Understanding Hodgkin lymphoma

About this booklet

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

The booklet explains the treatments you might have. It also has information about how to get advice and support about feelings, relationships, work and money.

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

This booklet does not cover lymphoma risk factors, signs and symptoms, or tests to diagnose lymphoma. You can find more information online. Visit macmillan.org.uk/lymphoma

We also have separate information about another type of lymphoma called non-Hodgkin lymphoma in our booklet Understanding non-Hodgkin lymphoma.

How to use this booklet

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

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

On pages 130 to 141, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people who have had Hodgkin lymphoma, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

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

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

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

Contents

About lymphoma

What is lymphoma?

Lymphoma is a type of blood cancer. It develops when blood cells called lymphocytes (page 8) become abnormal. Lymphocytes are part of the lymphatic system. Lymphoma is also called cancer of the lymphatic system.

Normally, signals in and around a cell tell it when to:

- grow
- divide to make new cells
- die.

With lymphoma, the abnormal lymphocyte cells do not work like this. They grow in an uncontrolled way and do not follow the normal signals to die. They do not fight infection well like a normal lymphocyte does. And they build up over time.

Eventually the build-up of abnormal cells causes symptoms. There may be enough cells to form a lump. The most common place for this to happen is in a lymph node. But it can happen in other parts of the body. Lymphoma that grows outside the lymph nodes is called extra-nodal lymphoma.

Lymphocytes travel around the body. This means that lymphoma can happen in more than 1 area of the body.

The lymphatic system

The lymphatic system is part of the body's immune system. This is the system that protects us from infection and disease.

The lymphatic system is made up of very fine tubes called lymphatic vessels. These tubes connect to groups of small lymph nodes throughout the body.

Fluid drains from the tissues of the body into the lymphatic vessels. The fluid travels through the vessels and lymph nodes, then into the bloodstream.

The lymph nodes remove germs (bacteria), disease and waste products from the fluid as it passes through. When you have an infection, some lymph nodes may swell as they fight the infection. Lymph nodes are sometimes called lymph glands.

Lymphocytes

Lymphocytes are a type of white blood cell. They fight infection. They are made in the bone marrow. They travel around the body and are found in lymph nodes and throughout the lymphatic system.

The main types of lymphocyte are:

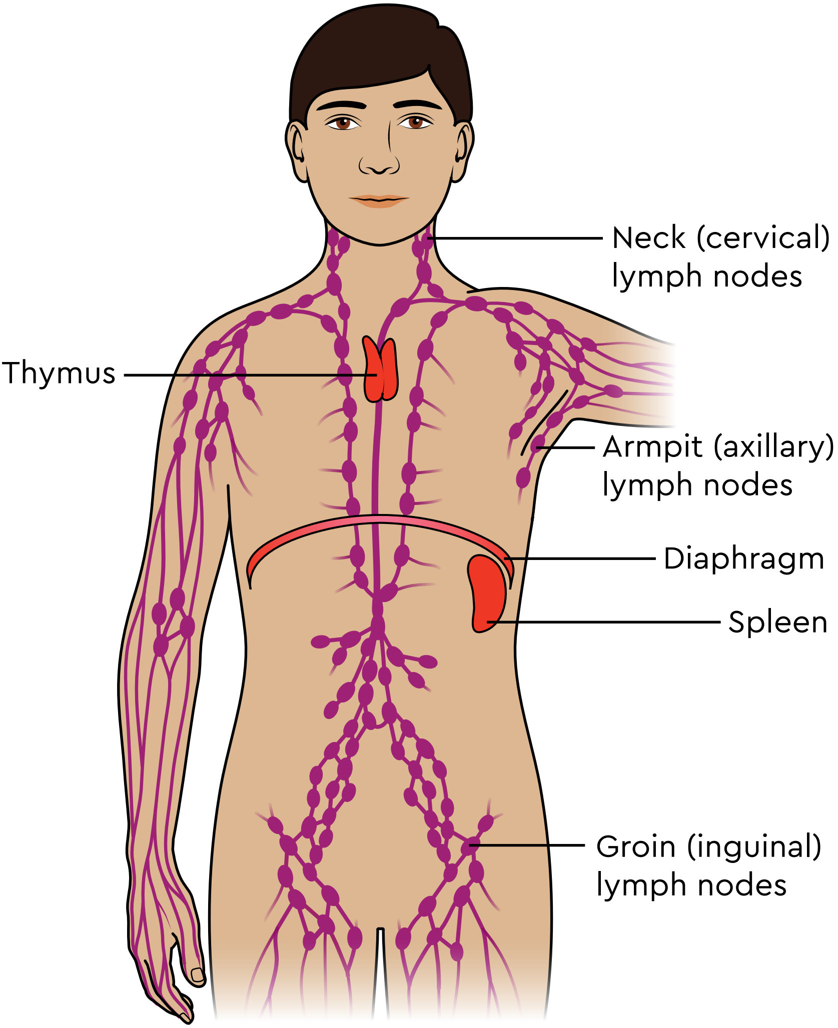
- B-cell lymphocytes
- T-cell lymphocytes
- NK lymphocytes.

Lymphatic organs

Lymphatic organs include the following:

- The thymus – T-cell lymphocytes mature in the thymus.
- The spleen – this helps fight and filter out disease and germs.
- The tonsils – these help fight and filter out disease and germs.

The lymphatic system



Bone marrow

Bone marrow is the spongy material in the middle of bones. It is another lymphatic organ and 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 are cells that help blood to clot and prevent bleeding and bruising.

Other lymphatic tissue

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.

About Hodgkin lymphoma

How lymphoma develops and the treatment you may need depends on the type of lymphoma. The 2 main types are:

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

Around 2,100 people are diagnosed with Hodgkin lymphoma in the UK each year. It can affect people at any age. It is one of the most common cancers to affect people in their teens and early 20s. But most people who are diagnosed with it are older than this. And it is more common in people over 70.

Hodgkin lymphoma can begin in almost any part of the body. 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.

Treatment for Hodgkin lymphoma is usually very effective, and this type of lymphoma can often be cured.

Types of Hodgkin lymphoma

There are 2 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. About 9 in 10 (90%) of all Hodgkin lymphomas are this type. Classical Hodgkin lymphoma is split into 4 subtypes, depending on how the cells look under a microscope:

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

These subtypes are all treated in a similar 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. It tends to be slower growing than classical Hodgkin lymphoma.

Rarely, NLPHL can change into a faster growing non-Hodgkin lymphoma (NHL). If that happens, it is treated as NHL instead of Hodgkin lymphoma.

Planning your treatment

> "After my diagnosis, I did some talking therapy through the NHS to help with my emotions, which I found helpful."

Jamal, diagnosed with Hodgkin lymphoma

Finding out you have lymphoma

Being diagnosed with cancer can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having lymphoma for a while. Or your diagnosis might have been unexpected.

This information is written for people who have already been diagnosed with lymphoma. We have more information about possible causes, risk factors and symptoms of lymphoma at macmillan.org.uk/lymphoma

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the cancer, or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on the Macmillan Support Line. They will be able to talk to you about what has happened and any worries you have.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Tests after diagnosis

You will have some of the following tests before you start treatment for lymphoma. These help your cancer team plan your treatment safely and effectively by giving information about:

- the stage of the lymphoma
- your general health and how well your heart, lungs, liver and kidneys are working
- the levels of different blood cells in your blood
- whether you have certain infections linked to lymphoma, such as HIV and hepatitis.

CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scanner looks like a large, thick ring. You lie still on a narrow bed that moves slowly backwards and forwards through the ring.

We have more information about having a CT scan on our website. Visit macmillan.org.uk/ct-scan

PET or PET-CT scan

A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer.

The scan takes about 30 to 60 minutes.

We have more information about PET and PET-CT scans on our website. Visit macmillan.org.uk/pet-ct-scan

MRI scan

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

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

During the scan, you need to lie still on a bed inside a long cylinder (tube). The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about having an MRI scan on our website. Visit macmillan.org.uk/mri-scan

Bone marrow biopsy

A biopsy is when a doctor or nurse removes a small piece of tissue or a sample of cells. This is then checked under a microscope. For a bone marrow biopsy, a small sample of bone marrow is usually taken from the back of the hip bone (pelvis). Rarely, the sample is taken from the breastbone (sternum).

