutinib (Imbruvica®) may also be used to treat MCL after other treatments have already been used. You take it as a tablet.

Side effects of rituximab and obinutuzumab

Your doctor and nurse will explain the side effects you may get. This will depend on which drug you are having. Your healthcare team will tell you how side effects can be managed and controlled. It is important to follow their advice. Always let them know about your side effects and if they get worse.

Infusion reaction

Sometimes, people have a reaction while being given a monoclonal antibody, or soon after. Symptoms may include:

- feeling hot or flushed
- a skin rash
- itching
- shivering.

A reaction is most likely to happen the first time you have the drug. Your nurse will give it slowly to reduce the chance of a reaction. Any reaction can be treated quickly.

Lowered numbers of blood cells

These drugs can temporarily reduce the number of normal white blood cells in your blood. This is more likely if you are having chemotherapy at the same time. During this time, you are more likely to get an infection.

If you have any signs of infection it is very important to contact the hospital for advice immediately.

These drugs can also reduce the number of red blood cells and platelets in your blood. This can make you tired. You may also bruise or bleed more easily.

We have more information about how these drugs are given, and possible side effects, on our website (see page 140).

Other common side effects

Other side effects may include:

- feeling sick
- diarrhoea
- constipation
- skin changes.

If you are having ibrutinib or bortezomib, your doctor or nurse will explain the side effects to you.

CAR-T therapy

CAR-T stands for chimeric antigen receptor T-cell. This immunotherapy involves collecting your own immune cells and changing them to be better at fighting cancer cells. These cells then target the lymphoma cells. It can be used when the lymphoma is advanced and when other treatments have not worked well. CAR-T therapy is complicated and can have serious side effects. It is only suitable for a very small number of people. Currently, it is only available in a few specialist hospitals.

We have more information about CAR-T on our website (see page 140).

Radiotherapy

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

Radiotherapy can be used to treat groups of lymph nodes that are affected by lymphoma.

When is radiotherapy used?

Radiotherapy may be given:

- as the main treatment for low-grade NHL that is only in one group of lymph nodes
- after chemotherapy to treat low-grade or high-grade NHL, to reduce the risk of it coming back
- to treat an area of NHL that has not completely responded to chemotherapy
- at diagnosis, if there is an area of lymphoma that is 10cm (4 inches) or more across (bulky disease)
- to treat NHL that has come back in just one group of lymph nodes
- to help control symptoms, such as pain.

Planning your radiotherapy

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They help the radiographer (person who operates the machines) make sure you are in the correct position for each session of radiotherapy. These marks will only be made with your permission. If you are worried about them, talk to your radiographer. They can give you information and support throughout your treatment.

Radiotherapy to the neck

If you are having radiotherapy to the neck, you may need to wear a mask during treatment sessions. The mask is made to hold your head and neck still and in exactly the right position. This is made before you have treatment.

We have more information on radiotherapy masks on our website (see page 140).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Having radiotherapy treatment

Radiotherapy is usually given as a number of short, daily treatments in a hospital radiotherapy department. You usually have radiotherapy as an outpatient from Monday to Friday, with a break 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 3 weeks.

At the beginning of each session, the radiographers will make sure you are in the correct position. They will tell you how long your treatment will take. When everything is ready, they leave the room and the treatment starts. The treatment itself is not painful. It does not make you radioactive. You will not be a risk to anyone during your treatment.

The radiographers can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

Side effects

Radiotherapy can cause side effects in the area of your body that is being treated. You may also have some general side effects, such as feeling tired. After treatment finishes, it may be 1 to 2 weeks before side effects start getting better. After this, most side effects usually slowly go away.

Your cancer doctor, specialist nurse or radiographer will tell you what to expect. They will give you advice on what you can do to manage side effects. If you have any new side effects or if side effects get worse, tell them straight away.

Radiotherapy can have long-term side effects or late effects (see pages 101 to 107). These are rare and will vary depending on the part of the body treated. Your cancer doctor can tell you more.

