About this book

This booklet tells you what Hodgkin lymphoma is, and how it is diagnosed and treated.

There are two main types of Hodgkin lymphoma, classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma.

The booklet is divided into chapters. You can dip in and out of it and read only the sections relevant to you at any given time.

- Shows chapter summaries.
- Is a space for questions and notes.
- Signposts to other resources you might find relevant.

This booklet uses some scientific words. Words that are in **bold** are explained in the Glossary on pages 122–127.

The information in this booklet can be made available in large print.
Your type and stage

Your treatment

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Introduction

You may be someone with Hodgkin lymphoma (also known as Hodgkin’s disease), which is a type of cancer of the lymphatic system. Perhaps someone close to you has it. You are not alone – nearly 2,000 people are diagnosed with Hodgkin lymphoma in the UK each year.

Few people have heard of lymphoma before they’re diagnosed. Lymphoma (including Hodgkin and non-Hodgkin lymphoma) is currently the 5th most common cancer in the UK and the most common cancer diagnosed in young people. Hodgkin lymphoma can affect people of all ages but is most common in people aged between 15 and 34 and over 60.

This booklet describes Hodgkin lymphoma and provides information on what you can expect from your medical team and your treatment, including potential side effects. It provides some practical advice on dealing with this illness, including its effect on your work, study and relationships.

You do not need to read this booklet from cover to cover. Concentrate on the sections that apply to you. If you are not sure, ask your medical team to point out the most relevant parts.

This booklet is intended for adults. We also produce information for children and young people with Hodgkin lymphoma that addresses their specific needs and concerns. We also have information for parents of children and teenagers with Hodgkin lymphoma.
About our information

We continually strive to improve our resources for people affected by lymphoma and we would be interested in any feedback you might have about this booklet. Please visit our website at www.lymphoma-action.org.uk/book-feedback or email us at publications@lymphoma-action.org.uk if you have any comments. Alternatively, please phone our helpline on 0808 808 5555.

We hope you find the information in this publication useful. If you would like to help make it available to other people affected lymphoma, please consider making a donation to support our work at www.lymphoma-action.org.uk/donate. We rely on voluntary donations. Thank you.

We produce other booklets that give information about lymphoma and what to expect from treatment. Please call us on 0808 808 5555 if you would like a copy of one.
Acknowledgements

This is the 6th edition (updated design) of a booklet first published in 2007. We would like to acknowledge the continued support of our Medical Advisory Panel, Lymphoma Action Nurse Forum and other expert advisers, whose ongoing contributions help us in the development of our publications. In particular we would like to thank the following people for their assistance with the 2016 revision of this booklet:

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Special thanks to Natalia, Adam, Ellie, Andy, Carol, John, Zoe and Hannah for sharing their experience of Hodgkin lymphoma. Quotations from their stories are featured throughout the book.

We would also like to thank the members of our Reader Panel who gave their time to review this booklet.

Lymphoma Action is committed to providing high-quality information for people with lymphoma, their families and friends. We produce our information using nationally recognised guidelines, including the DISCERN tool for information about treatments, the
NHS Toolkit for producing patient information, and the Campaign for Plain English guidelines. Lymphoma Action is an accredited member of The Information Standard independent quality assurance scheme, which is supported by the Department of Health.

Our publications are written by experienced medical writers, in close collaboration with medical advisers with expertise in the appropriate field. Some publications are written by professionals themselves, acting on guidance provided by Lymphoma Action.

In some instances, our publications are funded by grants from pharmaceutical companies. These sponsors do not have any involvement in the content of a publication and have no editorial input.

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What is the lymphatic system?

The lymphatic system is made up of a complex network of tubes called **lymph vessels** (lymphatics), **lymph nodes** (glands) and other body organs, such as the **spleen**. The **lymph nodes** and **lymph vessels** are present throughout the body. Some groups of lymph nodes are easy to feel, particularly in the neck, under the arms and in the groin. Others are deeper inside the body and can only be seen on scans.

*Figure: The lymphatic system*
The lymphatic system is a part of the body’s natural defence mechanism against infection – the immune system. The lymph nodes are an important part of it, fighting infections and draining waste fluids from the tissues. They are home to a large number of lymphocytes – a type of white blood cell that helps the body to fight infection.

What is lymphoma?

Lymphomas are cancers of the lymphatic system. They occur when some of the lymphocytes start to grow in an abnormal, uncontrolled way. Lymphoma is not just a disease. There are many different types, but they all start with a cancerous lymphocyte.

Lymphoma was first described in the 19th century by Dr Thomas Hodgkin. The type covered in this booklet is named after him and was previously called Hodgkin’s disease. All other types are called non-Hodgkin lymphoma. When you look at Hodgkin lymphoma under a microscope, you can see large abnormal cells called Reed-Sternberg cells. Non-Hodgkin lymphomas do not have Reed-Sternberg cells.

Each year, around 19,500 people are diagnosed with a form of lymphoma in the UK, making it the 5th most common cancer. Nearly 2,000 of those have Hodgkin lymphoma, making it much less common than non-Hodgkin lymphoma. It can occur at any age, including in children.
When I was diagnosed with Hodgkin lymphoma, I actually felt quite relieved to have a diagnosis. This meant my treatment could start, ultimately improving my health at a faster rate. Ellie

How do lymphomas develop?

Like other **white blood cells**, **lymphocytes** are always dividing to make new cells. When you are fighting an infection, the body makes many new **lymphocytes** very quickly. Many types of **lymphocytes** are being produced, but only those that are very specific to the target infection are useful to the **immune system**. Any **lymphocytes** that do not target that infection usually die and only the useful **lymphocytes** survive.

Lymphomas occur when this carefully controlled system breaks down. Instead of dying as they should, ‘rogue’ **lymphocytes** divide in an uncontrolled way. The ‘rogue’ **lymphocytes** collect together to form a lump, most often in a **lymph node**. This lump is lymphoma.

The ‘rogue’ **lymphocytes** may also collect in other parts of the body, such as the **spleen**, liver and **bone marrow**. Lymphoma that grows outside the **lymph nodes** is called ‘extranodal’.

Scientists don’t know exactly what makes the **lymphocytes** become cancerous. But they do know that:
• You are unlikely to have done anything to cause the lymphoma.
• You did not catch it and you can’t pass it on to others.
You can find more information about the possible causes of Hodgkin lymphoma on page 36.

What are the symptoms of lymphoma?

People with lymphoma can have a variety of symptoms. Some symptoms are common to many types of cancer, e.g., fatigue (extreme tiredness). Lymphoma cells take up energy and nutrients that healthy cells need, so people often feel very tired.

The most common symptom of lymphoma is a painless lump or swelling often in the neck, armpit or groin. This is a swollen lymph node.

I didn’t for a moment think it could be anything serious. I couldn’t understand how a lump in my neck could be connected to this mass in my chest. Adam

Some people have no symptoms other than a lump. Others can notice symptoms that include:

- weight loss for no obvious reason
- drenching sweats, especially at night
- fever and flu-like symptoms that don’t go away
- fatigue
- itching all over the body
- difficulty shaking off infections
- pain in the lymph nodes after drinking alcohol (this is quite rare).

These are known as ‘B’ symptoms.
Sometimes people can have lymphoma in other parts of the body, including the lungs and the bowels. **Symptoms** can vary, depending on where the lymphoma is. For example, lymphoma can cause:
- abdominal pain
- diarrhoea or change in bowel habit
- an ongoing cough or breathlessness.

Most of these **symptoms** are common in other illnesses. For example, it is quite common for **lymph nodes** to swell with an infection such as flu. When it’s the flu, the **lymph node** might be painful, but the swelling is likely to go away after 1–2 weeks. There is no single **symptom** that is unique to lymphoma, but a mixture of **symptoms** is typical.

"I had night sweats and a persistent cough. I also noticed that my body temperature didn’t seem to be regulating itself as it always had – I would feel really cold and then suddenly very hot.** Andy

**How is lymphoma classified?**

Lymphomas are classified (divided) into different types. Doctors classify your lymphoma by checking:
- what the cells look like under the microscope
- the chemicals or proteins on the surface of the cells
- the mutations (changes to genes) in the lymphoma cells.
The simplest way lymphomas are divided is:
• Hodgkin lymphoma
• non-Hodgkin lymphoma.

There are 2 types of Hodgkin lymphoma:
• classical
• nodular lymphocyte-predominant Hodgkin lymphoma.

There are more than 60 different types of non-Hodgkin lymphoma. Some non-Hodgkin lymphomas grow slowly (low-grade) and others grow faster (high-grade).

Summary

Lymphomas are cancers of the lymphatic system.

There are 2 main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma.

Lymphomas develop when white blood cells called lymphocytes start to grow out of control.

Lymphomas can cause very few symptoms. The most common symptom is a painless lump – a swollen lymph node. Other symptoms include weight loss, night sweats and tiredness.
When I was diagnosed I took things as they came and was actually glad that they’d found the root of my problems. At least it meant I could start getting better. Now in remission, having Hodgkin lymphoma has changed my perspective on life and I make the most of all opportunities that come my way.

Ellie, diagnosed with Hodgkin lymphoma in 2011
Diagnosis and staging

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How is lymphoma diagnosed?

Getting a diagnosis means finding out what is wrong. It is rarely possible for a GP to confirm whether or not you have lymphoma based on your symptoms alone. Your GP should send you to a doctor at a hospital for further tests. These tests almost always include a biopsy.

Having a biopsy

For most people, a biopsy is the only way to tell whether or not a lump is lymphoma. In this test, a doctor removes a sample of your cells for examination under a microscope. The procedure depends on where the swollen lymph nodes are and what the practice is at the hospital.

If you have an enlarged node that is easy to feel, a surgeon can remove either all or part of it. This is a procedure called an ‘excision’ biopsy. You are likely to have a general anaesthetic and to have to stay in hospital for the night.