For more information, visit macmillan.org.uk/bone-marrow-biopsy

Preparing for a CT scan

Staging

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

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

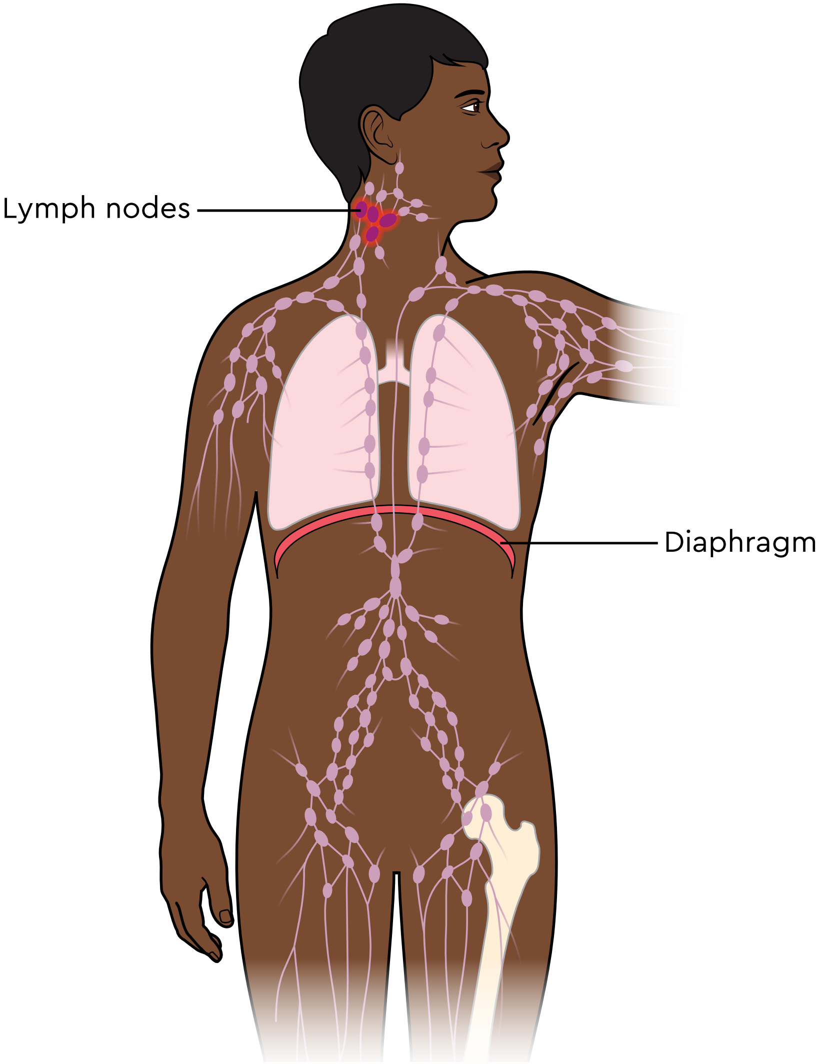
The stage of a lymphoma is usually described using numbers from 1 to 4. Stages 1 and 2 are also called early stage, limited or localised lymphoma. Stages 3 and 4 are sometimes called advanced lymphoma.

Stage 1

The lymphoma is either:

- in 1 lymph node or 1 group of lymph nodes
- in 1 part of the body outside the lymph nodes (extra-nodal).

Stage 1 – Lymphoma in a single group of lymph nodes



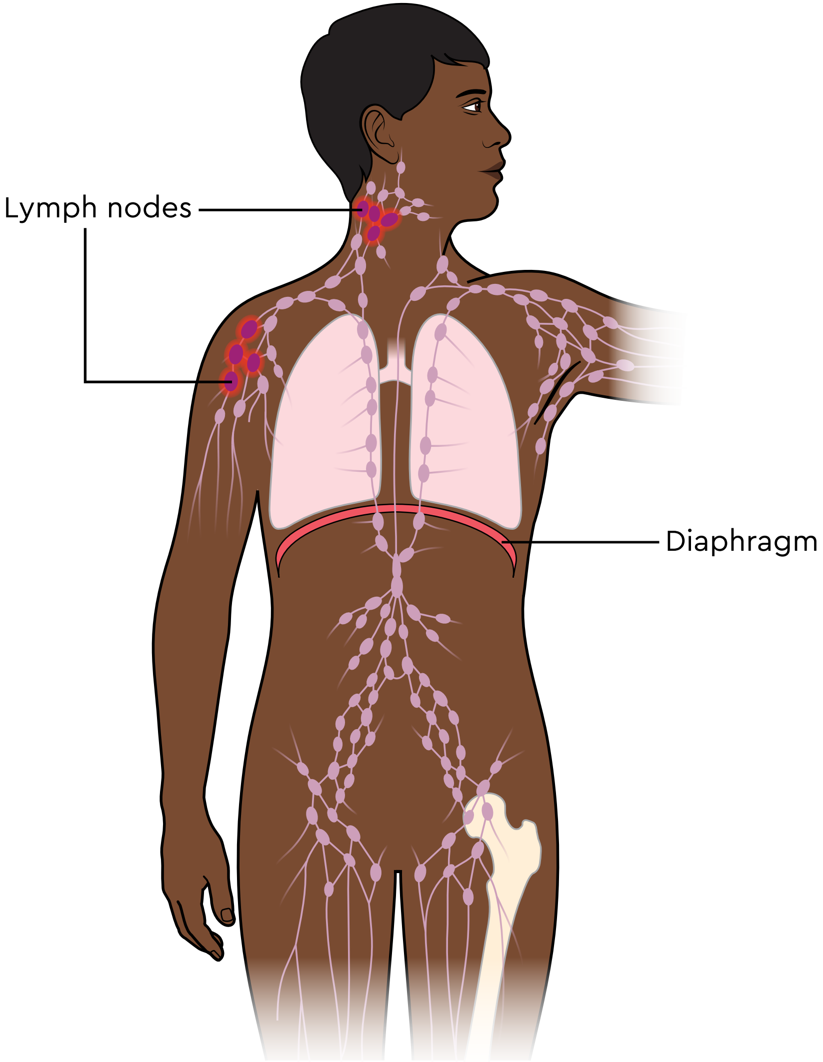
Stage 2

The lymphoma is either:

- in 2 or more groups of lymph nodes
- in another part of the body (extra-nodal) and in 1 group of lymph nodes.

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

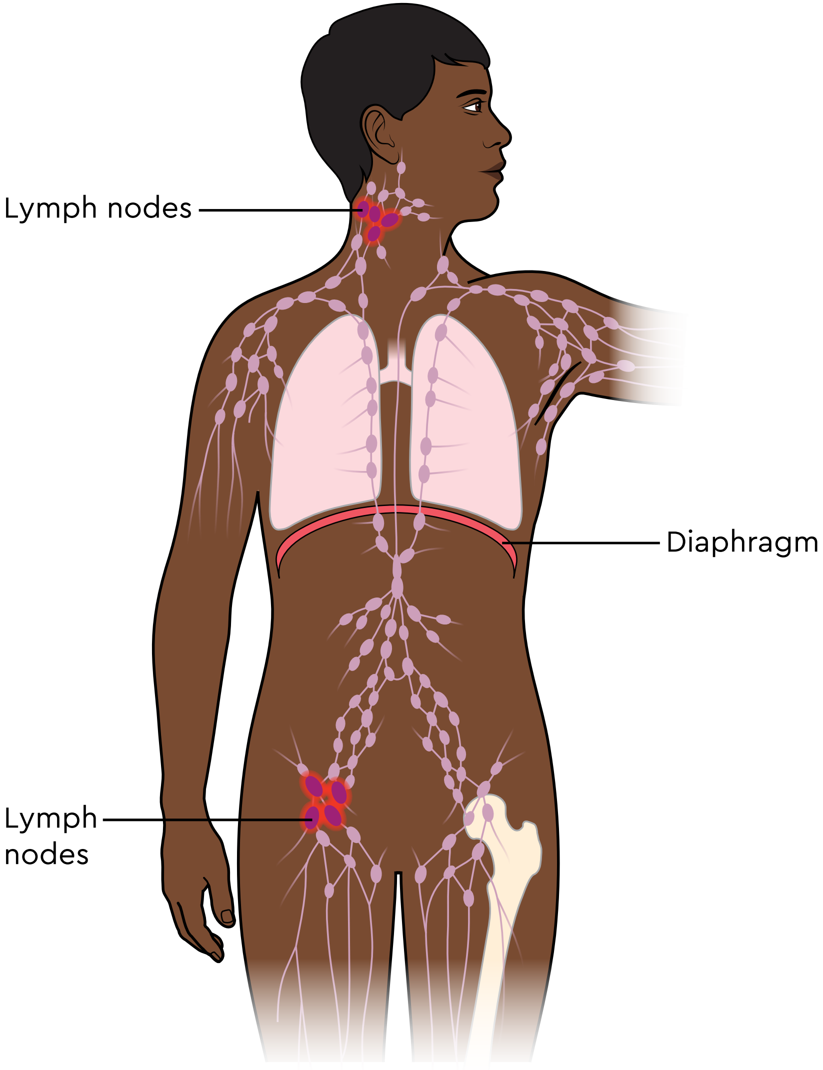
Stage 2 – Lymphoma in 2 groups of lymph nodes