Tiredness

Tiredness usually begins towards the end of treatment. After treatment finishes, you may continue to feel tired for weeks or months. If this does not get better, tell your cancer doctor or specialist nurse. There are things you can do to help.

We have more information about coping with tiredness in our booklet **Coping with fatigue (tiredness)** – see page 140.

Skin reactions

The skin in the area that is treated may:

- redden
- darken
- feel sore or itchy.

If your skin becomes sore, itchy or changes colour, tell your radiographer or specialist nurse straight away. They can give you advice and treatments if needed.

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

Feeling sick (nausea)

Treatment to the tummy area (abdomen) can make you feel sick or be sick (vomit).

If you feel sick, your doctor can prescribe anti-sickness (anti-emetic) drugs. If you do not 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.

Diarrhoea

Radiotherapy to the tummy area may irritate the bowel and cause diarrhoea. Your doctor can prescribe medicine to help. Eating a low-fibre diet may help reduce diarrhoea. You should also drink plenty of fluids.

Hair loss

Although radiotherapy can cause hair loss, this only happens in the area being treated. For example:

- radiotherapy to the lymph nodes in your neck may cause you to 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.

Stem cell transplant

Stem cells are early blood cells that make all the different types of blood cell you need. There are two types of stem cell transplant:

- using your own stem cells (autologous stem cell transplant)
- using stem cells from another person (allogeneic transplant).

Most people with lymphoma will not need a stem cell transplant. But it may be used to treat lymphoma:

- that does not respond well to standard chemotherapy treatment
- has a higher risk of coming back
- has come back (relapsed) after treatment.

The aim is to put the lymphoma into remission or increase the chance of being cured.

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. You are likely to be in hospital for several weeks and it may take many months to fully recover.

Research is being done to find the best ways to use stem cell transplants to treat lymphoma. Your specialist may talk to you about having a stem cell transplant as part of a research trial.

Occasionally, after a stem cell transplant some people may have maintenance treatment with a targeted therapy drug (see pages 76 to 78).

Autologous stem cell transplant (your own cells)

This involves being given your own stem cells (autologous stem cell transplant). The main benefit is that it allows you to have much more intensive doses of chemotherapy to treat the lymphoma.

We have more information in our booklet **Understanding stem cell transplants using your own cells (autologous)** – see page 140.

Donor stem cell (allogeneic) transplants

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. They also give you a new immune system which can fight any remaining lymphoma.

An allogeneic 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 treatments.

We have more information in our booklet **Understanding stem cell transplants using donor cells (allogeneic)** – see page 140.

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 60 to 73) 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. You or your donor usually have this done as an outpatient. You are then admitted to hospital to have more chemotherapy a few weeks later. This is called conditioning treatment. Sometimes you have radiotherapy as part of the conditioning treatment.

The aim of conditioning treatment is to remove any remaining lymphoma cells and to prepare your bone marrow for the transplant. Bone marrow is where blood cells are made.

After 1 or 2 days, 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. You will also need some time to recover when you go home from hospital.

> ‘I received a stem cell transplant. The haematology unit at King’s College Hospital were fantastic.’
>
> **Julian**

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials in our booklet **Understanding cancer research trials (clinical trials)** – see page 140.

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

AFTER YOUR TREATMENT

After treatment

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

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

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

How often you have follow-up appointments depends on:

- the type of lymphoma you had
- the treatment you had
- your situation.

Your specialist doctor or nurse will explain what to expect.

To begin with, your appointments may be every 3 months or so. After 2 years, you may have fewer appointments. Or you may stop having appointments.

Instead of appointments, some people are asked to get in touch when they need to see their lymphoma team. You are given advice on what to look out for and when to book an appointment, if needed.

If have any concerns in between appointments, you can always contact the hospital. You do not need to wait until your next appointment.

At your follow-up appointments

Your doctor will usually examine you. You may have blood tests and have your weight checked. You will not usually have scans, unless you develop symptoms that need to be checked.