Most commonly, you have a small sample of the lymph node removed instead. This procedure is called a ‘core’ biopsy. It is usually done by a radiologist, a doctor who specialises in X-rays and scans. They use an ultrasound or a computed tomography (CT) scan to see where to take the sample from. This is usually done under a local anaesthetic, and you are likely to be able to go home the same day.

For more information about CT scans see pages 25–26.
If the affected lymph nodes are deeper inside your body, a surgeon may remove all or part of a node using laparoscopic surgery (key-hole surgery). Sometimes you may have a core biopsy taken by a radiologist. A radiologist is a doctor who interprets radiographs (X-rays) and scans and may also perform biopsies using scans to ensure the right bit of tissue is taken to be examined.

You need to have a general anaesthetic for laparoscopic surgery and may need to stay in hospital. If you have a core biopsy, it is normally taken during a scan to make sure the biopsy is taken from the right place. You are likely to have a local anaesthetic and to be able to go home the same day.

The biopsy is then sent to a lab and examined under a microscope by an expert lymphoma pathologist. A pathologist is a doctor who diagnoses disease by looking at tissue samples removed from the body. The specialists might need to do more tests on the biopsy to find out exactly what type of lymphoma you have. These tests give more information about the cells, for instance, about changes to their DNA or to the proteins on their surface. The results usually take a week to come back, sometimes longer.

**What other tests might I need?**

Your doctors may want you to have other tests as well as the biopsy. This section describes some common tests for lymphoma, but don’t be worried if you don’t have all of them. Sometimes only a few of the tests are needed to find out enough information about your lymphoma.
You can have most of these tests as an outpatient, so you don’t have to stay in hospital overnight. It may take a couple of weeks to get all the results.

**Blood tests**
You need to have blood tests before you start treatment and at regular intervals during treatment. You may have these to:
- check your blood cell counts
- check that your kidneys and liver are working well
- provide information on how your lymphoma may behave (prognostic factors)
- look for infections such as hepatitis or HIV, which may also need treatment or could flare up with lymphoma treatments.

**Bone marrow biopsy**
The bone marrow is a spongy, jelly-like material found in the middle of your larger bones. The main job of the bone marrow is to make blood cells.

Your doctors may want you to have a bone marrow biopsy to look for lymphoma cells. Your doctors may call this test a bone marrow ‘aspirate’ (liquid is taken from the bone marrow) or bone marrow ‘trephine’ (harder bone marrow tissue is taken).

The test is quite simple, but if you are taking medicines to thin your blood, your doctor may ask you to stop taking them for a few days beforehand. You usually have the sample taken from the bone just above your hip (the pelvis). First, you have the area numbed with a local anaesthetic. Then the doctor passes the biopsy needle through the skin and into the bone.
Even with a local anaesthetic, having a bone marrow biopsy might still be uncomfortable. You may need painkillers before and after the procedure. If you are very anxious, it may be possible for you to have a sedative beforehand. You need to talk to your specialist about this as sedatives aren’t recommended for everyone. Ask about this when you’re told you need the test.

The whole test takes around 15–20 minutes and you can go home soon afterwards. To start with, you have a small dressing covering the biopsy site. Before you leave the hospital, your doctor or nurse should tell you when the dressing can be removed.

X-rays and scans
X-rays and scans are used by doctors to assess what parts of your body are affected by lymphoma.

X-rays
X-rays are used to look at various parts of your body. For example, you may have a chest X-ray to see if there are any enlarged lymph nodes in your chest. You don’t feel anything during the test, and it should only take a few minutes.

CT scans
CT scans use a series of X-rays to form pictures of your body in cross-section (‘slices’ through your body).

To have the scan, you lie on a padded table that moves your body into a doughnut-shaped camera. As the table moves, the camera takes pictures of the different layers of your body. The space is quite open so you shouldn’t feel ‘hemmed in’ or claustrophobic.
The scan doesn’t hurt and usually takes only a few minutes. You need to lie still during the scan. You might be asked to hold your breath for up to 20 seconds at a time.

Talk to the staff in the department if you are worried about anything regarding your CT scan.

Your doctor may ask you not to eat or drink on the morning of the scan. This is because most people have a special liquid dye (a contrast agent) before the scan. This is either a drink or an injection into a vein.

The dye makes it easier to see some of your internal organs on the scan pictures. It might make you feel hot all over but this usually only lasts a few minutes. Tell the staff if you feel this way. You should also tell the staff before you have a contrast agent if you:
- are allergic to iodine
- have had a reaction to a contrast agent before
- have asthma, emphysema, severe heart disease or kidney problems.

**PET scans**

*Positron-emission tomography (PET) scans* are very good for helping doctors work out which cells are cancerous and which are not. They use a radioactive form of sugar to look at how active the cells are. More active cells, like cancer cells, take up more sugar than normal cells. The radioactivity in the cancer cells is then detected with a special camera.

Nowadays, **PET/CT scans** are very often carried out before treatment starts and after it has been given for some weeks. These combine a **PET scan** with a **CT**
scan to give a clearer picture of exactly which areas are cancerous.

**PET/CT scans** are now available in most areas. Some hospitals are visited from time to time by mobile **PET/CT scanners**. In other areas, you might need to travel some distance to the nearest hospital with a scanner.

You should not eat or exercise on the day of your scan. When you arrive at the clinic, you have the radioactive sugar as an injection into a vein. You then have to rest for an hour or more while the cells take up the sugar.

**Note**: if you have diabetes, tell your doctor when they arrange your scan. You need instructions about how to look after your diabetes on the day of your scan.

The scan is similar to a CT but takes longer. The whole process usually takes about 2–3 hours. If you have any concerns about having a **PET** scan, talk to the staff in the department.

Many people with Hodgkin lymphoma now have **PET/CT scans** as they are a good way to check where the lymphoma is in the body. Knowing the location of your lymphoma is important for your doctors to decide which treatment you should have.

Results from clinical trials are now suggesting that **PET/CT scans** are very good at finding lymphoma in the **bone marrow**, too. In the future it may not be necessary to have **bone marrow** biopsies to look for Hodgkin lymphoma in the **bone marrow**.
You may also have a **PET/CT scan** to check how well your treatment has worked. Doctors continue to learn how best to use these scans, but they become an increasingly important way of assessing Hodgkin lymphoma.

**MRI scans**
Magnetic resonance imaging (**MRI** scanners) are similar to CT scanners, except they use strong magnets instead of X-rays. The pictures are slightly different and are particularly good for looking at soft tissues, such as the brain.

The cylinder uses a magnet. So before the scan, you have to take off all metal jewellery and any items of clothing that may have metal parts, such as bras. You should tell the staff if you have any metal implants, such as a pacemaker or an artificial joint. You should also mention any recent operations, including your biopsy. Sometimes surgeons use metal staples instead of stitches after an operation. Mention them if you still have them in.

To have the scan, you lie on a padded table that moves you into a cylinder (tube). The cylinder measures magnetic waves as they pass through your body. The scan is painless, but can take up to an hour. The scanner can be very noisy and, as you are in a small space, you may feel ‘hemmed in’ or claustrophobic. Do let the staff know if you are worried about this or anything else relating to having an **MRI**.
It is natural to feel anxious when you are waiting for medical tests and their results. But it’s very important for your doctors to have all the information they need about your lymphoma. This information helps them choose the most suitable treatment for you.

**What does ‘stage’ mean?**

Once all the test results are ready, your doctor can tell where the lymphoma is in your body. This is called the ‘stage’ of your lymphoma and is important in planning your treatment. The different stages are:

Stage 1  1 group of **lymph nodes** affected either above or below the **diaphragm** *

Stage 2  2 or more groups of **lymph nodes** affected either above or below the **diaphragm** *

Stage 3  **Lymph nodes** affected on both sides of the **diaphragm** *

Stage 4  Lymphoma is found in organs outside the **lymphatic system** or in the **bone marrow**

* the diaphragm is a sheet of muscle that separates the chest from the abdomen.

You may see stages of lymphoma written down as Roman numerals: I, II, III, IV.
Sometimes letters are added to the stage. ‘A’ means that you don’t have any of the symptoms described as ‘B symptoms’. ‘B’ means you have one or more of these symptoms: unexplained weight loss, drenching night sweats or fevers. ‘X’ means that you have bulky disease, which means very enlarged lymph nodes that are more than 10cm across. There may be other letters, showing that there is lymphoma outside the lymph nodes. This is usually an ‘E’, which stands for ‘extralymphatic’ or ‘extranodal’.

This means that if you have lymphoma on both sides of your diaphragm and you have been having night sweats, your lymphoma is stage 3B. If you have lymphoma in several groups of lymph nodes that are all above your diaphragm and you have had no B symptoms, your lymphoma is stage 2A.

Stage 1 lymphomas, and some stage 2 lymphomas, are early-stage (localised) diseases.

Some stage 2 lymphomas – such as those with bulky disease, for example – are grouped with stage 3 and 4 lymphomas. These are advanced-stage diseases.

There are good treatments available for lymphoma at all stages. Hodgkin lymphoma is not like many other cancers where advanced stage can mean the disease cannot be cured or there is little treatment available.

If you are not sure about the stage of your lymphoma, ask your specialist – the treatments are slightly different for each stage.
Summary

To diagnose lymphoma, you normally need a biopsy. This means having a sample of tissue removed to be looked at under a microscope.

The biopsy is usually taken from an enlarged lymph node. It can either be an excision biopsy (a surgery when all or a part of the lymph node is taken out) or a core biopsy (when a small sample is taken by a radiologist guided by a CT scan).

The sample is then sent to a lab to be examined. A number of tests are carried out on it to find out exactly what type of lymphoma you have.