Stage 3

There are areas of lymphoma above and below the diaphragm.

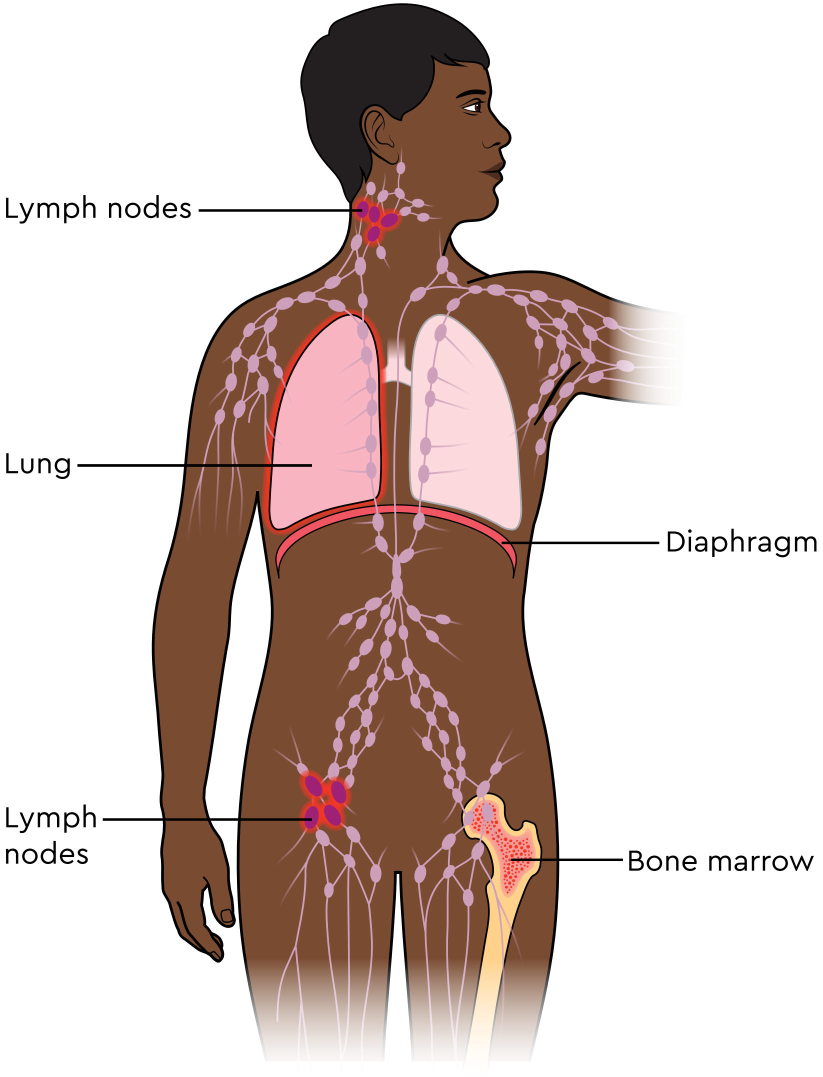
Stage 3 – Lymphoma in 2 groups of lymph nodes, above and below the diaphragm



Stage 4

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

Stage 4 – Lymphoma has also spread to other organs, such as the lung and bone marrow



Extra-nodal lymphoma

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

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

Bulky disease

If an area of lymphoma is large, it is often called bulky disease.

The letter X may be added after the stage number to show bulky disease. For example, the lymphoma may be described as stage 1X.

B symptoms

Lymphoma B symptoms include:

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

Doctors use information about B symptoms to help determine the stage of lymphoma and plan treatment.

The letter B is added after the stage number to show that you have B symptoms. For example, the lymphoma may be described as stage 2B.

If you do not have any of these symptoms, the letter A is used instead. For example, it may be described as stage 2A.

Lymphoma in the spleen

The letter S may be added after the stage number to show there is lymphoma in the spleen. For example, the lymphoma may be described as 1S.

How your treatment is planned

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

Multidisciplinary team (MDT) meeting

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

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

The MDT will usually include the following professionals:

- an oncologist – a doctor who treats people who have cancer
- a haematologist – a doctor who diagnoses and treats blood disorders and cancers
- a radiologist – a doctor who looks at scans and x-rays to diagnose problems
- a clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment
- a pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include other specialists, such as:

- a pharmacist – someone who gives out medicines and gives advice about taking medicines
- a dietitian – someone who gives information and advice about food and food supplements
- a physiotherapist – someone who gives advice about exercise and mobility
- an occupational therapist – someone who gives information, support and aids to help people with tasks such as washing and dressing
- a clinical trials nurse – a nurse who helps manage clinical trials into new ways of treating cancer
- a teenager and young adult (TYA) specialist nurse – a nurse who gives information and support to teenagers and young adults
- a psychologist – someone who gives advice about managing feelings and behaviours
- a counsellor – someone who is trained to listen to people's problems and help them find ways to cope.

Talking about your treatment plan

After the MDT meeting, you will usually meet with your cancer doctor and specialist nurse. They will talk to you about your treatment plan. It can help to write down your questions before you meet with them.

You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your cancer doctor should explain:

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

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

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

You may need more than 1 meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

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

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

We have more information about making treatment decisions in our booklet Making treatment decisions.

Choosing between treatments

Doctors sometimes ask you to choose between different treatments. This is usually when 2 treatments work in a similar way.

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

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

- the aim of the treatment – whether it is to cure the cancer or control it
- how long you need to have it for
- how it may affect your everyday life
- how much time you will need to spend in hospital
- the different side effects and how they are likely to affect you.

Your doctor or nurse may give you printed information or show you videos about your treatment options. They may also show you web-based tools to help you make your decision – these are called decision-making aids.

Giving your permission (consent)

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

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

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision.

You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

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

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

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

We have more information about getting a second opinion on our website. Visit macmillan.org.uk/second-opinion

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit macmillan.org.uk/clinical-trials

Taking part in a clinical trial

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

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

Fertility and cancer treatment

Fertility means being able to get pregnant or make someone pregnant. Some cancer treatments for lymphoma can affect your fertility.

If there is a risk your cancer treatment might affect your fertility, your cancer doctor or specialist nurse should talk to you about fertility preservation. This will happen before you start treatment.

We have more information in our Cancer and fertility booklet and on our website at macmillan.org.uk/fertility

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Hodgkin lymphoma treatments

Treatment overview

There are different types of treatment for Hodgkin lymphoma. You may need just 1 type of treatment or a combination of treatments. Treatment is usually very effective, and this type of lymphoma can often be cured.

Often treatment involves a combination of cancer drugs such as chemotherapy, steroids, targeted therapy or immunotherapy drugs. Cancer drug treatment is also called systemic anti-cancer therapy (SACT).

Other treatments that may be used include radiotherapy and stem cell transplant.

Your cancer doctor may also talk to you about taking part in a clinical trial. They can let you know if a trial is suitable for you.

You may not need treatment straight away.

