

# UNDERSTANDING HODGKIN LYMPHOMA



**If it wasn't for Macmillan, I could never have got to my prom or had my holiday. And I definitely wouldn't be sitting here now as a fully qualified childcare worker.**

**Megan, diagnosed with Hodgkin Lymphoma**



# About this booklet

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

The booklet explains what the signs and symptoms of Hodgkin lymphoma are, how it is diagnosed, and what treatment 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 the information 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.

We have included quotes from people who have had Hodgkin lymphoma, which you may find helpful. Some are from our Online Community ([macmillan.org.uk/community](https://macmillan.org.uk/community)). The others are from people who have chosen to share their experiences with us by becoming Cancer Voices. This includes Megan, who is on the cover of this booklet. To find out how you can share your experience, visit [macmillan.org.uk/cancervoices](https://macmillan.org.uk/cancervoices)

There is another type of lymphoma called non-Hodgkin lymphoma. We have another booklet about this called **Understanding non-Hodgkin lymphoma**. Call us on **0808 808 00 00** or visit [be.macmillan.org.uk](https://be.macmillan.org.uk) to order a free copy.

## How to use this booklet

This booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on the opposite page to help you.

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

At the end of this booklet there are details of other organisations that can help (see pages 109 to 115). There is also space to write down questions and notes for your doctor or nurse (see page 116).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

## 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](https://www.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](https://www.macmillan.org.uk/otherformats)** or call **0808 808 00 00**.

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# ABOUT HODGKIN LYMPHOMA

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# The lymphatic system

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

The lymphatic system includes:

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

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

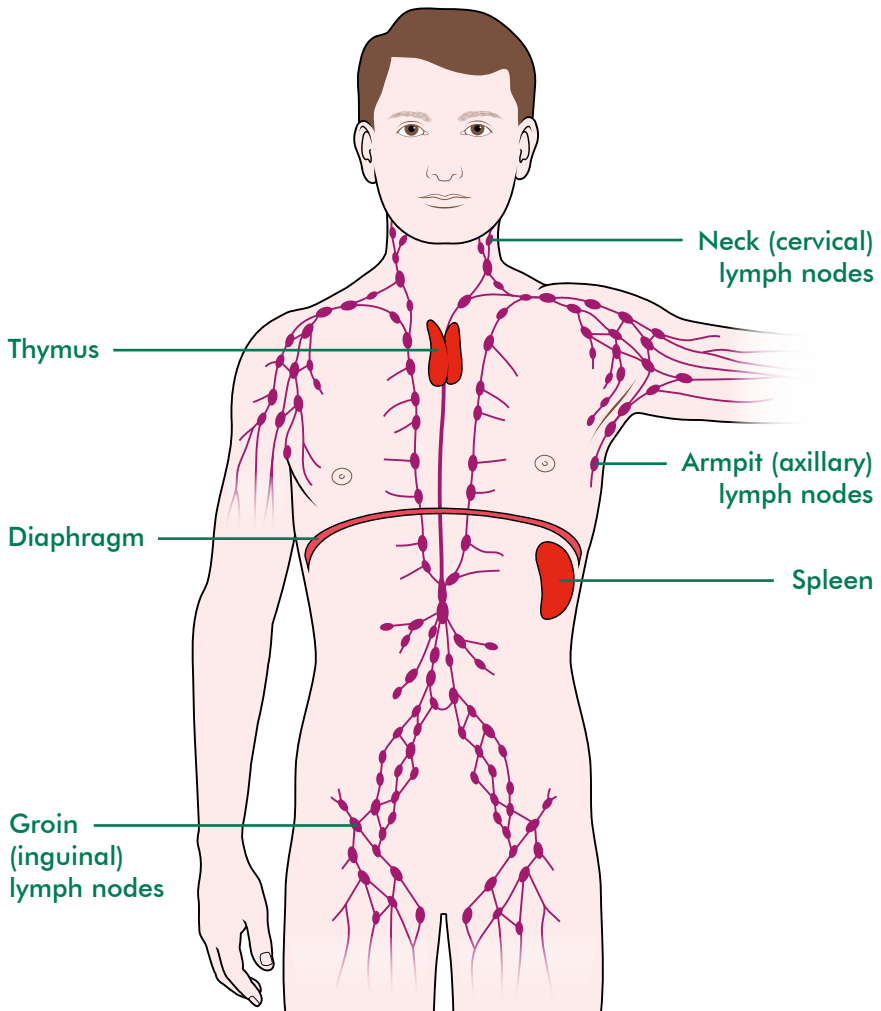
There are groups of lymph nodes around the network. As the lymph fluid passes through the nodes, they filter out disease and germs (bacteria and viruses).

The lymph nodes contain infection-fighting white blood cells called lymphocytes. Lymph nodes often swell when they are fighting infection. If you have a throat infection, you may be able to feel swollen lymph nodes in your neck below your jaw.

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



## The lymphatic system



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

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

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

# What is lymphoma?

Lymphoma is a cancer of the lymphatic system.

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

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

In 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. But lymphoma can start growing in other parts of the body.

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

# What is Hodgkin lymphoma?

There are many types of lymphoma. Different types develop and are treated in different ways. The two main sub-types are Hodgkin lymphoma and non-Hodgkin lymphoma. A doctor can only find out your lymphoma type by collecting some lymphoma cells and examining them under a microscope.

About 1 in 5 (20%) of all diagnosed lymphomas are Hodgkin lymphoma. Around 1,700 people are diagnosed with Hodgkin lymphoma in the UK each year. It can affect people at any age. However, it is more common in people who are 20 to 34 years old or over 70 years old.

Hodgkin lymphoma can begin in almost any part of the body. But it usually starts in the lymph nodes. The most common area is the lymph nodes in the neck. Often several areas of lymph nodes around the body are affected. Sometimes organs such as the spleen, bone marrow or liver are affected too.

# Types of Hodgkin lymphoma

There are two main types of Hodgkin lymphoma. Doctors can find out which type you have by examining some lymphoma cells under a microscope.