Your doctor and nurse 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 before appointments. This is natural. It can help to get support from family or friends.

Signs of lymphoma coming back

Sometimes lymphoma comes back. This is called a relapse or recurrence. If lymphoma comes back, it is usually discovered when symptoms develop. Your 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 does not go away
- a cough or breathlessness that does not get better.

You may have other new symptoms that are worrying you. If you have any symptoms, it is important to have them checked. Contact your specialist doctor or nurse for advice. They can arrange for you to have an appointment if needed. Lymphoma that comes back can often be treated again (see pages 54 to 55).

Late effects of treatment

You will have side effects during treatment and for a few weeks after. Usually, these effects improve and eventually disappear.

But some people may have side effects that continue for months after treatment. These are often called long-term effects. Other people may have side effects that develop months or years after treatment. These are often called late effects.

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 specialist doctor or nurse can give you more information. We also have more information about long-term and late effects on our website (see page 140).

Tiredness

Recovering from treatment can take time. You may feel tired for many months after treatment is over. Occasionally, tiredness may last for a 1 or 2 years, depending on the type of treatment you had.

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.

We have more information about coping with tiredness in our booklet **Coping with fatigue (tiredness)** – see page 140.

Emotional effects

Some people find they still experience strong emotions months or even years after treatment. It often takes time to adjust to and deal with these feelings. If these feelings do not improve or you are finding them hard to cope with, talk to your lymphoma team or GP. They may be able to refer you to see a counsellor or psychologist, or prescribe medicines to help.

We have more information about this in our booklet **Your feelings after cancer treatment** (see page 140).

Immune system

Your immune system protects you against infection. Lymphoma and treatment for it can affect how your immune system works. this can make you less able to fight infections.

It is important to report any signs of an infection (see page 65) to your lymphoma team or GP. Having it treated straight away can prevent serious complications.

Vaccines

Your specialist doctor may advise you to have vaccinations to protect you against infections such as flu or pneumonia. They usually also recommend that you have a coronavirus vaccination. These are inactivated vaccinations that can help reduce the risk of infection. People with weak immune systems can have these, as they are not live vaccinations. Ask them for advice about when you should have 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 if you have had NHL. Ask your specialist doctor or nurse whether a vaccination is safe for you to have before having it.

Preventing pneumonia

Pneumonia is a severe type of chest infection. Certain treatments can lower the number of lymphocytes that fight infection. This can last for several months. It can make you more likely to develop a type of pneumonia called PJP or PCP.

If you are at risk, your doctor will ask you to take tablets such as to help prevent infection. These may be co-trimoxazole (Septrin®). You may need to take them for several months. They reduce your risk of infection until the number of lymphocytes in your blood returns to normal.

Peripheral neuropathy

Treatment can affect the nerves, causing numb, tingling or painful hands or feet. This is called peripheral neuropathy. It usually slowly gets better after treatment ends.

Sometimes nerves do not fully recover. If this happens, you may continue to have difficulty with fiddly tasks. For example, it may be harder to pick up very small objects or do up buttons. Tell your doctor or nurse if this happens. People generally the changes become less noticeable over time as they adapt and find ways of coping.

We have more information about peripheral neuropathy on our website (see page 140).

Early menopause

People usually reach menopause between the ages of 45 and 55. But after treatment for lymphoma, you may have an earlier menopause. Your doctor or nurse can tell you if this is likely.

Symptoms can include:

- hot flushes
- night sweats
- joint pain
- reduced sex drive
- vaginal dryness
- disturbed sleep
- mood swings
- anxiety.

If you have any of these symptoms, tell your doctor or nurse. 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 the possible benefits and risks of HRT.

We have more information on managing the symptoms of menopause on our website (see page 140).

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 works.

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 specialist 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.

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.

We have more information about effects on the heart in our booklet **Heart health and cancer treatment** (see page 140).