The treatment you have will depend on:

- your age
- your general health and fitness
- the type and stage of the Hodgkin lymphoma
- your preferences.

Prognostic factors

Your cancer doctor will also consider other factors to help them decide the best treatment plan for you. These factors are sometimes known as prognostic factors or indicators. Before any treatment starts, they will look at:

- where and how many lymph nodes are enlarged in your body
- if you have a fever, sweats or weight loss (B symptoms)
- whether you have lymphoma outside the lymph nodes (extra-nodal lymphoma)
- the results of your blood tests.

Classical Hodgkin lymphoma

Classical Hodgkin lymphoma is the most common type of Hodgkin lymphoma. It is usually treated with chemotherapy and other drugs. Sometimes chemotherapy is followed by radiotherapy. Surgery is not used as a treatment for classical Hodgkin lymphoma.

Early stage classical Hodgkin lymphoma (stage 1 or 2)

If you have early stage classical Hodgkin lymphoma, you usually have chemotherapy and sometimes steroids.

You usually have a PET-CT scan after your first few cycles of chemotherapy. This is to check how the lymphoma is responding.

Depending on the results of your scan, you may have more chemotherapy. Some people may be offered radiotherapy as well. Your cancer doctor can talk to you more about these treatments.

Advanced stage classical Hodgkin lymphoma (stage 3 or 4)

If the lymphoma is more advanced, chemotherapy and sometimes steroids is usually the main treatment. You may have more chemotherapy or higher doses of treatment than for early stage lymphoma. You usually have a PET-CT scan after 2 cycles of chemotherapy to check how the lymphoma is responding. Depending on the results on your scan, you usually have more chemotherapy. Sometimes, you may also have radiotherapy.

Most people will not need any further treatment. But sometimes there may be signs of lymphoma remaining after treatment, or the lymphoma may come back. If this happens you might need more treatment.

Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL)

Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL) is a rarer type of Hodgkin lymphoma. NLPHL is usually treated like low grade non-Hodgkin lymphoma.

Early stage NLPHL (stage 1 or 2)

If you have stage 1 NLPHL, your doctor may suggest a small operation to remove any affected lymph nodes. Sometimes radiotherapy is used instead of surgery. If you have stage 2 NLPHL, your doctor may suggest having radiotherapy.

After surgery or radiotherapy, you may not need any further treatment. Instead, you may have regular appointments to monitor the lymphoma. This is called watch and wait. It may also be called active surveillance or active monitoring.

Advanced stage NLPHL (stage 3 or 4)

If you have advanced NLPHL and you do not have any symptoms, you will usually have regular appointments and tests to monitor the lymphoma. This is called watch and wait.

If your lymphoma causes symptoms that you find hard to manage, then your doctor will talk to you about starting treatment. You will usually have chemotherapy combined with a type of targeted drug called rituximab. Some people may have targeted therapy by itself.

Sometimes NLPHL can change into a type of aggressive non-Hodgkin lymphoma. If this happens, you will need to have treatment for non-Hodgkin lymphoma instead. We have more information in our booklet Understanding non-Hodgkin lymphoma.

We have more information about rituximab on our website. Visit macmillan.org.uk/rituximab

If the first treatment does not completely work

For most people, their first treatment is very effective and gets rid of all signs of the lymphoma. This is called complete remission. But for some people the lymphoma does not completely respond to treatment. This means there are still signs of lymphoma after your treatment is finished. This is called refractory lymphoma.

If you have refractory lymphoma, your cancer doctor will talk to you about treatment options. You may decide to have further treatment to get the lymphoma into a complete remission. Or you may decide to have treatments that will control the lymphoma and treat any symptoms it is causing.

You may be treated with further chemotherapy using different drugs. You can also have targeted and immunotherapy drugs.

Some people may have a stem cell transplant using their own stem cells (autologous) or a donor's (donor or allogeneic).

If Hodgkin lymphoma comes back

Hodgkin lymphoma can sometimes come back after treatment. This is called a relapse or a recurrence.

You can usually have more treatment. Treatment can still work well. This will depend on which treatments you have already had, how quickly the lymphoma has come back and where it has come back.

It may also depend on:

- the type of Hodgkin lymphoma
- how well you coped with treatment before
- your general health.

You may have 1 or a combination of the following treatments:

- Chemotherapy with different drugs that are usually stronger than you had before.
- Radiotherapy to treat a new area of lymphoma in the body or an area that is causing symptoms.
- Targeted and immunotherapy drugs, which are often used if the lymphoma comes back.
- High dose chemotherapy followed by autologous stem cell transplants (using your own stem cells). You may be offered this treatment after having further chemotherapy to get the lymphoma back into remission.
- A donor stem cell (allogeneic) transplant if the lymphoma does not respond well enough to other treatments. We have more information about stem cell transplants.

Watch and wait

If you have nodular lymphocyte predominant Hodgkin lymphoma (NLPHL), your cancer doctor may suggest not starting 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 may also be called active surveillance or active monitoring. It is a way of delaying treatment until it is needed.

Your cancer doctor may suggest watch and wait if you:

- had a small area of NLPHL completely removed by surgery or treated with radiotherapy
- have NLPHL and do not have symptoms
- have NLPHL and symptoms are not causing any problems
- have NLPHL that has come back, but do not have any symptoms or symptoms are not causing any problems.

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 need it.

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

Cancer treatments cause side effects. Some side effects may be long term or start to affect your health years after treatment. These are called late effects. Watch and wait means you can have treatment when you need it and avoid side effects for as long as possible.

> “I went into active surveillance, a watch and wait approach, for about 2 years.
> I had regular scans and blood tests.„

Jamal, diagnosed with Hodgkin lymphoma

Cancer drug treatments

Treatment for Hodgkin lymphoma often includes a combination of cancer drugs. You might hear this type of treatment described in several different ways. For example, your doctor or nurse might use the brand names of the drugs you are given.

Or they might use some of the following terms to describe your treatment:

- Chemotherapy drugs – these are anti-cancer (cytotoxic) drugs that destroy lymphoma cells. Cytotoxic means the drugs are toxic to cells.
- Steroids – these are drugs given with chemotherapy to help treat lymphoma. They may also help you feel better during treatment.
- Targeted therapy drugs – these are drugs that target something in or around the lymphoma cell that is helping it grow and survive.
- Chemoimmunotherapy – this means a combination of chemotherapy drugs and targeted or immunotherapy drugs. Having different types of drugs together means lymphoma cells are attacked in several different ways and can make treatment more effective.
- Monoclonal antibody – this is a type of targeted and immunotherapy drug. It is made of a protein that can recognise and target a specific cell in the body. For example, a monoclonal antibody might target and lock on to a protein found on lymphoma cells so that the cell cannot survive.

Your cancer doctor or specialist nurse will talk to you about your treatment. They will answer any questions you may have.

Your cancer doctor or specialist nurse will explain:

- which drugs you will have
- how long your treatment will last.

Treatment will depend on the stage and type of Hodgkin lymphoma you have. Sometimes your doctor may advise changes to your cancer drugs. This depends on your situation and your treatment plan.

Some people have a higher risk of more serious side effects with some combination drug treatments. Depending on your general health and age, your doctor may suggest combinations that have fewer side effects.

Usually, chemotherapy works very well for most people with Hodgkin lymphoma. But sometimes the lymphoma may not completely respond to the treatment. If this happens it can still be treated successfully. Your doctor may talk to you about having more intensive chemotherapy with a stem cell transplant.

Contraception

Your cancer team will advise you not to get pregnant or make someone pregnant while having cancer drug treatments and for some time afterwards. The drugs may harm a developing baby. It is important to use contraception to prevent pregnancy.

Follow your cancer team's advice about:

- what types of contraception to use
- how long after treatment you should continue to use contraception.

Having cancer drug treatment

Most people have treatment as an outpatient. You usually have a course of treatment over a few days. But sometimes you have it all in 1 day. Your doctor, nurse or pharmacist will discuss your treatment plan with you. They will give you information about the possible side effects of all the drugs you will have. It is important to follow their advice. Always tell them if you have side effects or if they get worse.

After your first treatment, you have a break of a few weeks without treatment. The break allows your body to recover from any side effects before you start the next cycle. Treatment and the rest period make up a cycle of your treatment.