## Classical Hodgkin lymphoma

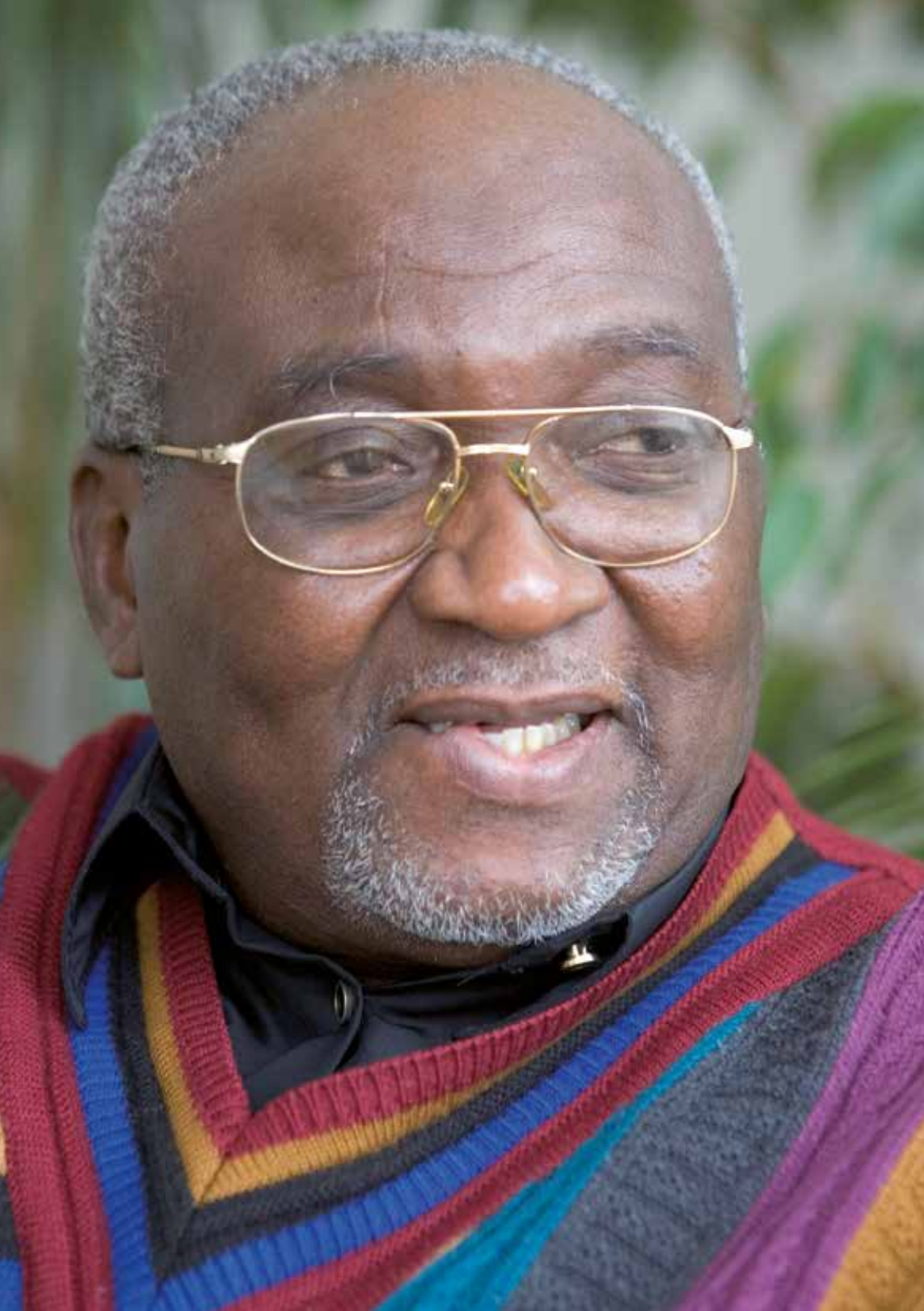
This is the most common type of Hodgkin lymphoma. There are four sub-types:

- nodular sclerosing
- mixed cellularity
- lymphocyte-depleted
- lymphocyte-rich.

These sub-types are all treated in the same way.

## Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL)

This is a rarer type of Hodgkin lymphoma. NLPHL develops and is treated differently to classical Hodgkin lymphoma. Rarely, NLPHL can change into a type of non-Hodgkin lymphoma. If that happens, it is treated as non-Hodgkin lymphoma instead of Hodgkin lymphoma.



# Risk factors and causes

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

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

## Age

Hodgkin lymphoma is more common in people who are 20 to 34 years old or over 70 years old.

## Gender

Hodgkin lymphoma is slightly more common in men than women.

## Infections

The Epstein Barr virus (EBV) is sometimes linked to Hodgkin lymphoma. EBV is the virus that causes glandular fever. It is very common in the UK and doesn't usually cause serious illness. It is very rare to develop lymphoma because of an EBV infection.

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

## A weakened immune system

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

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

## Previous non-Hodgkin lymphoma

People who have had non-Hodgkin lymphoma have a higher risk of developing Hodgkin lymphoma in the future. You can speak to your doctor about this.

## Having a close relative with lymphoma

People who have a parent, brother or sister with lymphoma have a slightly higher risk of developing Hodgkin lymphoma. We don't know why this is yet. It may be because there is a genetic change that runs in families. Or it may be because people in a family tend to have the same lifestyle and live in similar environments.

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



# Symptoms of Hodgkin lymphoma

The most common symptom of Hodgkin lymphoma is a lump where a lymph node is swollen. This is usually in the neck, armpit or groin. But other areas of lymph nodes can be affected and cause symptoms too. The lump is not usually painful, but some people may find that it aches.

Other symptoms may include:

- heavy drenching sweats, especially at night
- unexplained high temperatures
- unexplained weight loss
- tiredness
- a cough or breathlessness
- itchiness all over the body that doesn't go away.

Some people don't have any of these symptoms and the lymphoma is found during tests for other conditions.

Rarely, people with Hodgkin lymphoma have pain in the affected lymph node when drinking alcohol.

'One night I noticed a part of my neck was swollen. I was a bit under the weather at the time so I assumed it was part of that. But it didn't go away so I went to the doctor.'

**Terry**

**'I felt scared. I didn't know what was coming and I felt a bit lost as well.'**

**Megan**



# DIAGNOSING HODGKIN LYMPHOMA

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# How lymphoma is diagnosed

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

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

## Taking a tissue sample (biopsy)

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

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

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

## Lymph node biopsy

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

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

## Further tests

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

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

You may have some of the following tests:

### CT scan

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

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

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

### **PET/CT scan**

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan.

A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET/CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one.