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. They usually get better months or years after treatment ends. Sometimes bleomycin causes permanent damage to the lungs. This is more likely if:

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

If you smoke, quitting will improve your lung health and reduce your 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 tell your doctor or nurse that you have had bleomycin. Scuba diving is not recommended after treatment with bleomycin.

Irradiated blood products

You should only have irradiated blood if you need a blood transfusion at any time after:

- certain chemotherapy drugs or targeted therapy drugs
- a stem cell transplant
- CAR-T.

Your doctor will tell you if this applies to you.

This includes if you need blood products called red cells, platelets or granulocytes. This is still important after your lymphoma treatment ends and for the rest of your life, even if the lymphoma is in remission.

Irradiated blood products are treated with x-rays to get rid of white blood cells called lymphocytes. Rarely, these lymphocytes can cause a serious reaction in people who have had certain treatments for non-Hodgkin lymphoma.

Your specialist doctor will give you a card that explains this. You should show the card if you ever need treatment at hospital or need a blood transfusion. Some people also wear a medical ID bracelet or chain that carries this information. This is useful if you need emergency treatment and are not able to explain your medical history. Your pharmacist can give you more information.

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 your emotions 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.

> **‘I’ve been doing the Macmillan HOPE course which has been really good for me. I’ve also been keeping up with my blog and writing all my feelings and emotions down. It’s been like therapy for me.’**
>
> **Christina**

It is important to remember that although your treatment has finished, you may still need support from other people. This might come from family or friends, or from a member of your healthcare team.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups (see page 140).

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.

Drink sensibly

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 3 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**

Be 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 to:

- cope with stress
- increase your energy levels
- feel better.

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, some chemotherapy drugs, and certain targeted therapies and immunotherapies make your skin sensitive to sunlight. This means your skin is 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.

After a stem cell transplant it is very important to protect your skin from the sun.

Find ways to relax

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

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

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

Hospitals or support groups sometimes offer classes in relaxation techniques.

You may also find our **Relax and breathe CD** helpful (see page 140).

Consider complementary therapies

Some people use complementary therapies to help them feel better. Complementary therapies include 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.

We have more information in our booklet **Cancer and complementary therapies** (see page 140).

> My husband and I have a campervan. It’s great because it gives you the freedom and flexibilty to just get up and explore places.

Christina

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

> **My method of dealing with it has been to write a blog chronicling my story. This allows me to empty my brain and park my thoughts, and it helps my family and friends stay informed, so they don't have to constantly ask me.**
>
> **Christina**

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

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

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our Online Community can help you find local support groups (see page 140).