You may need to have other tests, which may include blood and bone marrow tests and scans. The results allow your doctors to work out the stage of your lymphoma, which means how far it has grown or spread. Accurate staging is important in planning your treatment.
I didn’t feel scared or angry and I didn’t think, ‘Why me?’ But I did find that the best way through diagnosis and treatment for me was adapting my life, being open with all those around me and keeping as fit as possible.

Andy, diagnosed with Hodgkin lymphoma in 2009
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What are the types of Hodgkin lymphoma?

There are 2 main types of Hodgkin lymphoma that can be identified under a microscope. One of them, classical Hodgkin lymphoma, can be sub-divided into 4 types. The other one is nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

After Dr Thomas Hodgkin first described lymphoma in 1832, scientists Dorothy Reed and Carl Sternberg used the newly developed microscope to look at samples from people with Hodgkin lymphoma. In many samples, they found a type of large cell that looked like ‘owl’s eyes’. This type of cell later became known as the Reed–Sternberg cell.

Since then, other experts have identified other types of large cells, which don’t have ‘owl’s eyes’, but which do have proteins on their surface and changes in their genes similar to those observed in Reed-Sternberg cells. These are called the Hodgkin cells.

**Classical Hodgkin lymphoma**

Classical Hodgkin lymphoma contains Reed–Sternberg or Hodgkin cells. You may come across specific names:

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

These are the 4 different types of classical Hodgkin lymphoma, but they’re all treated in the same way.
**Nodular lymphocyte-predominant Hodgkin lymphoma**

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is different to classical Hodgkin lymphoma; it looks different under a microscope and is treated slightly differently. It is much less common than classical Hodgkin lymphoma.

In NLPHL, the large, abnormal cells can look like pieces of popcorn – they are even nicknamed ‘popcorn cells’. They’re called ‘lymphocyte-predominant’ cells (LP cells).

LP cells have different proteins on their surface from Hodgkin and Reed–Sternberg cells. One of these proteins is known as CD20 and is found in many non-Hodgkin lymphomas.

> There is more about the treatment of NLPHL on pages 53 and 88.

**Who gets Hodgkin lymphoma?**

Hodgkin lymphoma is diagnosed in nearly 2,000 people in the UK each year. It can affect people of all ages, including children. In the UK it is most likely to develop in 2 age groups:

- 15 to 34
- over 60.

In general, non-Hodgkin lymphoma is much more common than Hodgkin lymphoma. However, in teenagers and young adults, Hodgkin lymphoma is almost twice as common as non-Hodgkin lymphoma.
What causes Hodgkin lymphoma?

Doctors continue to research risk factors for Hodgkin lymphoma, but they don’t know exactly what causes it yet.

Scientists have found that it is common for people diagnosed with classical Hodgkin lymphoma to have signs of past infection with the Epstein–Barr virus (EBV). This virus causes glandular fever and most adults have been in contact with it at some stage in their life.

Doctors also know that people who have human immunodeficiency virus (HIV) are more likely to develop Hodgkin lymphoma. Both these infections can affect the immune system and may be linked to an abnormal immune response. This may play a part in causing Hodgkin lymphoma in some people.

Lymphomas are not normally passed on from parent to child (inherited). There is some evidence that people who have a brother, sister or parent with Hodgkin lymphoma – particularly if it is NLPHL – have a slightly higher risk of developing the same illness. It may be that some people have a genetic tendency to abnormal immune responses.

It is important to point out that these risks are small. Many people get glandular fever, but only a few of them develop Hodgkin lymphoma. If you have Hodgkin lymphoma, the risk of a family member also getting it is higher than an average person’s risk, but it is still a very small risk.
How does Hodgkin lymphoma affect the body?

Like any cancer, Hodgkin lymphoma interferes with the way your body works. Exactly how it affects you depends on which parts of your body are involved. Hodgkin lymphoma can cause the same symptoms as other lymphomas (see page 17) but there are also ways in which its effects can be different.

Parts of the body affected

Most people with Hodgkin lymphoma have enlarged lymph nodes, very often in the neck.

In some people, the lymphoma grows mainly in the lymph nodes in the centre of the chest – this happens more often in younger people. Lymph nodes pressing on and irritating the airways can give people a cough and make them short of breath.

Sometimes there is a very large lump of lymphoma in the chest before it is diagnosed. Occasionally, this lump of lymphoma presses on large veins in the chest. This may cause headaches, dizziness and swelling of the face, arms and hands. Doctors call this ‘superior vena cava obstruction’ (SVCO). It means the lymphoma needs to be treated quickly.

A few people with Hodgkin lymphoma have lymphoma that starts in lymph nodes below the diaphragm. Occasionally, people have lymphoma that grows in areas outside of lymph nodes (‘extranodal’ disease). Symptoms depend on where exactly the lymphoma is growing.
Impact on the immune system
Having Hodgkin lymphoma means that you have less resistance to infection. Your body is making abnormal lymphocytes, so there are not enough normal lymphocytes left to fight infections.

But the effect on the immune system in Hodgkin lymphoma is complex. People who have had Hodgkin lymphoma can have a weak immune system even when they have enough normal lymphocytes again. This means you might have problems fighting infection even after your Hodgkin lymphoma has been cured.

Transfusion-associated graft-versus-host disease
The weak immune system caused by Hodgkin lymphoma can cause problems if you need a blood transfusion, too. If there are many donor lymphocytes in the blood, people with Hodgkin lymphoma can develop a serious condition known as transfusion-associated ‘graft-versus-host disease’ (TA-GvHD).

In most people these lymphocytes are easily destroyed and do not cause any problems. But if your immune system is not working properly, the donor’s lymphocytes are not destroyed and can start to attack your own cells.

This is extremely unlikely to happen as donor blood is filtered to remove white blood cells, including lymphocytes. However, anyone who has been diagnosed with Hodgkin lymphoma should receive irradiated blood (blood treated with X-rays) when they need a transfusion. Treating the blood with X-rays kills any donor lymphocytes that may be left in the blood.
The blood still works normally but can no longer cause TA-GvHD.

Your doctors should give you more information about TA-GvHD. They should also give you a card to carry in your wallet or purse in case you need a blood transfusion as you will need irradiated blood. They should also tell your hospital’s blood bank that you need irradiated blood in case you need transfusion during your treatment.

You need to always carry your card because you should continue to receive irradiated blood for the rest of your life. Your immune system can remain weak for a long time, even after you have been cured of Hodgkin lymphoma.

More information about irradiated blood is available from the National Blood Service.

**What is the outlook for Hodgkin lymphoma?**

The prognosis (outlook) for both types of Hodgkin lymphoma is generally good. Most people diagnosed are cured, even when the lymphoma is advanced when it is diagnosed.

In some people, Hodgkin lymphoma can relapse (come back), but there is still treatment available. Researchers continue to look for new treatments to improve the cure rate further.

It is hard to give exact figures for cure rates in general information. Statistics apply to a group of people and
not to any person in particular. Doctors look at a range of factors to estimate what your likely outcome of treatment is. These include:

• your age when you were diagnosed
• whether or not you have B symptoms (weight loss, fevers or night sweats)
• how many groups of lymph nodes are affected by lymphoma
• whether or not you have very enlarged lymph nodes in the centre of your chest
• results of your blood tests.

Your doctor may refer to ‘risk factors’ or an International Prognostic Score (IPS). The IPS is sometimes called the Hasenclever score. These features may be taken into account when your doctor plans your treatment.

The best person to talk to about the likely outcome of your treatment is your own lymphoma specialist. While they can’t give you any guarantees ahead of time, they have access to all the information needed to give you a more informed opinion.
There are 2 main types of Hodgkin lymphoma: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

You have classical Hodgkin lymphoma if there are Reed–Sternberg or Hodgkin cells in your biopsy. You have NLPHL if there are lymphocyte-predominant (‘popcorn’) cells in your biopsy.

Hodgkin lymphoma is diagnosed in nearly 2,000 people in the UK each year. It occurs most often in people aged 15 to 34 and over 60.

Doctors don’t know exactly what causes Hodgkin lymphoma. The classical type is more common in people who have lowered immunity or have had some types of infection in the past.

Hodgkin lymphoma commonly starts in the lymph nodes in the neck. In some people it grows in the lymph nodes in the chest.

Hodgkin lymphoma can lower your body’s resistance to infection, which can continue even after your lymphoma has been treated.

If you have had Hodgkin lymphoma, you should always receive irradiated blood when you need a transfusion. Carry a card with information about this need in case of emergencies.
I take each day at a time and try not to look too far ahead.

Adam, diagnosed with Hodgkin lymphoma in 2013
Treatment overview for Hodgkin lymphoma

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About your treatment

Once your doctors have the results of all your tests, they have the information they need to plan your treatment. They do this based on:

• whether you have classical or nodular lymphocyte-predominant Hodgkin lymphoma
• the stage of your disease
• whether you have B symptoms (weight loss, fevers or night sweats).

Other important points that your doctors take into account include:

• your age and your general health
• any other medical conditions that are affecting you
• the size of your lumps
• your blood test results
• your thoughts on treatment and what is important to you.

Although you have a lead consultant responsible for your care, your case is often discussed in a multidisciplinary team (MDT) meeting. At this meeting, a number of specialists discuss the most appropriate treatment for you on the basis of your test results and circumstances.

I don’t know whether I was in denial, but I left all the worrying to the specialist. I know I am no health expert, so I tried to focus on what I knew about, whenever I could. Carol

Sometimes people with the same type of Hodgkin lymphoma have different treatments. Don’t be worried if the people you talk to at the hospital are having
treatments different from yours. Your treatment is tailored to you.

Completing the tests and planning your treatment can take a few weeks. This might seem like a long time, but the information being collected is very important. Your doctor needs to know as much as possible about you and your illness before choosing the best treatment for you. It is natural to feel worried when you are waiting to find out more or to start treatment. You may find it helpful to talk about it to someone, maybe a specialist nurse or your GP.