You can't eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

## MRI scan

This test uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you've ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings including jewellery.

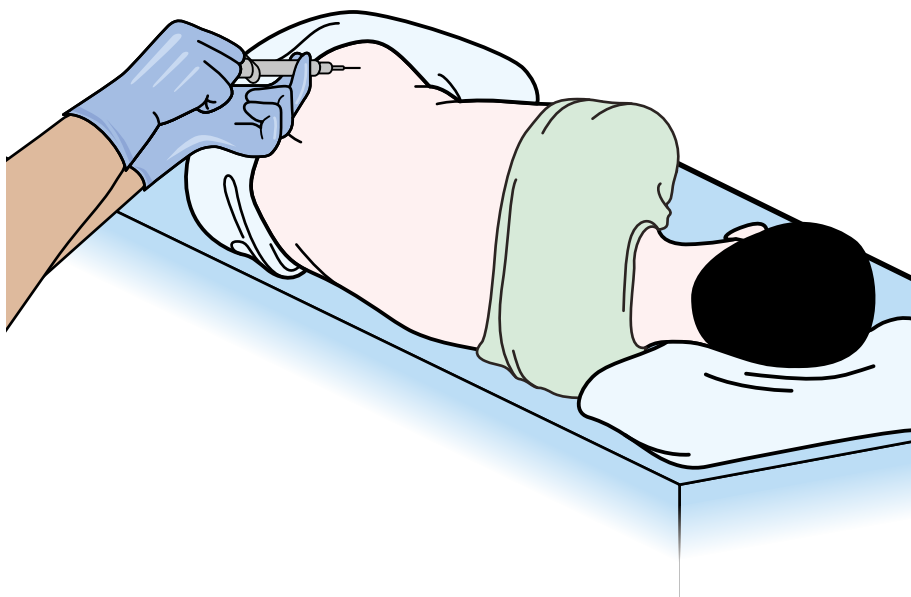
Some people are given an injection of a dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

## Bone marrow sample

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

### A bone marrow sample being taken



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

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



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

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

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

## Waiting for test results

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

# Staging

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

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

- **Stage 1** – there is only one area of lymphoma. This may affect one group of lymph nodes or another part of the lymphatic system.
- **Stage 2** – there are two or more areas of lymphoma on the same side of the diaphragm (the sheet of muscle underneath the lungs, see page 7).
- **Stage 3** – there are areas of lymphoma above and below the diaphragm.
- **Stage 4** – there are areas of lymphoma outside and separate from the lymphatic system. For example, this could be in organs such as the bone marrow, liver or lungs.

Stages 1 and 2 are also called early-stage, limited lymphoma. If stage 1 or 2 lymphoma has grown into nearby areas of tissue, this is called extra-nodal disease. The letter E may be added after the stage number to show it is extra-nodal disease, for example stage 1E.

Stages 3 and 4 are also called advanced lymphoma.

## B symptoms

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

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

If you don't have any of these symptoms, the letter A is used instead, for example stage 1A.

## Bulky disease

If an area of lymphoma is 10cm (4 inches) or more in diameter, this is called 'bulky' disease. The letter X may be added after the stage number, for example stage 1X.

### Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health 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. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry) To find out more details about the cancer registry in your area, see page 115.



# TREATING HODGKIN LYMPHOMA

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# Treatment overview

The main treatments for Hodgkin lymphoma are chemotherapy and radiotherapy. The treatment you have will depend on:

- the type of Hodgkin lymphoma you have
- the stage of the Hodgkin lymphoma (see pages 24 to 25)
- your age and general health
- which parts of your body are affected
- the results of your blood tests.

## Treating classical Hodgkin lymphoma

If you have early-stage classical Hodgkin lymphoma, you will usually be treated with chemotherapy followed by radiotherapy. If the lymphoma is more advanced, chemotherapy is usually the main treatment but you may also have radiotherapy.

Most people won't need any further treatment to get rid of the lymphoma. However, sometimes lymphoma comes back or there may still be signs of it after treatment. You might need more treatment if this happens (see pages 72 to 73).

## Treating NLPHL

If you have nodular lymphocyte predominant Hodgkin lymphoma (NLPHL), your doctor may suggest that you delay having treatment. Instead you will have regular tests and appointments to monitor the lymphoma. This is called watch and wait.

If you start treatment, you may have radiotherapy or chemotherapy to treat NLPHL. Some people have both treatments. Other people will have a targeted therapy such as rituximab. This is a common treatment for non-Hodgkin lymphoma.

NLPHL may come back, sometimes after a long period of time, and can be treated again with chemotherapy or radiotherapy. Rarely, NLPHL can change into a type of non-Hodgkin lymphoma. If this happens, you will have treatment for non-Hodgkin lymphoma instead.

We have more information about treatments for non-Hodgkin lymphoma. Order our booklet **Understanding non-Hodgkin lymphoma** from **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

## How treatment is planned

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

The MDT may include:

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

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





## Talking about your treatment options

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

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

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

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

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

## Deciding about treatment

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

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

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

## Second opinion

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

## Giving your consent

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

Before your doctor asks you to sign the form, they should give you information about:

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

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



# Watch and wait

If you have nodular lymphocyte predominant Hodgkin lymphoma (NLPHL), your doctor may suggest that you don't need to start treatment straight away. Instead, you will have regular tests and appointments to monitor the lymphoma and check for signs that you need to start treatment. This is called watch and wait. It is a way of delaying treatment until it is needed.

Your doctor may suggest watch and wait if:

- you had a small area of NLPHL that was completely removed by surgery or treated with radiotherapy
- you have NLPHL that is not changing or causing any symptoms
- you have NLPHL that has come back but you don't have any symptoms.

Sometimes people worry about delaying treatment.

However, cancer treatments cause side effects. Some side effects may be long-term or start to affect your health years after treatment. Watch and wait means you can have treatment when it is needed and avoid the risk of side effects for as long as possible.

NLPHL often develops slowly and you may not need treatment for a long time. Watch and wait does not make your treatment less effective when you do need it.

# Chemotherapy

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

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

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

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

'The treatment suite has a set of very comfortable recliner chairs so that you can have your chemotherapy sitting down and you can put your feet up if you wish.'