If you need more help

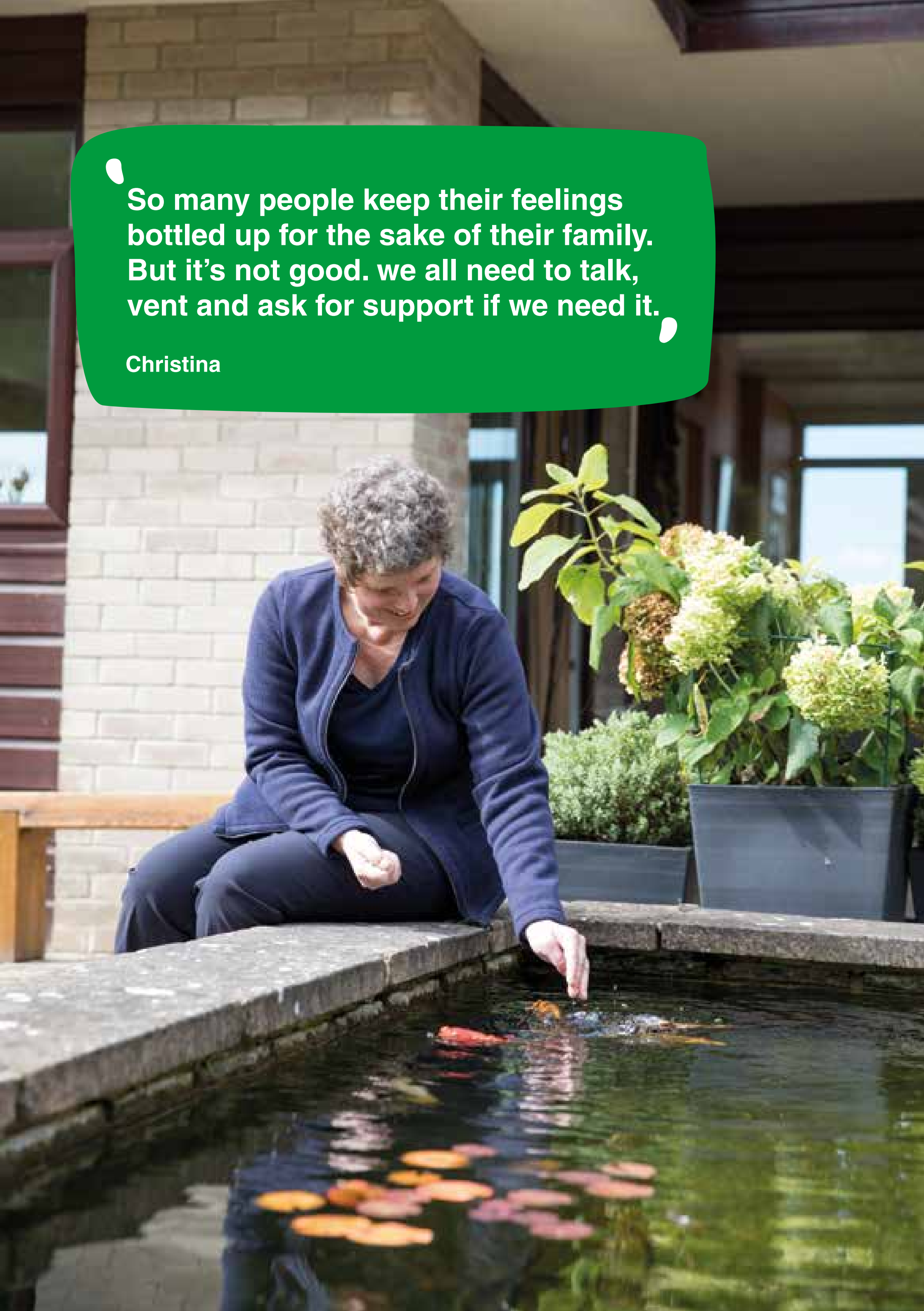
You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