Your whole course of treatment may last several months. You have regular check-ups at the hospital during this time. You usually have a scan before starting treatment and then again at the end. You may also have a scan part way through your course of treatment. These scans show your doctors if the treatment has shrunk the lymphoma.

Cancer drugs into a vein

Treatments given into a vein (intravenously) go directly into the blood and are carried to all areas of the body. Your treatment may be given through:

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

We have more information about cannulas, central lines, PICC lines and implantable ports on our website, including how to look after them:

- cannulas
- central-lines
- picc-lines
- implantable-ports

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

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

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

Your line or port

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

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

Chemotherapy for classical Hodgkin lymphoma

Chemotherapy and steroids are usually the first treatment for classical Hodgkin lymphoma. The most common treatments used include the following.

ABVD

ABVD is named after the initials of the chemotherapy drugs used in the treatment. This is a combination of the following drugs:

- doxorubicin (Adriamycin®)
- bleomycin
- vinblastine (Velbe®)
- dacarbazine (DTIC).

The combination is given into a vein.

Sometimes, some people may have a combination of these drugs but without the bleomycin. This is known as AVD.

Escalated BEACOPDac

This combination treatment uses the following chemotherapy drugs:

- bleomycin
- etoposide
- doxorubicin (Adriamycin®)
- cyclophosphamide
- vincristine (Oncovin®)
- dacarbazine (DTIC)
- prednisolone – this is a steroid tablet.

Prednisolone is a tablet. The other drugs are given into a vein.

Having cancer treatment into a vein

Targeted or immunotherapy for classical Hodgkin lymphoma

Your first treatment for classical Hodgkin lymphoma is not likely to include a targeted therapy or immunotherapy drug. But you may be offered 1 of the following drugs as part of your treatment, if lymphoma has not responded to chemotherapy or has come back:

- brentuximab vedotin (Adcetris®) – brentuximab is a monoclonal antibody
- nivolumab (Opdivo®) or pembrolizumab (Keytruda®) – these are checkpoint inhibitor drugs.

These drugs are all given into a vein as a drip (intravenous).

Drugs for nodular lymphocyte predominant Hodgkin lymphoma (NLPHL)

If you need treatment for NLPHL, you usually have a combination of a targeted therapy drug called rituximab with chemotherapy and a steroid.

If you are unable to have chemotherapy, you may have rituximab on its own.

The most common drugs used to treat NLPHL include the following.

Rituximab

Rituximab is a monoclonal antibody given into a vein or sometimes as an injection under the skin (subcutaneous). You can only have rituximab as a subcutaneous injection if you have already had at least 1 treatment given into a vein.

R-CVP

This is a combination of cancer drugs, including rituximab. It is given into a vein or sometimes as an injection under the skin (subcutaneous).

You also have chemotherapy drugs cyclophosphamide and vincristine. These are given into a vein. Prednisolone is a steroid, which is given as a tablet.

Sometimes, vincristine is replaced with another chemotherapy drug called vinblastine. This treatment is known as R-CVinbP.

R-CHOP

This is a combination of cancer drugs, including rituximab. It is given into a vein or sometimes as an injection under the skin (subcutaneous).

You also have the following chemotherapy drugs:

- cyclophosphamide
- doxorubicin (Adriamycin®)
- vincristine (Oncovin®).

The drugs are given into a vein. Prednisolone is a steroid, which is given as a tablet.

R-ABVD

This is a combination of cancer drugs, including rituximab. It is given into a vein or sometimes as an injection under the skin (subcutaneous). You can only have rituximab as a subcutaneous injection if you have already had at least 1 treatment given into a vein.

You also have the following chemotherapy drugs:

- doxorubicin (Adriamycin®)
- bleomycin
- vinblastine
- dacarbazine (DTIC).

The drugs are given into a vein.

Cancer drug side effects

Different drugs cause different side effects. This information is about some of the more common side effects of the drugs used to treat lymphoma.

You may get some of the side effects mentioned, but you are very unlikely to get all of them. Although side effects can be hard to deal with, they usually disappear gradually when your treatment ends.

It is important to tell your cancer team if you have any side effects while you are having treatment. They will give you 24-hour contact numbers for the hospital. If you feel unwell or need advice, you can call at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

Your cancer team may adjust your treatment to control side effects or to help to prevent more serious problems.

For more information about cancer drugs and side effects, contact our cancer support specialists on the Macmillan Support Line for free. Call 0808 808 00 00.

We have more information about specific drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

Chemotherapy side effects

Chemotherapy may cause the following side effects.

Risk of infection

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

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

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

Your white blood cell count will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

We have more information about infection and cancer treatment on our website. Visit macmillan.org.uk/infection

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red, brown or purple spots that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

Constipation

Chemotherapy can cause constipation. Constipation means that you are not able to pass stools (poo) as often as you normally do. It can become difficult or painful. Here are some tips that may help:

- Drink at least 2 litres (8 glasses) 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 on the 24-hour number for advice. They can give you drugs called laxatives to help.

If you have not been able to pass stools for over 2 days and are being sick, contact the 24-hour number straight away.

Changes to your taste

Some foods may taste different or have no taste. Try different foods to find out what tastes best to you. You may also get a bitter or metallic taste in your mouth. Your doctor, nurse or pharmacist can give you advice. It might help to try:

- sucking sugar-free sour or boiled sweets
- eating cold foods
- eating sharp-tasting fresh fruit.

Taste changes usually get better after treatment ends. We have more information about coping with changes to taste in our Eating problems and cancer booklet and audiobook.

Sore mouth and throat

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

Contact the hospital straight away on the 24-hour number, if:

- your mouth or throat is sore, or affecting how much fluid you can drink or food you can eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

They can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

Feeling tired

Feeling tired is a common side effect of chemotherapy. 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 use machinery.

Hair loss

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

If you want to cover up hair loss, there are different ways you can do this. Your nurse will give you information about coping with hair loss. We have more information in our Coping with hair loss booklet and audiobook and on our website at macmillan.org.uk/hair-loss

Remember to protect your skin from the sun. Use suncream with a sun protection factor (SPF) of at least 30 on your scalp. Or cover up with a hat or scarf.

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

Effects on the heart

Chemotherapy can affect how the heart works. You may have tests to check how well your heart is working. These may be done before, during and after treatment.

If the treatment is causing heart problems, your doctor may change the type of treatment you are having.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- breathlessness
- dizziness
- changes to your heartbeat
- swollen feet and ankles.

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

Always call **999** if you have:

- chest pain, pressure, heaviness, tightness or squeezing across the chest
- difficulty breathing.

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

Effects on the lungs

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

If you are a smoker, it is best to try and stop smoking as soon as you can before having treatment. Ask your GP for advice, or contact a stop smoking service.

Numb or tingling hands or feet (peripheral neuropathy)

Chemotherapy may affect the nerves in your fingers and toes. This can cause numbness, tingling or pain in your hands or feet. This is called peripheral neuropathy. You might find it hard to do fiddly tasks such as fastening buttons or tying shoelaces.

If you have these symptoms, always tell your doctor, nurse or pharmacist. They sometimes need to change the drug or the dose of the drug. The symptoms usually improve slowly after treatment ends. But for some people they continue and are a long term side effect of treatment.

We have more information about peripheral neuropathy on our website. Visit macmillan.org.uk/peripheral-neuropathy

Steroid side effects

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

Possible side effects of steroids include:

- tummy pain or indigestion
- increased appetite and weight gain
- swollen ankles
- increased risk of infection
- having more energy or feeling restless
- changes in your mood
- difficulty sleeping
- skin rash or acne
- increased sugar levels in the blood
- bone thinning (osteoporosis).

Tell your cancer doctor or specialist nurse if you have any side effects that are causing you trouble.

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

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

Sometimes steroids cause a temporary increase in your blood sugar level. You may have regular blood or urine tests to check this. During treatment, tell your cancer doctor or specialist nurse if you get very thirsty or if you are passing urine (peeing) more than usual.

If you have diabetes, your blood sugar levels may be higher than usual. Your cancer doctor will talk to you about how to manage this. You may need to change your insulin or tablet dose. If you have diabetes, tell your cancer doctor before you start taking steroids.