**Brian**

## Chemotherapy drugs for Hodgkin lymphoma

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

- **ABVD** – this is a combination of the chemotherapy drugs doxorubicin (Adriamycin®), bleomycin, vinblastine and dacarbazine (DTIC). They are given into a vein.
- **BEACOPP** – this is a combination of the chemotherapy drugs bleomycin, etoposide, doxorubicin (Adriamycin®), cyclophosphamide, vincristine (Oncovin®) and procarbazine. These are given into a vein except procarbazine, which you take as tablets. You also take steroid tablets called prednisolone.

All chemotherapy drugs can cause side effects. For some people, there is a higher risk that ABVD and BEACOPP may cause more serious side effects. Depending on your general health and age, your lymphoma doctor may suggest another chemotherapy that is safer for you. This may include:

- **VEPEMB** – this is a combination of the chemotherapy drugs vinblastine, cyclophosphamide, procarbazine, etoposide, mitoxantrone and bleomycin. These are given into a vein except procarbazine and etoposide, which you take as tablets. You also take prednisolone tablets.
- **ChIVPP** – this is a combination of one chemotherapy drug that is given into a vein and two types of chemotherapy tablets. The drugs are chlorambucil, vinblastine and procarbazine. You also take prednisolone tablets.

Our booklet **Understanding chemotherapy** discusses the treatment and its side effects in detail. We can send you a free copy. We also have information about individual chemotherapy drugs and their side effects. To order copies call us on **0808 808 00 00**.

'It's just the thought of chemotherapy that's a bit frightening, but you get used to it. It doesn't hurt and it's over and done with in a few minutes.'

**Trevor**

## How chemotherapy is given

### Chemotherapy into a vein

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

It can be given through:

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

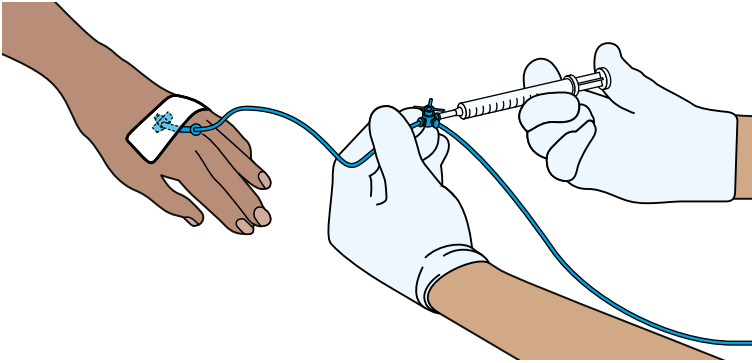
Your nurse will check that the cannula, line or port is working properly before giving you the chemotherapy.