How is treatment organised and where will I be treated?
You may have your treatment at a local hospital or at a larger hospital with a cancer centre. Sometimes people have their treatment shared between the 2 places.

Your GP, or the doctor who diagnoses your lymphoma, should send you to the nearest hospital with a lymphoma specialist. The specialist is either a doctor who specialises in diseases of blood cells (a haematologist) or a doctor who specialises in cancer (an oncologist). Lymphoma experts come from both of these fields of medicine. Clinical nurse specialists (CNSs) also play an important role in the care of people with lymphoma.

Children with Hodgkin lymphoma are under the care of a paediatric specialist at a children and young people’s cancer centre known as a Principal Treatment Centre (PTC). There are about 20 PTCs in the UK. Young people’s care may also be shared with a local hospital, with guidance from the PTC.
In the past, teenagers and young people with Hodgkin lymphoma were treated either in a children’s ward or in an adult ward, depending on their age and the policy of the hospital. Nowadays, teenage cancer units are a part of many NHS hospitals. These units are designed to meet teenagers’ needs. They allow teens to have treatment in a unit with others of similar age and get support from each other.

“I had the choice of a teenage unit at another hospital, but it was much easier to stay at the hospital I was diagnosed in. I was the youngest by far, but found so much fun and camaraderie on the ward – we actually had a great laugh!” Natalia

Your doctor doesn’t mind if you ask questions about your hospital and how your care is going to be arranged. Some of the questions you might like to ask are:
• Is your doctor going to meet regularly with other lymphoma specialists?
• Does the hospital have a lymphoma clinical nurse specialist or other specialist cancer nurse?
• Does the hospital have a laboratory on site for fast-tracked blood test results?
• Does the hospital have close links with specialist lymphoma pathologists?
• Does the hospital take part in clinical trials?
• What other experts are there to help if you need them? For example, can you meet with a dietitian or a counsellor if you need to?

Many people find it helpful to take a relative or a friend along with them to their hospital appointments. Your companion may remember parts of the discussion that you don’t, or may think of other questions or concerns that they know you have. Most doctors encourage their patients to bring someone along.

Research and clinical trials
Your doctor may ask if you would like to take part in a clinical trial. Clinical trials are research studies involving human volunteers. Some trials are designed to test new treatments that haven’t yet been tried in Hodgkin lymphoma. Others aim to improve treatments currently in use. They may test whether the lymphoma could be treated with fewer drugs or lower doses of radiotherapy, for example.

To make sure that their results don’t happen by chance, clinical trials have quite strict criteria for entry. They are usually restricted to a particular type and stage of lymphoma or a particular age group. They may also exclude people who have had certain types of treatment already, or have had other medical conditions in the past. So a particular trial is not suitable for everyone.

Not all hospitals conduct clinical trials. You may wish to ask your doctor if your hospital does when they are planning your treatment.
Clinical trials are voluntary. You don’t have to take part in a trial if you don’t want to. You can always opt to have standard treatment if you prefer. Before you agree to take part in a trial, it is important that you fully understand what is involved. The organisers should give you written information about the trial to take away with you. If you change your mind later on, you can withdraw at any time.

You may not benefit from taking part in a trial – no one can say which treatment is better until the trial is completed. You may be monitored more closely or have more tests while in the trial than you would in standard care. Some people find that reassuring. Although the effect participating in a trial will have on you is hard to predict, you will be helping other people get the best possible treatment for Hodgkin lymphoma in the future.

Treatments for Hodgkin lymphoma

The treatment you have depends mainly on the type and stage of your Hodgkin lymphoma. You may not be able to have some treatments if you are older or less fit.

Your consultant should discuss your treatment plan with other experts, including nurse specialists, at their regular multidisciplinary team (MDT) meeting. Do let them know if you have any strong views about your treatment. When your doctor recommends a treatment, ask why they think it is the best option for you.
In this section, there is information on treatment for:
• early-stage classical Hodgkin lymphoma (page 49)
• advanced-stage classical Hodgkin lymphoma (page 51)
• nodular lymphocyte-predominant Hodgkin lymphoma (page 53)
• Hodgkin lymphoma over the age of 60 (page 54).

If you are not sure which section applies to you, check with your doctor or clinical nurse specialist.

**Early-stage classical Hodgkin lymphoma**

Early-stage Hodgkin lymphoma means that you have stage 1A, or sometimes stage 2A, depending on other test results.

There are 2 possible ways of treating this form of lymphoma. They both work very well, but long term side effects can be different. Whichever treatment you have, it is very likely that your lymphoma will be cured.

**Chemotherapy and involved-field radiotherapy**

Many people in the UK have 2 to 4 cycles of chemotherapy followed by radiotherapy. This is sometimes called ‘combined modality therapy’.

Doctors use chemotherapy because it circulates throughout the body and treats lymphoma even in places where it is not visible on a scan. Doctors know from clinical trials that this gives better results than having radiotherapy alone.
Chemotherapy involves treatment with a number of different drugs that are repeated in cycles every few weeks. This is known as a chemotherapy ‘regimen’. The regimen most people have is called ABVD. The amount of treatment given varies between people, according to how far the lymphoma has spread before treatment starts.

Once you have finished chemotherapy, you have radiotherapy to the areas containing the enlarged lymph nodes. Doctors call this ‘involved-field’ radiotherapy. Treating only the areas where the lymph nodes were enlarged limits damage to healthy tissues.

In the future, the area treated may be even smaller. This is known as ‘involved-node’ radiotherapy, but it is still being tested in clinical trials. A typical course of involved-field radiotherapy would last 2–4 weeks.

The benefit of having chemotherapy combined with radiotherapy is that Hodgkin lymphoma is slightly less likely to come back (relapse) in the few years after treatment. At the same time, having both types of treatment may cause more late effects (side effects that can occur months or years after your treatment has finished). Some of these effects are probably less likely than they used to be. Radiotherapy used today is more targeted and given at a lower dose than it was 10–20 years ago, but these side effects can take a long time to occur.

Chemotherapy alone PET scans after a few cycles of chemotherapy can also help doctors decide who does and who does not need radiotherapy.
The evidence shows that for many people, chemotherapy alone is as effective as chemotherapy combined with radiotherapy. For people who have a clear PET scan after their initial treatment, chemotherapy given on its own can cure 90% of cases. As using radiotherapy increases the risk of late effects, your doctor might recommend that you stop treatment after chemotherapy if your PET scan is clear.

In choosing your treatment, your doctors try to balance the chances of your lymphoma coming back against your risk of side effects. Remember that chemotherapy alone and chemotherapy combined with radiotherapy each works very well.

**Advanced-stage classical Hodgkin lymphoma**

Advanced-stage classical Hodgkin lymphoma includes stage 3 and 4 lymphoma and sometimes stage 2.

If you have advanced-stage classical Hodgkin lymphoma, your doctor is likely to recommend you have chemotherapy. You are likely to get a number of different drugs at the same time repeated in cycles every few weeks (chemotherapy ‘regimen’).

Most people in the UK now have a regimen called ABVD, but there are others that doctors sometimes recommend. For example, you may have a treatment called ‘escalated BEACOPP’ if your lymphoma is very widespread. Older people, or those with other health problems, may need less intensive regimens. Children and teenagers also usually have different regimens.
Clinical trials continue to compare regimens to see what works best in what group of people. A recent trial looked into whether **PET scans** could be used to guide treatment decisions after the first 2 cycles of chemotherapy. Based on this new evidence, doctors recommend changing regimens depending on the results of an interim **PET scan**.

If your **PET scan** is negative after a few cycles of ABVD, your doctor is likely to recommend that bleomycin (‘B’ in ABVD) is dropped for later cycles. Bleomycin can cause lung damage. The research suggests people who respond well to the first few cycles of ABVD do just as well without bleomycin in their later cycles. If your scan is positive, you might continue with ABVD or be recommended a more intensive treatment.

You are likely to have chemotherapy for around 6–8 months. Usually you have your treatment as an outpatient, in a day case unit. You might need to stay in hospital for a while if you get an infection.

You have a **PET scan** after your chemotherapy to make sure you are in remission (no evidence of lymphoma).

Your doctors might suggest that you have radiotherapy after chemotherapy. This is more likely if you had very enlarged nodes originally (**bulky disease**) or if your **PET scan** suggests there might be some lymphoma remaining.
There is more detailed information about having radiotherapy on pages 92–96.

**Nodular lymphocyte-predominant Hodgkin lymphoma**

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is more often diagnosed at an early stage, without B symptoms, and it tends to grow more slowly than classical Hodgkin lymphoma. It also often responds well to gentler treatments.

If you have early-stage NLPHL, you may just have 1 or more affected lymph nodes removed. You then have no further treatment, but your doctor will keep a close eye on you in the clinic. If there are any further signs of lymphoma, you then have more treatment. Doctors call this approach ‘watch and wait’.

In some cases, radiotherapy may be given after surgery. This is more common for adults than for children. Children may have ‘watch and wait’ after surgery or may have low doses of chemotherapy to avoid the late effects of radiotherapy.

If you have advanced-stage NLPHL but are well, your doctor may suggest you may have ‘watch and wait’. If your lymphoma is causing symptoms, you are most likely to have chemotherapy, which may include the antibody therapy rituximab. Rituximab targets a protein on the NLPHL cells, called CD20. You may also have radiotherapy after chemotherapy.
Hodgkin lymphoma over the age of 60

More than a quarter of patients diagnosed with Hodgkin lymphoma are over 60. Treatment for lymphoma often has to be adapted slightly for this age group. If you are over 60, your risk of having severe side effects from chemotherapy is higher.

For this reason, your treatment might need to be adjusted. For example, you can’t have the chemotherapy drug Adriamycin® (the ‘A’ of ABVD) if your heart isn’t working well. Having heart disease means radiotherapy to the chest may not be good for you either. Bleomycin is usually not recommended for this age group and, if given, it tends to be in a much reduced dosage.