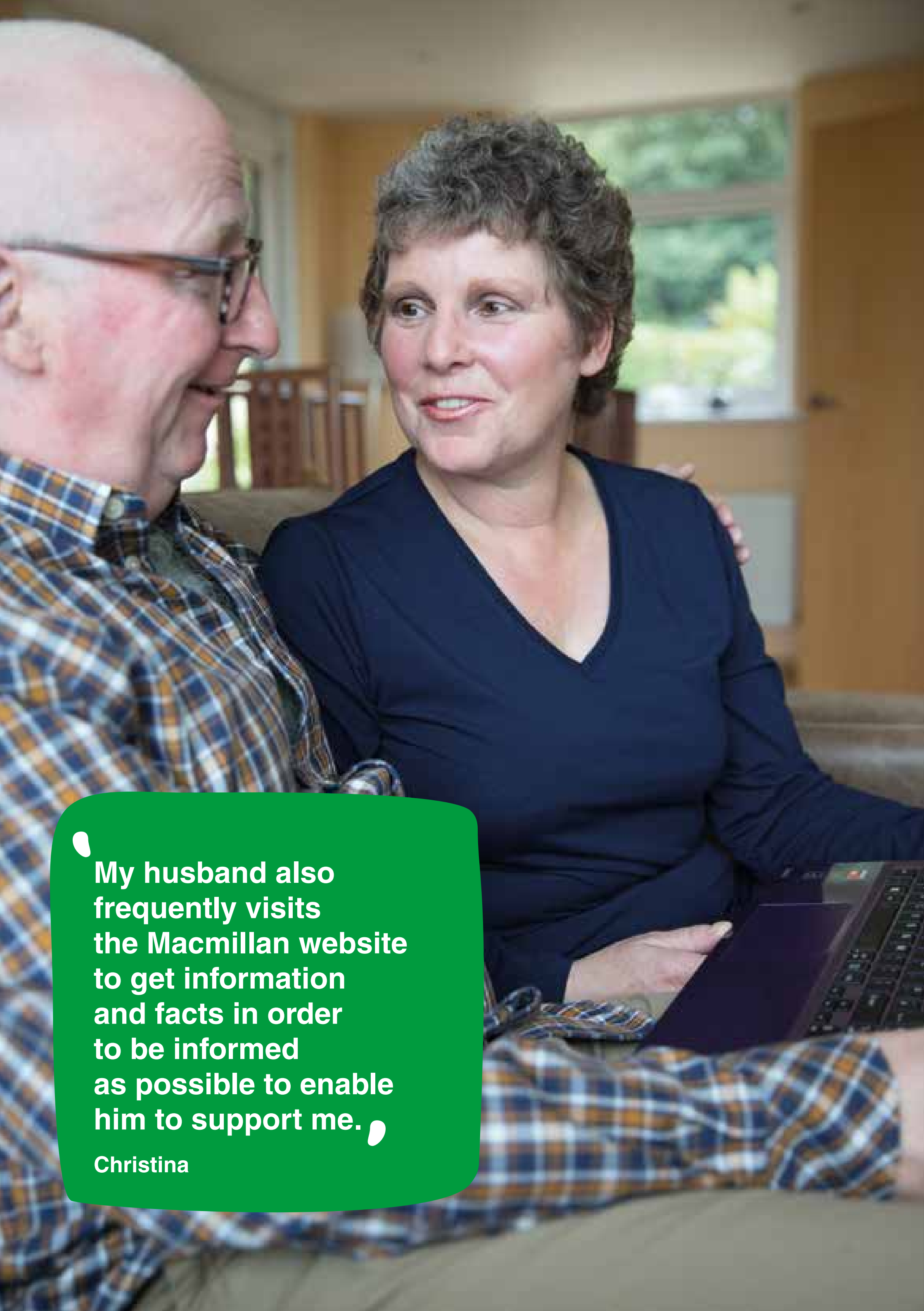
- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 140).



> “So many people keep their feelings bottled up for the sake of their family. But it’s not good. we all need to talk, vent and ask for support if we need it.”
>
> **Christina**



> My husband also frequently visits the Macmillan website to get information and facts in order to be informed as possible to enable him to support me.
>
> Christina

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is 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. Visit **macmillan.org.uk/learnzone** to find out more (see page 140).

We have more information in our booklet **Talking with someone who has cancer** (see page 140).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 140).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too.
For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information about talking to children and teenagers when an adult has cancer in our booklet **Talking to children and teenagers when an adult has cancer** (see page 140). We also have a video on our website about talking to children.

Who can help?

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. You may continue to need help after your treatment is over, while you recover.

During your treatment, someone from your healthcare team will be your main contact person. This is often called a clinical nurse specialist. In England, this person may be called a key worker. You should be given their name and contact details. 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 different emotions during your treatment. This is normal and support is available if you need it.

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, a counsellor, nurse specialist, or religious leader. There are also ways for you to talk to other people affected by cancer.

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 do not 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. You can try going 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. To find out more, go to **macmillan.org.uk/community**

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

> **‘Without Macmillan’s help, I don’t think I would have a job. My husband is retired, and I am on sickness benefit, not a lot of money coming in. I am now working 20 and a half hours a week, occasionally cooking and in control of the kitchen.’**
>
> **Leslie**

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

> **‘Finances were tight as I was on half pay following the transplant. This meant that a summer holiday was out of the question. Macmillan provided me with a grant that enabled me to take my children on a weekend break 4 months after my transplant. It was so lovely to be able to do this.’**
>
> **Julian**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (see page 140). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see pages 149 to 150).