## Cannula

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

## Giving chemotherapy into a cannula

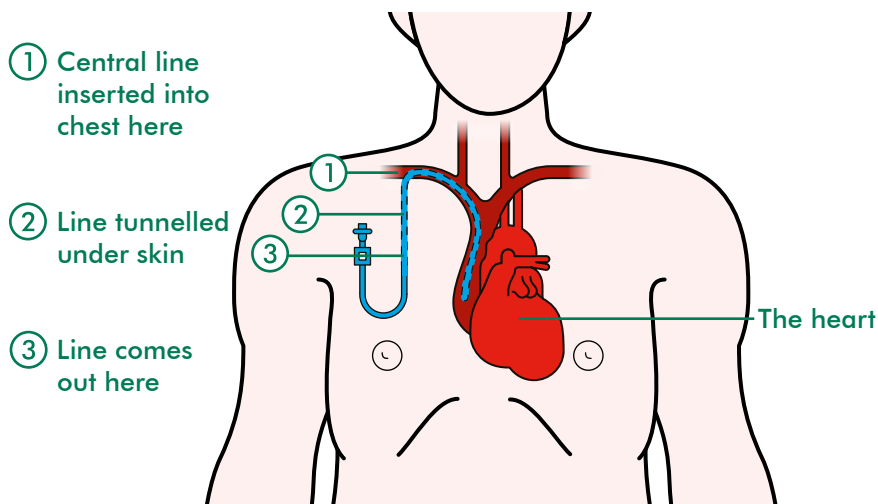


## Central line

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

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

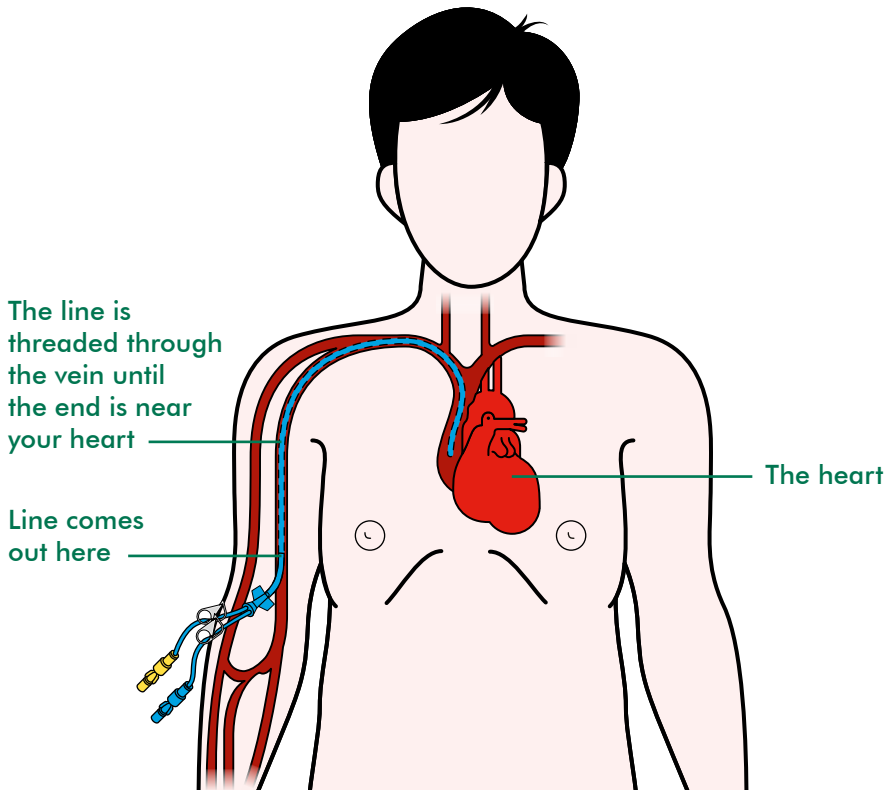
## Positioning of a central line



## PICC (Peripherally Inserted Central Catheter) line

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

### Positioning of a PICC line

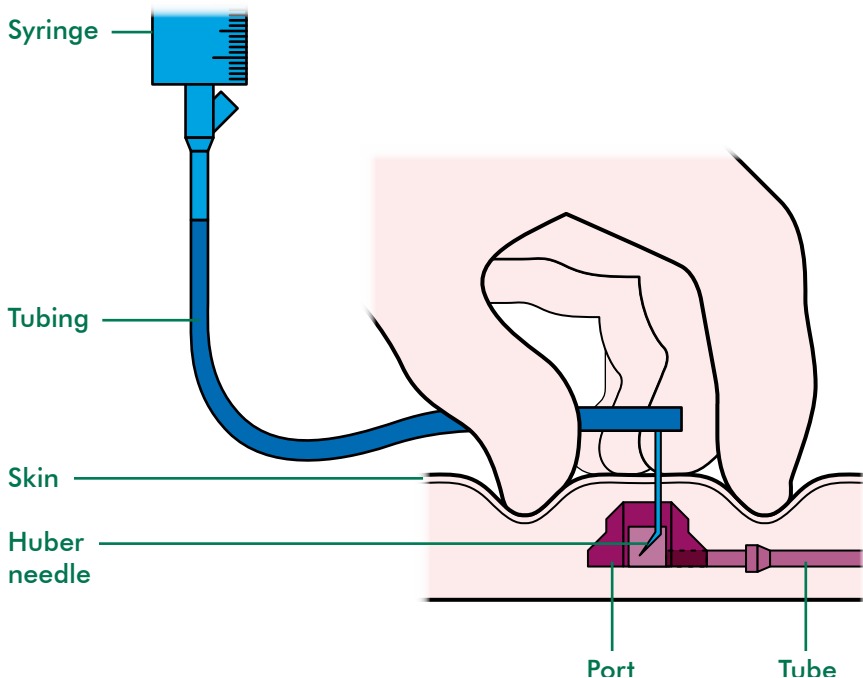


## Implantable port (portacath)

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

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

## Using an implantable port



## Your line or port after chemotherapy

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

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

We can send you more information about central lines, PICC lines, and implantable ports.

'Most of the time I was barely aware of my PICC line. It was covered by an elastic bandage and I just left it alone and never had a problem. Now it's out, all that's left is a tiny round mark.'

**Lynne, Online Community member**

## Chemotherapy tablets

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

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

It is very important to:

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

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

## Side effects of chemotherapy

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that's planned for you.

The main side effects are described here as well as some ways to reduce or control them.

## **Risk of infection**

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

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

- your temperature goes over 37.5°C (99.5°F), depending on the advice given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection, such as:
  - feeling shivery
  - a sore throat
  - a cough
  - diarrhoea
  - needing to pass urine often.

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

## **Anaemia (reduced number of red blood cells)**

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

Anaemia can be treated with blood transfusions. This should help you to feel more energetic and ease the breathlessness.

People affected by Hodgkin lymphoma should only have blood that has been treated with x-rays (irradiated). For more information about irradiated blood, see page 75.

## **Bruising and bleeding**

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

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

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



## Feeling sick

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

We have more information about controlling sickness and vomiting.

## 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.

Our booklet **Coping with fatigue** has more helpful tips. You can order it by calling **0808 808 00 00** or from **be.macmillan.org.uk**

## Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. It depends on what chemotherapy drugs you are having (your doctor or nurse can tell you more about what to expect).

If you do experience hair loss your hair should start to grow back within about 3 to 6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

We have more information and tips for hair loss. You can read more by visiting [macmillan.org.uk/hairloss](https://www.macmillan.org.uk/hairloss) Or you can order our booklet **Coping with hair loss** from [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

## Constipation

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

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

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



**‘When I started to lose my hair, my Macmillan nurse Julie put me in touch with a wig specialist and showed me how to wear a headscarf. She explained that it was normal to feel the way I felt.’**

**Megan**

## Taste changes

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

Our booklet **Eating problems and cancer** has more information and helpful tips.

## Effects on the heart

Some of the drugs used to treat lymphoma can affect the heart. It can depend on the type of drugs and how much you are given. Your doctor will plan your treatment carefully and monitor the doses you are given. You may have tests to check your heart health before, during and after treatment.

We have more information in our booklet **Heart health and cancer treatment**.

## Effects on the lungs

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

If you are a smoker, it is a good idea to stop smoking before having treatment. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

## 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.

We have more information about peripheral neuropathy we can send you.

**‘Chemotherapy wasn’t easy and I struggled with some of the side effects throughout, but it was doable.’**

**Siobhan**

## Sex and chemotherapy

### Sex

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

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

### Contraception

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

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

Our booklets **Cancer and your sex life – information for men** and **Cancer and your sex life – information for women** have more information and helpful advice. To order free copies, call **0808 808 00 00** or visit **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

## Possible effects on fertility

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

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

### Women

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

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

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

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

You can read more about this in our booklet **Cancer treatment and fertility – information for women**. To order a free copy, call **0808 808 00 00** or visit **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

## Men

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

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

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

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

You can read more about this in our booklet **Cancer treatment and fertility – information for men**. To order a free copy, call **0808 808 00 00** or visit **[be.macmillan.org.uk](http://be.macmillan.org.uk)**





# Steroid therapy

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

## Side effects of steroids

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

Possible side effects include:

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

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

If you have indigestion, it can help to take your steroids with food. Your doctor may also prescribe drugs to prevent indigestion.

Tell your doctor if you have stomach pains while taking steroids.

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

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

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

# 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 beams are aimed at.

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

Our booklet **Understanding radiotherapy** gives more details about this treatment and its side effects.

## When is radiotherapy used?

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

Some people will have radiotherapy after chemotherapy to treat classical Hodgkin lymphoma. Others may have radiotherapy to treat a group of lymph nodes that are still affected by lymphoma after having chemotherapy. But some people may also have radiotherapy even if there are no signs of lymphoma after chemotherapy. This is because radiotherapy may reduce the risk of lymphoma coming back.

If you have NLPHL (see page 11), you may have radiotherapy as your main treatment after a small early-stage lymphoma has been removed with an operation.