Being over 60 can also mean you may be more troubled by side effects of chemotherapy. This is because you are both more likely to get side effects and less likely to recover from them quickly. Of course you are not bound to get side effects, but your doctors need to think carefully about how the treatment could affect you.

You might not be able to have as much treatment as someone who’s younger. Your bone marrow may also take longer to recover after each cycle of chemotherapy. So your doctors may have to lengthen the gaps between treatments or give you lower doses to keep your blood counts at safe levels. You might also receive treatment with growth factors (eg G-CSF).

Your doctors need to work out what treatment they think is best for you. This decision depends on how fit you are, especially how well your heart, lungs and kidneys
are working. The doctors may arrange for you to have special tests before you start treatment, such as an echocardiogram (a heart test) or spirometry (a lung test).

Your doctors want to give you as much treatment for your lymphoma as they safely can. They need to balance the potential benefits of treatment against the risks of it making you more ill and causing complications.

The chemotherapy regimens used more often in people over 60 are ChlVPP and VEPEMB. There is more information about these on page 75.

People with nodular lymphocyte-predominant Hodgkin lymphoma who are not well enough to have chemotherapy might be able to have the antibody treatment rituximab on its own.

Talk to your consultant about your treatment and what you can do to support your own recovery. Don’t be afraid to ask your team what is happening and why they think the chosen treatment is best for you.

**What happens during treatment?**

It is hard to predict exactly how you will feel during your treatment and how it will affect your day-to-day life. If you have had lots of symptoms from your lymphoma, you may feel much better once you start treatment.
Some people have few side effects from their treatment and are able to carry on almost as usual. Others need to make changes, at least for a while. If you are having radiotherapy, side effects may be worse when you are near the end of your treatment course and for a short time afterwards.

There is more information on possible side effects of chemotherapy, radiotherapy and targeted therapy on pages 101–110.

Day-to-day life (working, studying, hobbies and socialising)
If you work, you should let your employers know about your illness and treatment. Most will be sympathetic and flexible. They need to know because, at the very least, you are going to need to take time off work for hospital appointments. In practice, most people take more time off, reduce their number of hours or change the kind of work they do. You can discuss your work-related concerns with your medical team.

Physically, work was hard and sometimes I found it difficult even to walk up the stairs. But mentally, it did me so much good and helped me recover. Carol

It is possible that you can claim benefits even if you are working. Many people miss out on what they are entitled to. Some benefits are not means-tested and are non-contributory, so may be claimed if you are in work, off sick, a carer or retired. There are a number of places you can go to find out more about benefits such as GOV.UK, Citizens Advice and Macmillan Cancer Support.
Studying
It is likely your studies will be affected by your illness and treatment. You will probably need to take time off, so it is best to tell your school, college or university what is happening.

If you are at school, you should be able to get help with your studies. Universities and colleges are usually flexible, too. Depending on the time you miss and how much your work has been affected, you may decide it is best to delay taking exams and consider deferring or suspending your studies.

I was determined from the start to keep up my education, as it was an element of my life I felt I maintained control over. Ellie

Hobbies and socialising
It is important that while you’re being treated for lymphoma you allow yourself time to do the things you enjoy. When you feel well enough, you should try to continue as much as possible with your hobbies and social life. Seeing friends, getting out or having a change of scenery can help to make you feel more ‘normal’. Remember that there may be times when you should avoid crowds because of the risk of infection – your hospital team will give you advice about this. Do check with your hospital team if any of your hobbies are adventurous, very active, or in any way dangerous.
Holidays and special events
During treatment, a holiday (especially abroad) may not be the best idea. At times, for example when your blood count is low, you are likely to feel safer staying close to home. But it may be possible to make small adjustments to your treatment schedule so that you can go away. Do discuss well in advance with your hospital team if you have any special events or plans, so that they can offer you the best advice.

If you are thinking about a holiday once you have finished treatment, discuss this with your team. You might need to consider where you travel to, your accommodation and whether you need any vaccinations. Depending on where you are going, finding travel insurance at a reasonable price can also be a problem, so it is important to think ahead.

Sex and contraception
There is no reason you shouldn’t have sex during treatment if you feel like it, but there are some specific precautions you should take. Traces of chemotherapy may remain in the body possibly for up to 5 days following treatment. To limit your partner’s exposure, use condoms during this time and avoid oral sex and open-mouthed kissing where saliva is exchanged.

Continue to use contraceptives throughout the course of your treatment if there is any chance that you or your partner could become pregnant. Treatments may damage sperm or eggs and could be harmful to a developing baby. If you do become pregnant, it can make it more difficult to treat your lymphoma. Oral contraceptive
tablets may be metabolised more quickly by your body when you’re having treatment. Always discuss with your doctor or nurse what method of contraception is best for you during your lymphoma treatment.

Advice does vary, but if you are having chemotherapy doctors often recommend that:
• Women with lymphoma don’t become pregnant during their treatment and for up to 2 years afterwards.
• Men with lymphoma prevent making their partner pregnant while they are having chemotherapy and for at least 3 months afterwards.

Everybody’s circumstances are different, so it is important to discuss these issues with your medical team. They can give tailored advice on what they feel would be best for you.

**What happens after treatment?**

‘Remission’ means that the lymphoma is under control. There are different degrees of remission. A **complete remission** means that there is no sign of the lymphoma on scans after treatment. A **partial remission** means that the lymphoma has shrunk by at least half. Specialists treating Hodgkin lymphoma aim for long-term **complete remission**.

You may find that your specialist prefers to say ‘you are in remission’ rather than ‘you are cured’. This is because he or she cannot be sure whether or not your disease will come back. The longer you have been in remission, the more likely it is that you have been cured.
I was told I was in remission. It was overwhelming.
Carol

In a small number of people, Hodgkin lymphoma does not respond well to treatment. Lymphoma that does not go into remission after treatment is known as ‘refractory’ lymphoma. It is usually treated in the same way as Hodgkin lymphoma that has relapsed (come back). There is more information about this on page 65–69.

**Follow-up**
When your course of treatment has finished, you see your specialist or another member of the medical team regularly in the clinic. These follow-up appointments are to see how you are feeling, to monitor your recovery from treatment and to check there are no signs of lymphoma relapsing.

At each appointment, you have a brief physical examination and may have blood tests. Unless there is a particular reason to do them, you are unlikely to have routine X-rays or scans. They are usually unnecessary and doctors prefer to keep their patients’ exposure to radiation to a minimum.

People who have had Hodgkin lymphoma usually have follow-up appointments for several years after the end of their treatment. To start with, your appointments are scheduled about once a month or every 6 weeks. If you stay well, the appointments become less frequent – at first every 6 months and eventually once a year.
If you are worried about your health at any time, you don’t have to wait for your next appointment. Contact your GP or hospital team to discuss your concerns. If necessary, they can arrange an early clinic appointment for you. Keep the contact details of your medical team, even after you have finished treatment.

You might worry when your follow-up appointments are coming up. They are an inevitable reminder of your illness when you are trying to move on. But remember, these appointments are an important part of your care. They give you a chance to talk about anything that might be on your mind. It can help to write down what’s bothering you when you think of it and take a list of questions with you to the appointment.
Summary

Your treatment is planned just for you so it may be different from someone else’s.

Doctors usually treat early-stage classical Hodgkin lymphoma with both chemotherapy and involved-field radiotherapy. Where appropriate, they treat it with chemotherapy only.

Advanced-stage classical Hodgkin lymphoma is treated with chemotherapy and sometimes with radiotherapy, too.

Nodular lymphocyte-predominant Hodgkin lymphoma often responds to gentler treatments. In some cases ‘watch and wait’ may be more appropriate.

You continue to see your hospital team for several years after your treatment has finished. The appointments are frequent to start with, but go down to once a year if you stay well.
Initially to be told that I needed 6 months of treatment and then to find that it had not worked was fairly emotional. It was quite a rollercoaster. At that point, stem cell transplants were thrown into the mix.

Hannah, diagnosed with Hodgkin lymphoma in 2014
What happens if Hodgkin lymphoma comes back or doesn’t respond to treatment?

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What is ‘relapsed’ and ‘refractory’ Hodgkin lymphoma?

Many people with Hodgkin lymphoma go into long-term complete remission by their first course of treatment. In some people the lymphoma comes back after treatment (relapse). In a small number of people it does not respond to the first treatment (it is refractory).

Lymphoma is most likely to come back within 2 years of the end of your first treatment. But it can happen later than this. Later relapses are more common in nodular lymphocyte-predominant Hodgkin lymphoma than in classical Hodgkin lymphoma.

Can relapsed and refractory Hodgkin lymphoma be treated?

Relapse of Hodgkin lymphoma can be upsetting, but it can still be cured. Treatment depends on:

- the type of treatment you’ve had before and how your lymphoma responded to it
- how well you coped with the treatment
- how quickly your lymphoma came back
- how fit you are at the time of your relapse.

If Hodgkin lymphoma has relapsed or has not responded to treatment, you may have additional chemotherapy. If you are fit enough, it is likely to be stronger than your first treatment. This is sometimes called ‘salvage treatment’. You often have this type of treatment over a few days, while you stay in hospital. If chemotherapy reduces your
lymphoma and you are well enough, your doctor is likely to suggest high-dose therapy and a stem cell transplant to give you the best chance of a long-lasting remission.

Less intensive chemotherapy regimens are usually given to people with relapsed nodular lymphocyte-predominant Hodgkin lymphoma. However, your doctor might consider recommending a stem cell transplant if you relapse several times.

**Stem cell transplant**

Higher doses of treatment can often work when initial treatments didn’t. However, they also cause damage to your bone marrow to the extent that it might not be able to recover by itself. Stem cells are special cells from the bone marrow that can make normal blood cells. If your bone marrow is damaged, you might not have enough stem cells to make the normal blood cells you need.