Having high doses of steroids can cause bone loss and increase the risk of fractures. The risk can increase the longer you take them. Doing regular exercise, such as walking, and eating a healthy diet can improve your bone health. We have more information in our booklet Bone health and cancer treatment.

Side effects usually get better when you finish taking steroids. But you may feel tired, have aches and pains, or have low moods for 2 to 3 days after you stop taking them. This is because your body is adjusting to the change in steroid levels.

We have more information about side effects in our Side effects of cancer treatment booklet and audiobook.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Monoclonal antibody side effects

The monoclonal antibodies brentuximab and rituximab may have the following side effects.

Infusion reaction

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

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

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

Lowered numbers of blood cells

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

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

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

Other common side effects

Other side effects may include:

- feeling sick
- diarrhoea
- constipation
- numb or tingling hands or feet – this called peripheral neuropathy
- skin changes.

Checkpoint inhibitor side effects

Checkpoint inhibitors may also cause a reaction when they are first given. Your nurse will monitor you for signs of this.

Common side effects of nivolumab and pembrolizumab include:

- feeling tired
- skin changes
- diarrhoea
- feeling short of breath
- hormone problems.

Side effects may be mild, but sometimes they can become serious very quickly if they are not treated. Side effects can start weeks, months or sometimes more than 1 year after treatment ends.

Your cancer doctor, specialist nurse or pharmacist will give you information about managing side effects. It is important to tell them about any side effects you have, even if this is after treatment.

They will also give you a card with information about your treatment on it. It is important to always have the card with you during treatment and after treatment finishes. You should show it to any doctor or healthcare professional you need to meet with.

Radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given.

Some normal cells in the area being treated can also be damaged by radiotherapy. This can cause side effects. As the normal cells recover, the side effects usually get better.

Radiotherapy is always carefully planned by a team of experts. They will plan your treatment, so it does as little harm as possible to normal cells.

We have more information about radiotherapy:

- in our Understanding radiotherapy booklet and audiobook
- on our website at macmillan.org.uk/radiotherapy

Radiotherapy for classical Hodgkin lymphoma

You may be treated with radiotherapy at diagnosis if chemotherapy is not possible. Or in the following situations:

- If you have early stage classical Hodgkin lymphoma, you may have radiotherapy after chemotherapy to reduce the risk of it coming back.
- If you have advanced stage classical Hodgkin lymphoma, you may have radiotherapy if there are any lymphoma cells that remain after chemotherapy.

Radiotherapy for nodular lymphocyte predominant Hodgkin lymphoma (NLPHL)

You may be treated with radiotherapy in the following situations:

- If you have early stage NLPHL, you may have radiotherapy as the main treatment. Or you may have it if there are any lymphoma cells left behind after lymph node surgery.
- You may have radiotherapy if NLPHL comes back and you need more treatment.

Planning your radiotherapy

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. Some people may have an MRI or a PET scan. During the scan, you need to lie in the position that you will be in for all your radiotherapy treatments.

You will not receive any results from this scan. Your radiotherapy team uses information from it to plan the:

- dose of radiotherapy and effect on surrounding tissues
- area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them or already have a tattoo in the treatment area, tell your radiographer. They can discuss this with you.

Radiotherapy to your chest

If you have radiotherapy to your chest, your therapeutic radiographer may teach you how to take a deep breath and hold it briefly while having treatment. This is called deep inspiration breath hold (DIBH). DIBH helps protect your heart by moving it away from the area being treated.

If DIBH is required, your therapeutic radiographer will discuss this further and answer any questions you may have.

Respire has more information about DIBH.

Radiotherapy to the head and neck

You may need to wear a mask during treatment sessions if you are having radiotherapy to the:

- head
- neck
- upper chest.

The mask is made to hold your head and neck still and in exactly the right position. This is made before you have treatment.

We have more information about radiotherapy masks on our website. Visit macmillan.org.uk/radiotherapy-masks

Having radiotherapy treatment

Radiotherapy is normally given as a number of short, daily treatments in a hospital radiotherapy department. A radiotherapy machine aims high-energy rays at the area of the body being treated. This type of radiotherapy is sometimes called external beam radiotherapy.

You usually have radiotherapy as an outpatient. You sometimes have it during a hospital stay. Usually, each appointment takes about 10 to 30 minutes. Your radiotherapy team will explain how many treatments you will have and when you will have them. Your course of treatment may last up to a few weeks.

The person who operates the machine is called a radiographer. They give you information and support during your treatment.

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

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

During treatment, the radiotherapy machine may stop and move into a new position. This is so you can have radiotherapy from different directions.

Smoking

If you smoke, it is important to try to stop. Stopping smoking may make radiotherapy work better. It may also reduce the side effects of treatment.

It can be difficult to stop smoking, but you can get support. Your doctor or nurse can give you advice, and you can contact a stop smoking service.

Side effects of radiotherapy

Radiotherapy can cause side effects in the area of your body that is being treated. You may also have some general side effects, such as feeling tired. Sometimes side effects get worse for a time during and after you have finished radiotherapy before they get better.

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

Radiotherapy can have long term side effect or late effects. These are rare and will vary depending on the part of the body treated. Your cancer doctor, specialist nurse or radiographer can tell you more.

> "I was receiving radiotherapy to the neck, so I experienced mouth ulcers, a loss of facial hair from the side of my face, and I started getting really tired throughout the days towards the end of treatment."

Jamal, diagnosed with Hodgkin lymphoma

Tiredness

Radiotherapy often makes people feel tired. Tiredness (fatigue) may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired.

But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as going for short walks
- eat a healthy diet and drink plenty of fluids
- ask for help with everyday tasks, if you have friends or family members who can support you.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information about coping with tiredness (fatigue):

- in our Coping with fatigue (tiredness) booklet and audiobook
- on our website macmillan.org.uk/fatigue

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.

Skin reactions

The skin in the area that is treated may:

- redden or darken if you have white skin
- darken if you have black or brown skin
- feel sore or itchy.

Your radiographer or specialist nurse will give you advice on taking care of your skin. If your skin becomes sore or itchy, or changes colour, tell them straight away. They can give you advice and treatments if needed.

Skin reactions should get better within 4 to 6 weeks of treatment finishing.

During your treatment, you are usually advised to:

- wear loose-fitting clothes made from natural fibres, such as cotton
- wash your skin gently with soap and water and gently pat it dry
- avoid rubbing the skin
- avoid very hot things, for example heating pads
- avoid cooling pads but these may be helpful in some situations so speak to your team about using these first
- avoid wet shaving
- avoid hair-removing creams or products, including wax and laser treatment
- follow your radiotherapy team's advice about using moisturisers and deodorants
- protect the treated area from the sun.

Feeling sick (nausea)

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

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

We have more information about feeling sick on our website.

Diarrhoea

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

Hair loss

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

- radiotherapy to the lymph nodes in your neck may cause you to lose the hair on the back of the neck
- radiotherapy to the lymph nodes in the chest may make the hair on your chest fall out.

Hair usually grows back after treatment ends. We have more information in our Coping with hair loss booklet and audiobook and on our website at macmillan.org.uk/hair-loss

Stem cell transplant

Stem cells are blood cells at the earliest stage of development. All our blood cells develop from stem cells in the bone marrow (page 10). When the blood cells are fully developed, they go into the bloodstream. Stem cells stay inside the bone marrow.

A stem cell transplant is a treatment that can be given after high dose chemotherapy and sometimes radiotherapy.

There are 2 types of stem cell transplant: autologous and allogeneic.

Using your own stem cells is called an autologous transplant or high dose chemotherapy with stem cell support. Your own stem cells are collected and stored. You then have high dose chemotherapy. This destroys lymphoma cells, but it also affects your healthy blood cells.

To help your body recover, you have your collected stem cells through a drip (infusion). The stem cells travel through the blood to the bone marrow. They then begin to make new blood cells and help you recover from the chemotherapy.

Using stem cells from another person is called a donor or allogeneic transplant. You have stems cells from a donor after high dose chemotherapy and sometimes radiotherapy. The donor stem cells help your body recover by making new blood cells. They may also produce immune cells that recognise and attack any remaining lymphoma cells.