Some people will have radiotherapy to treat lymphoma that comes back in a group of lymph nodes.

## Planning your radiotherapy

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

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

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

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

## Treatment sessions

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

## Possible side effects of radiotherapy

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

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

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

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

### Tiredness

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

We have more information in our booklet **Coping with fatigue**. You can order a copy by calling **0808 808 00 00** or by visiting **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

### Feeling sick (nausea)

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

## Skin reaction

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

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

## Hair loss

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

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

Most side effects should gradually disappear once your treatment finishes, but tell your doctor if they continue. We can send you more information about all the side effects listed here. Call us on **0808 808 00 00** for more details.

# Targeted therapy

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

This type of treatment is not often used to treat Hodgkin lymphoma. Some people have a targeted therapy called rituximab to treat NLPHL. Another drug called brentuximab vedotin (Adcetris®) may be used as part of the treatment for classical Hodgkin lymphoma that has come back. Sometimes targeted therapy drugs are given in a research trial (see the opposite page) to find out how effective they are.





# Research – clinical trials

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

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

Trials are the only reliable way to find out if a different type of treatment is better than what is already available.

## Taking part in a trial

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

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

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

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail. You can order a copy by calling **0808 808 00 00** or by visiting **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

## Blood and tumour samples

You may be asked if blood or tumour samples taken when you were diagnosed can be used for research. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

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

# Coping with treatment

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

## Who can help?

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

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

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

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

## Sharing your experience

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

## Support groups

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

'Macmillan helped me with a support group. It was fine actually. Sometimes you can hear some pretty negative opinions, but it is always interesting to speak to people who are going through the same thing as you. They understand in a different way.'

**Jas**

## 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](https://macmillan.org.uk/community)**

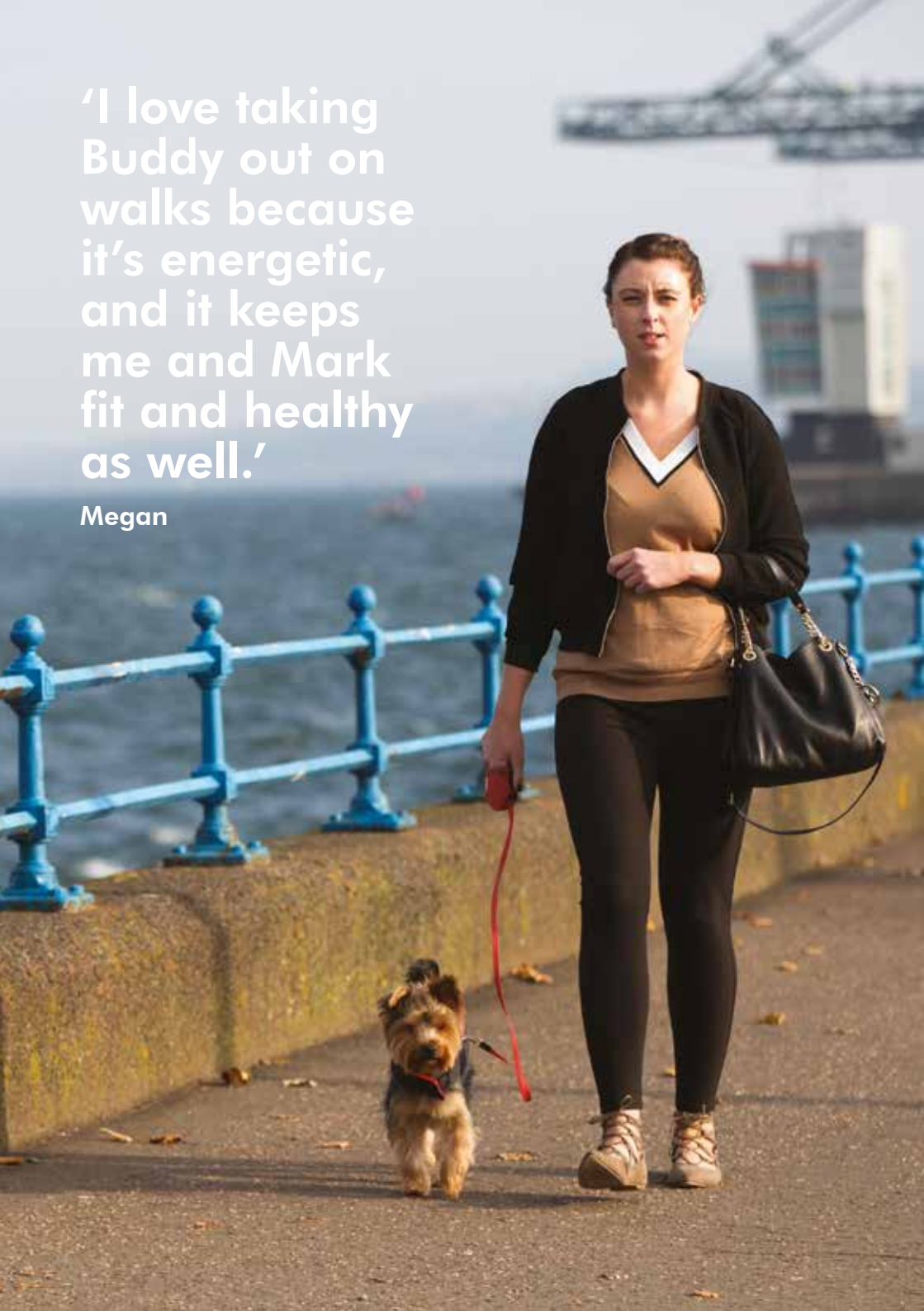
## Complementary therapies

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

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

'I love taking  
Buddy out on  
walks because  
it's energetic,  
and it keeps  
me and Mark  
fit and healthy  
as well.'

Megan



# AFTER YOUR TREATMENT

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## Follow-up

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

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

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

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



## At your follow-up appointments

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

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

Our booklet **Life after cancer treatment** gives useful advice for people whose treatment is over apart from regular check-ups.

## Signs of lymphoma coming back

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

Possible signs and symptoms include:

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

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

# If Hodgkin lymphoma comes back

For most people, treatment for lymphoma is very effective and gets rid of all signs of the disease. This is called complete remission. However, in some people:

- there are still signs of lymphoma after treatment (partial remission)
- lymphoma comes back again (relapse or recurrence).