A stem cell transplant allows you to have high-dose treatment by giving you healthy stem cells after the treatment. Usually, your stem cells are collected before high-dose chemotherapy (and sometimes radiotherapy). If your own stem cells are collected and given back to you, it is called an ‘autologous’ stem cell transplant. Most people with Hodgkin lymphoma have an autologous stem cell transplant. Rarely, people have stem cells from a donor – an ‘allogeneic’ stem cell transplant.

BEAM chemotherapy is often used as the high-dose treatment:
- B – BiCNU® or carmustine
- E – etoposide
- A – Ara-C or cytarabine
- M – melphalan
You have these chemotherapy drugs for a week and then are given stem cells, just like a blood transfusion. They settle in your **bone marrow** where they start to grow and make new blood cells for your body.

Stem cell transplants take several weeks to complete. They carry risks as well as benefits, especially if you are having donor stem cells. They are not suitable for everyone – you need to be quite fit. If your doctors are thinking about this form of treatment for you, they will talk to you in detail about it.

**For information about stem cell transplants call 0808 808 5555 or visit www.lymphoma-action.org.uk**

**Newer treatments for relapsed and refractory Hodgkin lymphoma**

A newer drug called brentuximab vedotin has been shown to work well in people with relapsed or refractory Hodgkin lymphoma. It is licensed for use in people:
- whose Hodgkin lymphoma has come back after a stem cell transplant
- who are not able to have a stem cell transplant and have had at least 2 other types of treatment.

Your doctor can advise you whether you are suitable for this treatment and whether it is available to you on the NHS.

Your doctor might suggest you enter a clinical trial.
Doctors carry out clinical trials to look for better treatments for Hodgkin lymphoma that has relapsed or has not responded to treatment. New treatments for Hodgkin lymphoma are often tried first in clinical trials in people with relapsed or refractory disease. Clinical trials can give you access to new, experimental treatments.

For more information about clinical trials, please call 0808 808 5555 or visit www.lymphoma-action.org.uk

Summary

**Relapse** is when your Hodgkin lymphoma comes back some time after being successfully treated.

**Refractory** disease is Hodgkin lymphoma that does not respond to the first treatment.

You might have treatment with a more intensive chemotherapy regimen. This is sometimes called ‘salvage treatment’.

If you are fit enough, you might have high-dose therapy and a stem cell transplant.

You might be able to have a newer treatment, like brentuximab vedotin, or your doctor might suggest a clinical trial of an experimental drug.
I don’t know whether I was in denial, but I left all the worrying to the specialist. I know I am no health expert, so I tried to focus on what I knew about, whenever I could.

Carol, diagnosed with Hodgkin lymphoma in 2004

Photo credit: Magi Haroun
More about treatments for Hodgkin lymphoma

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Chemotherapy

Chemotherapy is treatment with drugs. Chemotherapy drugs work by stopping cancer cells from dividing. Different chemotherapy drugs target cells in different ways. Chemotherapy for lymphoma usually involves giving more than one kind of drug – a regimen. Using several drugs increases the chances of killing as many cancer cells as possible.

Chemotherapy works best on cells that are dividing quickly – like cancer cells. To kill as many cells as possible, you usually have chemotherapy as repeated courses, often called ‘cycles’. A cycle is a block of chemotherapy that is followed by a rest period that allows the healthy cells to recover. With each treatment cycle, more cells are destroyed and the lymphoma gradually shrinks.

How is chemotherapy given?

You have a number of treatment cycles, each of which usually takes 3 or 4 weeks. The whole treatment can take several months. The exact timetable for your treatment depends on the particular chemotherapy drugs you are having.

You usually have chemotherapy for Hodgkin lymphoma as an outpatient. You go to the hospital on treatment days and go home afterwards. Whatever type of treatment you are having, you may need to stay in hospital if you have severe side effects, for example, very low blood counts or an infection.
Your medical team should give you specific information about your treatment and what to expect.

You can find the most common side effects of chemotherapy described on pages 78–87.

Most chemotherapy is given intravenously (through a drip or injection via a thin tube into a vein). Some chemotherapy drugs can be taken as tablets or capsules.

**Intravenous chemotherapy**
Typically, you have intravenous drugs via a cannula – a small tube put into one of your veins. Usually the cannula is removed before you go home and another one put in at your next visit.

Some people need to have their chemotherapy through a more permanent intravenous tube, called a ‘central venous catheter’ or ‘central line’. This makes it easier to have frequent treatments or blood tests. Central lines are designed to stay in for longer, hopefully for all of your treatment. They can be capped when you are not having treatment. Your nurse should show you how to look after your line to help prevent infection and tell you who to contact if you have any problems with it.

You can have some intravenous drugs as an injection into the cannula or central line over a minute or two. Your doctor may call this a ‘bolus’ or a ‘push’ dose. Other intravenous drugs have to be given through a drip (infusion). The drug is diluted with another fluid in a bag, and the bag is set up to drip into the cannula over a set time.
Some chemotherapy drugs can sting as they go into the vein – especially the drug dacarbazine (the ‘D’ in ABVD). Tell your nurse if you have any discomfort as things can be done to relieve it.

**Oral chemotherapy**
You may have chemotherapy tablets or capsules that you take orally (by mouth). You are given instructions on what to take and when, and how to store the drugs.

It is important that chemotherapy tablets are not handled by anyone other the person who is taking them. If you are helping someone to take their chemotherapy drugs, wear gloves when handling any tablets.

**Chemotherapy regimens for Hodgkin lymphoma**
Chemotherapy regimens are usually known by a series of letters, usually the initials of the drugs included.

**ABVD chemotherapy**
The most common chemotherapy for Hodgkin lymphoma is ABVD. It works well for most people at any stage of Hodgkin lymphoma. ABVD is made up of 4 **intravenous** drugs: doxorubicin (**Adriamycin®**), bleomycin, vinblastine and dacarbazine.

You usually don’t need to stay in hospital for the treatment, which you have in 4-week **cycles**. You have treatment on the first day of each **cycle** and again 2 weeks later. Then you have 2 weeks without treatment before another **cycle** begins.
Other chemotherapy regimens

There are many other chemotherapy drug combinations (regimens) used for Hodgkin lymphoma – too many to describe in a booklet. Some of the other common regimens include:

- **BEACOPP** – bleomycin, etoposide, doxorubicin (Adriamycin®), cyclophosphamide, vincristine (Oncovin®), procarbazine and prednisolone. The escalated BEACOPP regimen is given in higher doses. It is more likely to control lymphoma than other regimens, but also causes more side effects. It is much more likely to cause infertility.

- **ChlVPP** – chlorambucil, vinblastine, procarbazine and prednisolone. This regimen was commonly used in the past. It is now mainly used for older people or those whose medical problems mean they can’t have ABVD.

- **VEPEMB** – vinblastine, cyclophosphamide (Endoxana®), procarbazine, prednisolone, etoposide, mitoxantrone and bleomycin. This regimen was designed for older people or those whose medical problems mean they can’t have ABVD.

People with nodular lymphocyte-predominant Hodgkin lymphoma sometimes have rituximab with ABVD but may have different regimens, such as:

- **R-CHOP** – rituximab, cyclophosphamide, doxorubicin (or hydroxydaunorubicin), vincristine (Oncovin®) and prednisolone.

- **R-CVP** – rituximab, cyclophosphamide, vincristine and prednisolone.
Children and teenagers may have different regimens, such as:

- **COPP** – cyclophosphamide, vincristine (Oncovin®), procarbazine and prednisolone.

- **OPEA** – vincristine, (Oncovin®), prednisolone, etoposide and doxorubicin (Adriamycin®).

Your hospital team should give you full information about your treatment, including what you have and when. They should also be able to tell you what side effects to expect from the drugs you are having. Do ask your team if there is anything about your treatment that you don’t understand.
In May 2015, I was 20 and studying at university. I felt completely well, but noticed a lump in my neck. I went to see my GP who thought it best to have it checked out.

A biopsy of the lump, followed by a PET scan, confirmed I had classical Hodgkin lymphoma, stage 4A. I was in shock and felt completely lost.

I started ABVD chemotherapy straight away with 4 sessions (2 cycles) followed by a PET scan. The aim was to remove the bleomycin for the following 4 sessions.

While everyone around me seemed to be struggling with ABVD, I had virtually no side effects. I actually wanted to feel ill to reassure myself that the drugs were working. However, I found losing my hair difficult. At the time of collecting my wig, I still had all my hair and never thought I was going to need it. But after my second chemotherapy I lost a dramatic amount of hair. I hated the thought of the wig; it just was not me at all. Instead, I began to comb all my hair back, wear a ponytail and avoid pictures.

The plan had always been to have 2 cycles of ABVD (4 sessions), a PET scan, and based on that PET scan, reduce the drugs to AVD, removing the B, which is known to cause long term lung damage. However the PET scan showed that my chest was still affected.
I needed to change to a more toxic chemotherapy, advanced BEACOPP. Even though I felt overwhelmed, I managed the BEACOPP well, despite this involving far more treatment, and I needed to be an inpatient for some of it.

On 11 November 2015, after nearly 6 months of chemotherapy, tears, fears and support, I was told my PET scan was negative. I was in remission. I cannot put into words the relief; I could breathe again.

However, I realise that cancer doesn’t simply end when you get the ‘all clear’. I had never really come to terms with having cancer. Now in remission, it seems even stranger to think I no longer have it.

### Side effects of chemotherapy

The side effects you get depend on what drugs you are having. The hospital should give you information about your drugs and what to expect, but it is impossible to say before you start treatment which side effects you will get. Each person gets slightly different side effects, even if they are having the same treatment as someone else.

Most side effects are short-term. Sometimes chemotherapy can have long-term or permanent effects. Your doctors should discuss this with you before your treatment starts.