Our booklet **Help with the cost of cancer** has lots more information (see page 140).

> ‘Make sure you know your rights. Speak to your Macmillan nurse. Get in touch with Macmillan. They’re just on the other end of the phone and are really easy to contact.’

Leslie

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 140). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 140).

> **'I was surprised when I found out, as I don't see myself as disabled. But it makes sense, because cancer does have an impact.'**
>
> **Leslie**

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 booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring 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 would 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**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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 would 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 is 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.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have 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 are 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**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

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

Lymphoma support organisations

Anthony Nolan

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

Blood Cancer UK

Tel **0808 2080 888** (Mon to Fri, 10am to 7 pm and Sat to Sun, 10am to 1pm)
Email **hello@bloodcancer.org.uk**
www.bloodcancer.org.uk
Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Provides information about blood cancers and treatments.

Lymphoma Action

Tel **0808 808 5555** (Mon to Fri, 10am to 3pm)
Email **information@lymphoma-action.org.uk**
www.lymphoma-action.org.uk
Provides information and support to anyone affected by lymphoma. Has a helpline, newsletter and network of support groups.

General cancer support organisations

Cancer Black Care

Tel **0208 961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

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.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

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.

Maggie’s

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 1pm)
Email **helpline@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

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, benefits advice and an online ‘Ask the nurse’ service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK’s biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (7 days a week, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 9am to 5pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
Email **info@ukcp.org.uk**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317** (Mon to Fri, 8am to 6pm)
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 by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Disability and Carers Service

Tel **0800 587 0912** (Mon to Fri, 9am to 5pm)
Textphone **028 9031 1092**
nidirect.gov.uk/contacts/disability-and-carers-service

Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.gov.uk

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

Jobs and Benefits office Enquiry Line Northern Ireland

Helpline **0800 022 4250** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Law Centres Network

www.lawcentres.org.uk

Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland). You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.wales/welsh-local-authority-links

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

Tel **0141 572 0237**
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

StepChange Debt Charity

Tel **080 0138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
Email **contact@unbiased.co.uk**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
Textphone **020 7562 2050**
Email **contactus@redcross.org.uk**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disabled Living Foundation (DLF)

Helpline **0300 999 0004** (Mon to Fri, 10am to 4pm)
Email **info@dlf.org.uk**
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

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.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 10am to 6pm)
Email **info@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 carers

Carers Trust

Tel **0300 772 9600** (Mon to Fri, 9am to 5pm)
Email **info@carers.org**
www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777** (Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

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 **0207 654 8000**
Email **enquiries@phe.gov.uk**
www.ncras.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel **0131 275 7777**
Email **nss.csd@nhs.net**
www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 037 3500**
Email **general.enquiries@wales.nhs.uk**
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel **0289 097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

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, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editor, Professor Rajnish Gupta, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Katrina Farrell, Consultant Haematologist; Dr Eve Gallop-Evans, Consultant Clinical Oncologist; Dr Jonathan Lambert, Consultant Haemato-oncologist; Karen Stanley, Macmillan Lymphoma Clinical Nurse Specialist; and Sarah Wells, Lymphoma Clinical Nurse Specialist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

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

Sources

Below is a sample of the sources used in our non-Hodgkin lymphoma information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

National Institute of Health and Care Excellence (NICE). Blood and bone marrow cancers. NICE Pathway (updated 09 December 2020). Last accessed 3 December 2020.

Newly Diagnosed and Relapsed Follicular Lymphoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up; European Society for Medical Oncology (2020).

Non-Hodgkin's lymphoma: diagnosis and management; NICE Guideline (July 2016)

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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 / /

Do not 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.

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

Registered with
FUNDRAISING REGULATOR

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

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.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can. For information, support or just someone to talk to, call **0808 808 00 00** 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

Help us improve our information. Scan the QR code below to tell us what you think.

Trusted
Information
Creator
Patient Information Forum