Hodgkin lymphoma can often be treated again. Some people will have a complete remission with more treatment. Other people will have treatments that control the lymphoma and treat any symptoms.

If you need more treatment, your lymphoma doctor will explain what to expect. The type of treatment you have may depend on the treatments you had before. It may also depend on the stage and type of lymphoma, your age and your general health.

Chemotherapy and radiotherapy can often be used again. Some people have a treatment called high-dose chemotherapy with stem cell support.

## Effects after treatment

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

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

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

### Tiredness

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

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

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

## Immune system

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

Your lymphoma doctor may advise you to have vaccinations to protect you against infections such as flu or pneumonia. 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 Hodgkin lymphoma. Ask your doctor whether a vaccination is safe for you to have before having it.

## Irradiated blood products

If you need a blood transfusion at any time after your diagnosis, you should only have irradiated blood. 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 with Hodgkin lymphoma.

Your lymphoma 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 information about this. This is useful if you need emergency treatment and aren't able to explain your medical history. Your pharmacist can give you more information.

## Peripheral neuropathy

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

## Early menopause or menopausal symptoms

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

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

## Thyroid changes

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

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

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

## Second cancer

Chemotherapy and radiotherapy can lead to a slightly increased risk of developing a second cancer later in life. However, 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 whether there is a risk that 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.

## Effects on the lungs

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

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

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

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





## Well-being and recovery

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

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

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

'After my treatment had ended, that's when I felt lost. I had a chat with my Macmillan nurse Julie, and she suggested that maybe I should start getting ready to move on with my life. I started looking at college courses; I started getting myself a career.'

**Megan**

## 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.

We have more information on eating well in our booklet **Healthy eating and cancer** and on our website (see page 104).

## Stick to sensible drinking

NHS guidelines suggest that both men and women should:

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

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

There is more information about alcohol and drinking guidelines at **[drinkaware.co.uk](http://drinkaware.co.uk)**

## 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.

## Get physically active

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

**'My daily walks around the millpond give me a reason to get out of the house on even the bluest of days. And walking down the high street, to the sailing club, a friendly face is never far away.'**

**Kate**

## Take care in the sun

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

## Try to deal with stress

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

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

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

Hospitals or support groups sometimes offer classes in relaxation techniques.



**'I've seen more of my friends and my family than I have done for a really long time. And you start to understand what you're really capable of when you're pushed to your limits – and how strong your relationships are.'**

**Kate, diagnosed with Hodgkin lymphoma**

# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

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

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

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again.

At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.



## Fear and anxiety

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

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

## Anger

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

## Avoidance

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

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

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

'I was worried about speaking to my friends and my mum and dad in case I started worrying them, because I knew how much weight they had on their shoulders with everything going on.'

**Megan**

## Guilt and blame

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

## Feeling alone

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

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

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

## If you need more help

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

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

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them. You can order a copy by calling **0808 808 00 00** or by visiting **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

'Since I've actually sought help, people have been so supportive. I guess I worried I was going to be judged in some way, and that couldn't be further from the truth. People have been so, so helpful.'

**Kate**



# If you are a relative or friend

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

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

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

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

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It is based on carers' experiences and has lots of practical tips and information. You can order a copy by calling **0808 808 00 00** or by visiting **[be.macmillan.org.uk](https://be.macmillan.org.uk)**

We have more information about supporting someone with cancer at **[macmillan.org.uk/carers](https://macmillan.org.uk/carers)**

# Talking to children

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

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

## Teenagers

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

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

Our booklet **Talking to children and teenagers when an adult has cancer** has more suggestions. You can order a copy by calling **0808 808 00 00** or by visiting **be.macmillan.org.uk**

# What you can do

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

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

## Finding ways to cope

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

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

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



# Who can help?

Many people are available to help you and your family.

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

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

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses.

However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

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

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



# WORK AND FINANCIAL SUPPORT

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# Financial help and benefits

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

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

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

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

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

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

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

## Help for carers

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

## More information

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

We've just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and at **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living.

You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice. See page 113 for contact details.

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at [macmillan.org.uk/gettingfinancialhelp](https://www.macmillan.org.uk/gettingfinancialhelp) useful.

## Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 109 to 115.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful. You can order copies by calling **0808 808 00 00** or by visiting [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

# Work

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

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

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

## Employment rights

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

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





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# About our information

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

## Order what you need

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

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

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

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

## Help us improve our information

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

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

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



# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

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

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

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## Talk to others

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

## Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **[macmillan.org.uk/selfhelpandsupport](https://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](https://macmillan.org.uk/community)**

## The Macmillan healthcare team

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

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00**

to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **[macmillan.org.uk/financialsupport](https://macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

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

### My Organiser app

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

# Other useful organisations

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

## Lymphoma support organisations

### Anthony Nolan Trust

**Tel** 0303 303 0303

**www.anthonynolan.org.uk**

Provides information about stem cell or bone marrow transplants and support.

Runs a UK-based register of stem cell donors

### Bloodwise

**Support Line** 0808 2080 888  
(Mon to Fri, 10am to 4pm)

#### Email

support@bloodwise.org.uk

**www.bloodwise.org.uk**

Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Provides information about blood cancers and treatments.

## Children's Cancer and Leukaemia Group (CCLG)

**Tel** 0116 252 5858

**Email** info@cclg.org.uk

**www.cclg.org.uk**

Provides information for children, young people and families affected by cancer in children.

## Lymphoma Action

**Helpline** 0808 808 5555

(Mon to Fri, 10am to 3pm)

**Email** information@lymphomas.org.uk

**www.lymphomas.org.uk**

Open Mon to Fri, 9am to 5pm.

Provides information and support to anyone affected by lymphoma.

## General cancer support organisations

### Cancer Black Care

**Tel** 020 8961 4151

**Email**

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### Cancer Focus

#### Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

**Email** [nurseline@](mailto:nurseline@cancerfocusni.org)

[cancerfocusni.org](http://cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

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

### Cancer Research UK

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**[www.cancerresearchuk.org](http://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@cancersupport](mailto:info@cancersupportscotland.org)  
[scotland.org](http://scotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

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

### Maggie's Centres

**Tel** 0300 123 1801

**Email** [enquiries@](mailto:enquiries@maggiescentres.org)  
[maggiescentres.org](http://maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Has a network of centres in various 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, 9.30am to 5pm)

**Email**[helpline@pennybrohn.org.uk](mailto:helpline@pennybrohn.org.uk)**[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)**

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

**Riprap****[www.riprap.org.uk](http://www.riprap.org.uk)**

Developed especially for teenagers who have a parent with cancer.