Your doctors and nurses aren’t always going to ask how you are feeling – they might assume you are all right if you don’t say anything. Let them know about any side effects you are having and about any changes you feel
during your treatment. There are usually things that can be done to help with any discomfort you might have.

You can find some tips for coping with chemotherapy side effects on pages 101–110.

Low blood counts and risk of infection
Most chemotherapy regimens cause temporary damage to the bone marrow. The most important side effect to know about is damage to the bone marrow. Your bone marrow makes your body’s blood cells. These include white blood cells, which help to fight infection. A neutrophil is the most important white blood cell.

A low neutrophil count (neutropenia) is common after many types of chemotherapy for Hodgkin lymphoma. This white cell count tends to be at its lowest about 7–10 days after each dose of chemotherapy.

Many people feel well even though their blood cell counts are low. But if you have neutropenia your risk of infection is higher than normal. If you do get an infection, it can be serious, sometimes even life-threatening.

Contact your hospital immediately when if you have any of the following:
• a fever (a temperature above 38°C; note your temperature might not be raised if you are taking steroids)
• chills, shivers or sweats, or if you feel generally unwell or disoriented
• get mouth sores or ulcers
• a cough or a sore throat
• redness or swelling around sores on the skin
• diarrhoea
• a burning sensation when passing urine
• an unusual vaginal discharge or itching.

An infection in someone with neutropenia needs urgent treatment. You usually have to stay in hospital for intravenous antibiotics and careful monitoring.

If your white cell count is too low when your next cycle of treatment is due, your doctors may delay it until your blood count has had a chance to recover. You may have other drugs to help boost your blood count, for example, growth factors.

For more information on steroids and growth factors see page 91.

Other blood cells can be affected by chemotherapy. A shortage of red blood cells is called anaemia. Because red cells carry oxygen, when there aren’t enough of them, you can feel tired or short of breath. Platelets are cells that help to stop bleeding. A shortage of these is called thrombocytopenia and can cause easy bruising, rashes of tiny red spots, blood in urine or bleeding gums.

You have regular blood tests to check your blood count during your treatment.

Common general side effects
Some side effects are common with many different chemotherapy drugs.
• Nausea (feeling sick) and vomiting: You are given anti-emetic (anti-sickness) drugs during treatment.
• **Sore mouth** due to mucositis (damage to cells lining your mouth). You could get mouth ulcers or infections. You might be given mouthwashes to help.

• **Change in taste and problems eating.**

• **Hair loss**, which usually starts within a couple of weeks of starting treatment. Your hair should start to grow back within 1–2 months after your treatment has finished.

• **Fatigue** (extreme tiredness), which should gradually get better in the months after treatment. Evidence shows that doing regular, gentle exercise can help people feel better more quickly.

I was shocked by how fatigued I felt; it was like someone had taken the batteries out. Andy

There are tips for coping with each of these side effects on pages 104–108.

**Peripheral neuropathy (nerve damage)**

Some chemotherapy drugs can damage the nerves that carry information about touch, temperature and pain, or nerves involved in muscle movement. This is called ‘peripheral neuropathy’.
Peripheral neuropathy is usually related to particular drugs. One drug often used in Hodgkin lymphoma that can cause neuropathy is vinblastine (the ‘V’ in ABVD), but it doesn’t often cause problems. Neuropathy can also affect people having brentuximab.

Neuropathy most often affects the nerves in your hands and feet, causing symptoms like numbness and tingling in your fingers and toes. You might feel it in other places, too. Sometimes it affects the nerves of the internal organs, which is known as ‘autonomic’ neuropathy. This can cause symptoms like abdominal cramps and constipation.

**Symptoms** of neuropathy usually develop soon after you have had several cycles of treatment: the effect is cumulative. If you do have any problems, you should tell your doctors or nurses **before** you have your next dose of chemotherapy. They might want to adjust your treatment to prevent these problems getting worse.

For most people **symptoms** of neuropathy are temporary. Some people can have long-term or permanent damage.

You must notify the Driver and Vehicle Licensing Agency (DVLA) if you have peripheral neuropathy.

**Cancer-related cognitive impairment or ‘chemo brain’**
Some people develop memory, thinking and concentration difficulties when they have cancer or during their treatment. This is cancer and treatment-related cognitive impairment (CRCI). It is often referred to as ‘chemo brain’ because it was first described by patients during and after having chemotherapy.
People who experience CRCI describe a feeling of ‘fogginess’, inability to concentrate and having problems with learning and retaining new information.

Symptoms are often mild and usually improve with time.
In 2013, I was 27 and working on a cruise ship. I woke up with a really tight feeling in my neck and when I prodded my neck I felt a lump. As the ship had a doctor, I went to have it checked out. He gave me a chest X-ray and said he could see a mass. This shocked me as I didn’t for a moment think it could be anything serious.

The ship doctor said I needed to have it investigated at a hospital immediately, despite the fact that we were in Halifax, Nova Scotia. I couldn’t have been further from home.

I had several tests, including a fine needle biopsy, and was closely monitored for a week. The tests were inconclusive, but they mentioned Hodgkin lymphoma, something I had never heard of.

The same day I flew back to England, my GP referred me to hospital. A lymph node biopsy revealed that I had Hodgkin lymphoma stage 3A.

Treatment started immediately with 12 sessions of ABVD chemotherapy over a 6 month period. A scan part-way through showed there was still evidence of the lymphoma, so it was decided I would have radiotherapy.

I had been warned I would lose my hair, but it was losing my eyebrows that I found most upsetting. It seemed to change my looks completely and I thought it made me look really ill. Also, because of the steroids
I was on, and because I wasn’t taking much exercise, I put on 2 stone in weight. My face in particular was much rounder.

After the chemotherapy had finished, I had radiotherapy every weekday for 3 weeks. For me, this was the easiest part of treatment, although I felt more and more tired as the time went on and I had some soreness and redness where the radiotherapy was targeted.

After treatment, friends and family found it hard to understand why I was still struggling. Instead of being delighted to finish treatment, it was at this stage I began to feel angry, asking ‘Why me?’ I felt really fatigued and also found that I could no longer concentrate or focus on things, something the doctor told me is known as ‘chemo brain’.

It has taken me 2 years to get over the side effects of treatment. I am getting physically and emotionally stronger day by day, but feel I have had to find a new normal.

**Effects on fertility**

Some treatments for lymphoma can affect your fertility. The extent varies and many people are able to have children after treatment without any problem, particularly if they were treated with ABVD.

Other chemotherapy drugs, particularly those used before stem cell transplants, are more likely to cause problems with fertility. It’s impossible to know how
your fertility will be affected, but your specialist should discuss potential changes to your fertility with you before treatment starts. There may be options available to help preserve your fertility.

**Lung problems**
While most people never develop lung problems, they can be a side effect of bleomycin (the ‘B’ in ABVD). You may have tests to see how well your lungs are working before you start treatment.

Some people develop fibrosis (scarring) of the lungs. Once scarring develops, it is usually permanent. Sometimes it is mild – you can see it on X-rays or scans but it doesn’t cause any symptoms. If it does cause symptoms, you may become short of breath and find you can’t do as much exercise as you could before. If you have symptoms, tell your doctor immediately as your treatment may need to be changed to prevent permanent damage.

If you ever need to have an operation after having been treated with bleomycin, tell your anaesthetist.

Lung problems are much more likely in people who smoke. If you are a smoker and have had bleomycin, consult your GP for guidance on giving up smoking.

**Heart problems**
Some of the treatments for classical Hodgkin lymphoma can cause heart problems years later. Your doctor may avoid certain drugs like doxorubicin (Adriamycin®, the A in ABVD) if your heart function is not good at the time of your diagnosis or if you have a history of heart trouble.
If you are going to have a drug that can affect the heart, you may have heart tests such as an **echocardiogram** to see how well your heart is working before you start treatment. Your doctor should monitor your heart regularly during and after your treatment.

**Blood problems**
Some chemotherapy treatments slightly increase your risk of developing some blood disorders in the future, such as myelodysplastic syndrome (MDS) and leukaemia. This risk is still small.

MDS is a condition where the **bone marrow** doesn’t make enough healthy blood cells. It most often causes a shortage of **red blood cells (anaemia)**, which may need to be treated with blood transfusions.

**Targeted therapy**
Targeted therapies are also called ‘biological’ therapies. They use the biological functions of the body, especially the **immune system**, to target lymphoma cells. The main type of targeted therapy used in lymphoma is an **antibody** therapy, also called **immunotherapy**.

**Antibodies** are produced by our bodies to fight infection. They bind (stick) to specific **antigens** (proteins) on the surface of bacteria and viruses and attract other cells of the immune system that help to destroy the infection.

Antibodies used to treat lymphoma are made in a laboratory to recognise a particular antigen that is more common on the surface of lymphoma cells than on
the surface of normal cells. When the antibody binds to the antigen on the lymphoma cell, it either kills the lymphoma cell directly or helps your immune system to find and destroy it.

Some antibodies activate the immune system to destroy abnormal cells. These include newer drugs in clinical trials for lymphoma, like nivolumab and pembrolizumab.

There are some targeted treatments already beginning to be used for Hodgkin lymphoma and many others are in development.

Funding of new cancer drugs in the UK constantly evolves. Some drugs are routinely available on the NHS, others may be made available in England through the Cancer Drugs Fund. Your doctor is likely to have the most up-to-date information about how to access particular treatments.

**Rituximab in nodular lymphocyte-predominant Hodgkin lymphoma**

The antibody therapy rituximab (MabThera®) targets CD20, an antigen found on NLPHL and B-cell non-Hodgkin lymphoma cells but not on classical Hodgkin lymphoma cells. It is used to treat many types of non-Hodgkin lymphoma and is now being used to treat NLPHL. You may have rituximab on its own, or along with chemotherapy.

You have rituximab through a drip (infusion) in the same way as other intravenous drugs. You can usually have it
as an outpatient. You have the first infusion quite slowly, to help prevent side effects. It may take a few hours.