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

- not responded to other treatments
- a higher risk of coming back
- come back (relapsed) after treatment.

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

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

Because stem cell transplants are complicated treatments and carry some risk, they are done in specialist hospitals. This means you may have to be treated in a hospital some distance from your home. You are likely to be in hospital for several weeks and it may take many months to fully recover.

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

We have more information about stem cell transplants on our website. Visit macmillan.org.uk/stem-cell

Having a stem cell transplant

A stem cell transplant works best if you are in remission at the time. For this reason, you will have chemotherapy to put the lymphoma into remission before having a stem cell transplant.

Once you are in remission, stem cells are collected from either your own blood or the donor's blood and they are stored. You or your donor usually have this done as an outpatient. You are then admitted to hospital to have several more days of chemotherapy a few weeks later. This is called conditioning treatment. Sometimes you also have radiotherapy.

The aim of conditioning treatment is to remove any remaining lymphoma cells and to prepare your body for the healthy cells.

After the conditioning treatment, you have the stem cells into the blood through a drip. The stem cells travel to the bone marrow. After a few weeks, the bone marrow starts to make blood cells again. Until the bone marrow recovers, you are at a high risk of getting an infection and will need to stay in hospital. You will also need some time to recover when you go home from hospital.

A stem cell transplant is a complex treatment. Anthony Nolan and Lymphoma Action have detailed information.

Consultant

After your treatment

After treatment

People often have many different feelings when they finish lymphoma treatment. You may feel relieved that treatment has finished, but worried about what will happen in the future.

You will have appointments with your cancer doctor or specialist nurse less often than before. But at the same time, you may have new challenges to cope with and things to think about.

We have information about some of the things people ask about after lymphoma treatment. But you may have other questions or need information about something else.

If there is something you want to talk about at any point after treatment, you can:

- call the Macmillan Support Line
- chat to our specialists online
- visit our Online Community to talk to people who have been affected by lymphoma, share your experience and ask an expert your questions.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm. ☎

Follow-up appointments

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

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

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

How often you have follow-up appointments depends on:

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

Your cancer doctor or specialist nurse will explain what to expect. Appointments may be face to face in a clinic. Or they may be by phone or video call.

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

Instead of appointments, some people are asked to get in touch when they need to meet with their lymphoma team. This is sometimes called patient initiated follow-up (PIFU). You are given advice on what to be aware of and when to book an appointment, if needed. If you have any concerns in between appointments, you can always contact the hospital. You do not need to wait until your next appointment.

At your follow-up appointments

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

Your cancer doctor and specialist nurse will want to know how you are feeling. They will be checking for any signs that the lymphoma may have come back. They also want to check how you are recovering from any side effects. Appointments are a good time for you to talk to your cancer doctor or specialist nurse about any concerns you have.

Many people find they get anxious before appointments. This is natural. It can help to get support from family or friends.

Signs of lymphoma coming back

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

Possible signs and symptoms include:

- new lumps or swellings
- heavy, drenching sweats at night
- unexplained high temperatures, over 38°C (100.4°F)
- unexplained weight loss
- extreme tiredness
- general itching or a rash that does not go away
- a cough or breathlessness that does not get better.

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

Late effects of treatment

Side effects from lymphoma treatments usually improve during or in the weeks and months after treatment. But sometimes a side effect might not go away. And some side effects may only develop months or years after treatment. These are called long term or late effects.

Not everyone has long term or late effects after lymphoma treatment. And many side effects do get better over time. Your cancer doctor or specialist nurse will explain if there is a risk that your treatment may cause this type of side effect. This can depend on different factors, such as the type of treatment and your age when you have it.

Your cancer doctor or specialist nurse can give you information about:

- what side effects are most likely for you
- how side effects can be treated or managed
- who to contact if you have ongoing or new side effects.

We have more information about late effects of cancer treatment on our website. Visit macmillan.org.uk/late-effects-of-treatment

Tiredness

Recovering from lymphoma treatment can take time. It is not unusual to feel tired for many months after treatment is over. Occasionally tiredness may last for 1 or 2 years, depending on the type of treatment you had.

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

Sometimes tiredness is a sign of:

- depression
- sleep problems
- pain
- changes in the thyroid gland.

These are problems that can be treated. If tiredness is not going away, talk to your lymphoma team or GP.

Emotional effects

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

Immune system effects

Your immune system protects you against infection. Lymphoma and lymphoma treatments can affect how your immune system works. Your body may be less able to fight infections. It is important to tell your lymphoma team or GP if you have signs of an infection. Having it treated straight away can prevent serious complications.

Vaccines

Your cancer doctor may advise you to have vaccinations for flu, pneumonia and coronavirus (covid). If you are over 50, they may also suggest vaccination for shingles. These reduce your risk of serious illness from these infections. Most people can have these vaccines, including people with weak immune systems. Ask your doctor for advice about when you should have them.

Some vaccines contain a very weak version of the illness they will protect you against. They are called live vaccines. You should not have live vaccines if you have had Hodgkin lymphoma. This is because the vaccine may make you unwell.

Ask your cancer doctor or specialist nurse whether a vaccination is safe for you before having it.

Preventing pneumonia

Pneumonia is a severe type of chest infection. After some types of lymphoma treatment, you may have a higher risk of a type of pneumonia called PJP or PCP.

If you are at risk, your cancer doctor will give you antibiotic tablets to help prevent infection. You may need to take them for several months until your immune system is stronger.

Preventing shingles

Shingles is a viral infection that can cause a painful rash. It is caused by the reactivation of the virus that causes chickenpox. This is more likely to happen when the immune system is weak.

If you are at risk of shingles, your cancer doctor will give you antiviral tablets called aciclovir to help prevent it. You may need to take them for several months until your immune system is stronger.

Peripheral neuropathy

Some drugs used to treat lymphoma can affect the nerves, causing numb, tingling or painful hands or feet. This is called peripheral neuropathy.

Tell your cancer doctor or nurse if you notice any new symptoms or have symptoms that are getting worse. If you do have nerve damage, it is better if it is diagnosed as early as possible.

Most people find that their symptoms gradually improve with time as the nerves slowly recover. This may take several months or more. For some people, nerve damage will be permanent.

In this situation, however, many people find that their symptoms become less troublesome over time, as they adapt and find ways of coping with the changes.

We have more information about peripheral neuropathy on our website. Visit macmillan.org.uk/peripheral-neuropathy

Early menopause

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

Symptoms can include:

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

If you have any of these symptoms, tell your doctor or nurse. You may have blood tests to check for signs of the menopause.

Hormone replacement therapy (HRT) can help reduce menopausal symptoms. Your doctor will explain the possible benefits and risks of HRT.

We have more information about menopause on our website. Visit macmillan.org.uk/menopausal-symptoms

Thyroid and hormone changes

Some lymphoma treatments may affect how your body makes hormones. Hormones control many different processes in the body.

Radiotherapy to the neck may affect a small gland in the front of the neck called the thyroid gland. A few years after treatment, the thyroid may stop producing enough hormones. This is called an underactive thyroid or hypothyroidism. It can cause symptoms such as weight gain, tiredness and constipation.

Checkpoint inhibitors drugs such as nivolumab and pembrolizumab can affect hormone-producing glands. This can cause symptoms such as:

- increased sweating
- weight gain or weight loss
- dizziness or fainting
- feeling more hungry or thirsty than usual
- constipation
- loss of sex drive
- passing urine (peeing) more often than usual
- headaches that do not go away
- feeling tired (fatigue)
- mood changes.

Your cancer doctor will explain if your treatment could cause thyroid changes. You will have regular blood tests to check your hormone levels. If you have any of these symptoms during treatment or after it finishes, tell them. You may need drugs to control your hormone levels.

Second cancer

Chemotherapy and radiotherapy can lead to a slightly increased risk of developing a second type of cancer later in life. This means a different cancer to lymphoma.

Treatments are designed to limit these risks as much as possible.

If your treatment involved radiotherapy to the chest area, your cancer doctor may give you information about the following:

- Signs and symptoms of skin cancer. If you notice any changes to the skin in the treated area, get them checked. Skin cancer can be treated very effectively at an early stage.
- Breast cancer symptoms and screening. Women, and other people assigned female at birth, who are under the age of 30 should have regular screening for breast cancer. 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.