**Tenovus****Helpline** 0808 808 1010

(Daily, 8am to 8pm)

**Email**[info@tenovuscancercare.org.uk](mailto:info@tenovuscancercare.org.uk)**[www.tenovuscancercare.org.uk](http://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****[www.hscni.net](http://www.hscni.net)**

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

**Healthtalk****Email** [info@healthtalk.org](mailto:info@healthtalk.org)**[www.healthtalk.org](http://www.healthtalk.org)****[www.healthtalk.org/young-peoples-experiences](http://www.healthtalk.org/young-peoples-experiences)**

(site for young people).

Has information about cancer, and videos and audio clips of people's experiences.

Also provides advice on topics such as making decisions about health and treatment.

**NHS.UK****[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website.

Has service information for England.

**NHS Direct Wales****[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

### **NHS Inform**

**Helpline** 0800 22 44 888

(Daily, 8am to 10pm)

**www.nhsinform.scot**

NHS health information site for Scotland.

### **Counselling**

#### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

#### **UK Council for Psychotherapy (UKCP)**

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto: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

**Text** 86463

**Email** [info@mind.org.uk](mailto: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](mailto:jo@samaritans.org)

**www.samaritans.org**

Samaritans branches are located across England, Northern Ireland, Scotland and Wales. Gives confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial or legal advice and information

### Citizens Advice

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

#### England

**Helpline** 03444 111 444  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

#### Wales

**Helpline** 03444 77 2020  
**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

#### Scotland

**Helpline** 0808 800 9060  
**[www.citizensadvice.org.uk/scotland](http://www.citizensadvice.org.uk/scotland)**

#### Northern Ireland

**Helpline** 0800 028 1881  
**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

### Carer's Allowance Unit

**Tel** 0345 608 4321

**Textphone** 0345 604 5312

(Mon to Thu, 8.30am to 5pm,  
Fri, 8.30am to 4.30pm)

**[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)**

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

### Department for Work and Pensions (DWP) Personal Independence Payment (PIP) Helpline

**0345 850 3322**

**Textphone** 0345 601 6677  
(Mon to Fri, 8am to 6pm)

### GOV.UK

**[www.gov.uk](http://www.gov.uk)**

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

## Advice on living with a disability

### Disability Rights UK

**Tel** 0207 250 8181

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

**Email** enquiries@disabilityrightsuk.org

**www.disabilityrightsuk.org**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

### Scope

**Helpline** 0808 800 3333

(Mon to Fri, 9am to 5pm)

**Email** helpline@scope.org.uk

**www.scope.org.uk**

Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

## Support for older people

### Age UK

**Helpline** 0800 055 6112

**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 10pm, and Sat 10am to 6pm)

**Email** helpline@lgbt.foundation

**www.lgbt.foundation**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.



You can search for more organisations on our website at [macmillan.org.uk/organisations](http://macmillan.org.uk/organisations) or call us on 0808 808 00 00.

## Support with sight loss

### Royal National Institute of Blind People (RNIB)

**Helpline** 0303 123 9999

(Mon to Fri, 8.45am to 5.30pm)

**Email** [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)

**www.rnib.org.uk**

Offers support and advice to blind and partially sighted people in the UK.

## Support with hearing loss

### Action on Hearing Loss

**Helpline** 0808 808 0123

(Mon to Fri, 9am to 5pm)

**Textphone** 0808 808 9000

**SMS** 07800 000 360

**Email** [information.line@hearingloss.org.uk](mailto:information.line@hearingloss.org.uk)

[www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)

**Offers support and practical advice to people in the UK with hearing loss and tinnitus.**

**Offers support and practical advice to people in the UK with hearing loss and tinnitus.**

## Cancer registries

### The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations

plan and improve health and care services. There is one in each country in the UK:

### National Cancer Registration and Analysis Service

**Tel** 020 7654 8000

**Email** [enquiries@phe.gov.uk](mailto:enquiries@phe.gov.uk)

**www.ncras.nhs.uk**

**Tel** (Ireland) 021 4318 014

**www.ncri.ie** (Ireland)

### Scottish Cancer Registry

**Tel** 013 1275 7777

**Email** [nss.csd@nhs.net](mailto:nss.csd@nhs.net)

**www.isdscotland.org/**

**Health-Topics/Cancer/**

**Scottish-Cancer-Registry**

### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

**Tel** 029 2037 3500

**Email** [general.enquiries@wales.nhs.uk](mailto:general.enquiries@wales.nhs.uk)

[www.wcisu.wales.nhs.uk](http://www.wcisu.wales.nhs.uk)

**www.wcisu.wales.nhs.uk**

### Northern Ireland Cancer Registry

**Tel** 028 9097 6028

**Email** [nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)

**www.qub.ac.uk/nicr**

# YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a structured area for student input.

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

With thanks to: Dr Eve Gallop-Evans, Consultant Clinical Oncologist; Sarah Grantham, Clinical Nurse Specialist; Dr Chris Hatton, Consultant Haematologist; Dr Pam McKay, Consultant Haematologist and Dr Nick J Morley, Consultant Haematologist. Thanks also to the people affected by cancer who reviewed this edition.

We welcome feedback on our information. If you have any, please contact **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

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

Collins G, et al. Guideline on the management of primary resistant and relapsed classical Hodgkin lymphoma. *British Journal of Haematology*. 2014. 164: 39–52.

Follows G, et al. Guidelines for the first line management of classical Hodgkin lymphoma. *British Journal of Haematology*. 2014. 166: 34–49.

McKay P, et al. Guidelines for the investigation and management of nodular lymphocyte predominant Hodgkin lymphoma. *British Journal of Haematology*. 2016. 172: 32–43.

Treleaven J, et al. Guidelines on the use of irradiated blood components prepared by the British Committee for Standards in Haematology blood transfusion task force. *British Journal of Haematology*. 2011. 152: 35–51.



# Can you do something to help?

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

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



## **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](http://macmillan.org.uk/getinvolved)

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

urname

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

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Signature

Date / /

## Don't let the taxman keep your money

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

☐

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

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

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

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

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

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

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

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

**MACMILLAN**  
**CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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