If you have HIV, you may have an increased risk of anal cancer after lymphoma treatment. Your cancer doctor can give you information about signs and symptoms of anal cancer and possible check-ups.

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

There are things you can do to improve your heart health and reduce your risk of heart problems after lymphoma treatment. These include being active, not smoking and a healthy diet. We have more information in our booklet Heart health and cancer treatment.

Effects on the lungs

Some treatments used to treat lymphoma may sometimes cause changes to the lungs. Tell your cancer doctor, nurse or GP if you develop:

- breathlessness
- a cough that does not go away
- wheezing.

You should also tell them if any existing breathing problems get worse. You may have tests to check your lungs. If you smoke, stopping will improve your lung health and reduce your risk of breathing problems.

Bleomycin

The drug bleomycin can cause permanent damage to the lungs.

This is more likely if you:

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

After treatment with bleomycin, breathing in high doses of oxygen can cause lung problems. If you need to have a general anaesthetic or oxygen therapy for any reason, always tell the doctor that you have had bleomycin. Some people choose to wear a medical alert identifier.

You should not scuba dive for a year after treatment with bleomycin. After this, you should have tests to check whether scuba diving is safe for you. Your cancer doctor can give you more information about this.

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

Wellbeing and recovery

Making lifestyle changes after treatment can help with your recovery and your overall health. These changes can also help your body recover, improve your sense of wellbeing, and lower your risk of getting other illnesses.

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

Stop smoking

If you smoke, stopping 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.

If you want to stop smoking, it is never too late to stop. Ask your GP for advice, or contact a stop smoking service.

Eat well and keep to a healthy weight

There are lots of reasons your weight might change during lymphoma treatment. 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 eat:

- a balanced diet with lots of fruit and vegetables
- less saturated fat and sugar.

We have more information in our Healthy eating and cancer booklet and audiobook.

Follow drinking guidelines

Alcohol is high in calories and can cause weight gain. It is also linked with an increased risk of some cancers. Following the recommended drinking guidelines is good for your health and weight.

NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

1 unit of alcohol is:

- half a pint of ordinary strength beer, lager or cider
- 1 small glass (125ml) of wine
- 1 single measure (25ml) of spirits.

Drinkaware has more information about alcohol and drinking guidelines.

Be physically active

Being active after lymphoma treatment has lots of benefits. It can:

- reduce your risk of heart disease, stroke and diabetes
- help you manage tiredness
- help you keep to a health weight
- keep your bones strong
- reduce stress and anxiety.

If you feel worried about starting physical activity, it can help to get advice. Talk to your cancer doctor, nurse or GP before exercising. Start slowly and increase your activity over time. We have more information in our booklet Physical activity and cancer.

Take care in the sun

Radiotherapy and some drugs used to treat lymphoma can make your skin sensitive to sunlight. This means your skin is more likely to burn in the sun and may increase your risk of developing a skin cancer.

It is important to take care in the sun. Protect your skin by covering up. Be extra careful to always cover 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.

We have more information about sun safety on our website. Visit macmillan.org.uk/sun-safety

Find ways to relax

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

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

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

Hospitals or support groups sometimes offer classes in relaxation techniques.

Consider complementary therapies

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

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

We have more information:

- in our Cancer and complementary therapies booklet and audiobook
- on our website at macmillan.org.uk/complementary-therapies

> **"I spent a lot of time colouring and it was great for mindfulness and helping me relax. I have a paint by numbers and I've bought some books, things that take me off my phone."**
>
> Mariam, diagnosed with Hodgkin lymphoma

Your feelings and relationships

> “I saw my role as supporting others, but suddenly I was vulnerable and having to look for support myself.”

Cerian, diagnosed with Hodgkin lymphoma

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions:

- in our How are you feeling? The emotional effects of cancer booklet and audiobook
- on our website at macmillan.org.uk/emotions

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. Get more information or help to find local support groups, or talk to other people on our Online Community.

There is more information on pages 126 to 129 about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships in our booklets:

- Talking about cancer
- Cancer and relationships: support for partners, families and friends – this is also available as an audiobook.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone in our Talking with someone who has cancer booklet and audiobook.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers:

- in our Looking after someone with cancer booklet and audiobook
- on our website at macmillan.org.uk/carers

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our Talking to children and teenagers when an adult has cancer booklet and audiobook.

Money and work

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to.

We also have information for carers.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits and recommend other useful organisations that can help. You can speak to them by calling the Macmillan Support Line. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our Help with the cost of cancer booklet and audiobook has lots more information.

Grants

You may be able to get some financial help from other charities – for example, one-off grants. For further information, contact the Macmillan Support Line.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance online.

We have more information about travel insurance in our Travel and cancer booklet and audiobook.

Our Online Community forum on travel insurance may also be helpful.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm. ☎

Work

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

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

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

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets have more information that may be helpful:

- Work and cancer - this is also available as an audiobook
- Working while caring for someone with cancer – this is also available as an audiobook
- Self-employment and cancer
- Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Further information

About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

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

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

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

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

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Lymphoma support organisations

Anthony Nolan

Tel **0303 303 0303**
www.anthonynolan.org
Information and support for people with blood cancer or a blood disorder who need a stem cell transplant. Runs a stem cell register of potential donors. Offers telephone support, grants, online community and support days.

Blood Cancer UK

Tel **0808 208 0888**
www.bloodcancer.org.uk
Information and support for people with leukaemia, lymphoma, myeloma and all types of blood cancer. Offers information and support online, by phone, by email, and through support groups and buddy systems. Also has a clinical trials support service.

Lymphoma Action

Tel **0808 808 5555**
www.lymphoma-action.org.uk
Information and support to anyone affected by lymphoma. Offers a helpline, live chat, email support, newsletter and network of support groups. Also has a clinical trials information service called Lymphoma TrialsLink.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

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

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Respire

www.respire.org.uk
Aims to improve the patient experience by helping patients to prepare for radiotherapy.

Tenovus

Helpline **0808 808 1010**
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

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

NHS.UK

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

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Northern Health and Social Care Trust

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

Patient UK

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

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way Scotland

Tel **0800 84 84 84**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0800 085 2219**
Text 'HMQ' to **80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the therapist directory page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
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**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Citizens Advice

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

England

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

Scotland

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

Wales

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

GOV.UK

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

Law Centres Network

www.lawcentres.org.uk
Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 123 3233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct

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

StepChange Debt Charity

Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for young people

Teenage Cancer Trust

Tel **0207 612 0370**
www.teenagecancertrust.org
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Support for older people

Age UK

Helpline **0800 678 1602**
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.

Support for LGBTQ+ people

LGBT Foundation

Tel **0345 330 3030**
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.

OUTpatients

www.outpatients.org.uk
Supports and advocates for LGBTIQ+ cancer patients in the UK, inclusive of all genders or types of cancer. Also produces information, and runs a peer support group with Maggie's Barts.

Cancer registries

The cancer registry is 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 a cancer registry in each country in the UK. They are run by the following organisations.

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/population-health/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Your notes and questions

Disclaimer

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editor, Professor Chris Fox, Haematologist.

With thanks to: Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology; Professor Andrew Davies, Professor of Haematological Oncology; Dr Maggie Harris, Clinical Oncologist; Dr Robert Lown, Consultant Haematologist; Dr NJ Morley, Consultant Haematologist; Nicola Shepherd, Clinical Nurse Specialist; Dr P Sriskandarajah, Consultant Haematologist; and Karen Stanley, Advanced Nurse Practitioner.

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

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

Sources

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

Follows GA, Barrington SF, et al. Guideline for the first-line management of Classical Hodgkin Lymphoma – A British Society for Haematology guideline. Br J Haematol, 2022; 197, 558–572 [accessed April 2024].

McKay P, Fielding P, et al. Guidelines for the investigation and management of nodular lymphocyte predominant Hodgkin lymphoma. British Journal of Haematology, 2015; 172, 32–43 [accessed April 2024].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

2. **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.

3. **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?

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

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

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

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

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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

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

The booklet explains treatments for Hodgkin lymphoma. It also has information about feelings, practical issues and money.

At Macmillan, we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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