You can have the following infusions more quickly (often over 60–90 minutes), unless you have major side effects the first time. Rituximab can be given by subcutaneous injection (injection under the skin) in some people with other types of lymphoma. This form of the drug has not yet been tested in NLPHL.

Many side effects of an antibody therapy happen while you are having your infusion. The most common reactions are shivers, fevers and flu-like symptoms. You are more likely to get these with your first infusion, which is why you have it more slowly. You should be given drugs to help prevent side effects before the infusion starts.

Occasionally, people have an allergic reaction. If this happens, you may need to stay in hospital to be monitored for a while. You might need to have rituximab more slowly in the future or stop the antibody therapy altogether.

Most antibody therapies can temporarily affect the way the bone marrow works. This can sometimes cause low blood counts and an increased risk of infection.

**Brentuximab vedotin in classical Hodgkin lymphoma**

An antigen called CD30 is found on most Hodgkin and Reed–Sternberg cells. Antibodies targeting CD30 don’t work well on their own. Brentuximab vedotin (Adcetris®) is a type of treatment called an ‘antibody–drug conjugate’.
This is an **antibody** joined to a chemotherapy drug. The **antibody** binds to CD30 on the lymphoma cells and carries the chemotherapy directly to them.

Brentixumab is licensed for use in people:
- whose Hodgkin lymphoma has come back after a stem cell transplant
- who are not able to have a stem cell transplant and have had at least 2 other types of treatment.

You have brentuximab every 3 weeks, as an intravenous infusion over 30 minutes. You usually have it as an outpatient. As with other antibody therapies, you can have a reaction during the infusion. So your nurse will monitor your pulse and blood pressure closely while you are having the drug.

Brentuximab can cause the same reactions during infusion as other antibody therapies including shivers, fevers and flu-like symptoms. Later, it may cause nausea, diarrhoea, hair loss, fatigue, itching and a rash. More serious side effects include nerve problems (peripheral neuropathy) and low blood counts, especially neutropenia, which increases your risk of infection.

**Supportive care (steroids, growth factors)**

Supportive care refers to treatments that do not directly treat your lymphoma but can still be an important part of your care. They may help to limit the side effects of treatments and they may make you feel better in yourself.
**Steroids**
Steroids are drugs that mimic hormones produced naturally by the body. They are used to treat some types of lymphoma. For Hodgkin lymphoma, they are most often used to control sickness and help you feel better.

You usually have steroids as tablets. Steroids can have side effects including difficulty sleeping, mood changes, raised blood sugar, and increased appetite. However, these side effects are more likely if you take high doses of steroids or take them for a long time. Side effects should go away after treatment.

**Growth factors**
Growth factors are hormones that occur naturally in the body and tell the bone marrow to make blood cells. They can also be made in a lab and used to keep your blood cell counts up when you are having chemotherapy.

The growth factor most commonly used is a granulocyte-colony stimulating factor (G-CSF). You have G-CSF as an injection into the fatty tissue under your skin (a ‘subcutaneous’ injection). They are given into the tummy, the top of the leg or the top of the arm. You can give yourself the injections at home or ask a friend or relative to do it for you.

The injections can sting and G-CSF can cause side effects. You may have flu-like symptoms, bone pain or headaches. Mild painkillers such as paracetamol can help, but do ask your hospital team before you take anything. If you have any unusual symptoms or feel unwell during your growth factor treatment, you should contact your hospital straightaway.
Radiotherapy

Radiotherapy uses high-energy X-rays, similar to those used to take an X-ray picture but in much higher doses. The X-rays are directed to precise areas. They can kill cancer cells in this area by stopping them from dividing.

Lymphoma cells are very sensitive to radiotherapy, but you can only have treatment to small areas. You are most likely to have it for early-stage Hodgkin lymphoma or for areas where the lymph nodes are very large (‘bulky’ disease).

You may have radiotherapy on its own to treat early-stage nodular lymphocyte-predominant Hodgkin lymphoma. For classical Hodgkin lymphoma, you normally have it after chemotherapy.

How you have radiotherapy

Radiotherapy is usually given daily, Monday to Friday, and treatment is spread over a few weeks. You can go home after each treatment. Radiotherapy is only available at specialist centres, so you may need to travel for your treatment. Your care there is overseen by a clinical oncologist (radiotherapist). They will see you to discuss your treatment before it begins.

A radiotherapy department can feel high-tech and impersonal, with big machines and no windows. It can be unnerving at first, particularly when you’re left alone for some of the time. The staff are there to make you feel comfortable, so do let them know if you are worried about anything.
You might need to make several visits to the radiotherapy department to plan your treatment before it starts. It is very important that precisely the same area is treated each time.

Each treatment takes 5–20 minutes and is painless. Most of this time is spent making sure you are in the correct position. Radiotherapy for lymphoma does not make you radioactive. There is no risk to those close to you.

**Side effects of radiotherapy**
Although radiotherapy itself is completely painless, it can have uncomfortable side effects. Side effects of radiotherapy depend on which part of your body is being treated. Your radiographer should give you information about what to expect and how to take care of yourself. You may have no side effects to start with – they tend to become more obvious towards the end of the course. Most radiotherapy side effects are short-term, but some may be long-term or permanent.

It is important to let your medical team know about any side effects you have. Tell them if any of your side effects change during the course of your treatment. There are usually things that can be done to help with side effects.

Many people have **fatigue** (feel very tired) after radiotherapy. It can take months after treatment for fatigue to go away completely.

In the area being treated, you might have:
- **Sore skin** – skin reactions are usually worst a few days after the end of the treatment course but then your skin
starts to heal. Follow your radiographers instructions about caring for your skin.

• **Hair loss** – your hair in the treated area should start to grow back after a few months.

Other side effects can happen if you have radiotherapy in certain areas:

• **Sore mouth and difficulty swallowing** – this can happen if you have radiotherapy to your head, neck or upper chest. If you have a dry mouth, it may take several months to improve and sometimes the change may be permanent.

• **Nausea (feeling sick)** if you have radiotherapy to your abdomen (tummy).

• **Effects on the blood** usually if there are large bones in the treatment area. A low **white blood** cell count (**neutropenia**) can increase your risk of infection. A shortage of **red blood cells (anaemia)** can increase fatigue and make you feel short of breath. Rarely, radiotherapy can cause a shortage of platelets (**thrombocytopenia**).

Long-term and **late effects** (side effects that develop months or years after treatment) can happen. The effects you are at risk of depend on what area of your body was treated. It is important to know that much of what is known about the risks of **late effects** comes from older studies. Modern treatments have been adjusted to minimise the risk of these complications.

**Increase in risk of heart disease and stroke**
Heart problems become more common 10 years or more after radiotherapy that includes your heart. Radiotherapy
that includes the heart can increase your risk of heart disease. Radiotherapy to the chest or neck might also cause hardening of your arteries. This can affect the blood supply to your brain or heart, increasing your risk of stroke.

The risk to your arteries depends on the dose of radiotherapy and the exact area you had treated. Modern treatments have been designed to reduce the risk of heart problems. You can help to lower these risks further by following lifestyle advice to keep your heart healthy, including maintaining a healthy weight and giving up smoking.

**Lung problems**
Scarring of lung tissue, or fibrosis, can be a side effect of radiotherapy to the chest. Once it develops, it is usually permanent. If it is mild, it can show up on X-rays or scans but doesn’t cause any symptoms. Some people can become short of breath and find they are able to do less exercise than they used to. The risk of scarring is lower if you do not smoke.

**Reduced thyroid function**
Radiotherapy to the neck can damage your thyroid gland, which may then make less of the hormone thyroxine. This is called hypothyroidism and may slow your metabolism resulting in you feeling cold and tired, and gaining weight easily. Hypothyroidism is easily treated with thyroxine tablets.
Hypothyroidism can develop any time after treatment, even many years later. It can be diagnosed by a simple blood test at your GP surgery.

Second cancers
Statistically, people treated for Hodgkin lymphoma have a higher risk of developing a second cancer later in life. But much of what is known about this increase in risk comes from older clinical trials when people were often treated with bigger doses of radiotherapy given to larger areas of the body. Nowadays, doctors use smaller doses of X-rays in a much more targeted way, which lowers the risk of a second cancer.

Your risk of developing a second cancer later in life depends on what part of your body is treated, for example:
• radiotherapy to breast tissue in women increases the risk of breast cancer; you might be offered regular breast screening at an earlier age than normal
• radiotherapy to the chest increases the risk of lung cancer; stopping smoking is vital to limiting this risk
• radiotherapy to the neck increases the risk of developing thyroid cancer.

Your specialist should tell you what your risks of second cancers are and give you advice on how to reduce them.
Summary

There are a few types of treatments for lymphoma. Which one you get depends on the type of disease you have, among other factors.

Chemotherapy
Chemotherapy means drug treatment, often with a combination of several drugs.

Chemotherapy usually lasts a few months. You have a series of treatments (cycles), with breaks in between them to allow your healthy cells to recover. You don’t usually have to stay in hospital.

There are lots of possible side effects of treatment. Your side effects depend on what kind of treatment you are having. You should be given information about likely side effects.

If you develop signs of infection or notice any side effects, tell your medical team immediately.

Most of the side effects of chemotherapy are short-term and should improve within a few weeks of the treatment finishing. Some side effects can be long-term. Your doctor should tell you about any risks of side effects before your treatment starts.

Some treatments for Hodgkin lymphoma can affect your fertility but many people go on to have children after treatment for Hodgkin lymphoma, especially if they have had treatment with ABVD chemotherapy.
Targeted therapy

The main targeted therapies used in lymphomas are **antibody** therapies. These work by attaching themselves to proteins on the lymphoma cells. Then they kill the cells or help your **immune system** to find and destroy them.

The **antibody** therapy rituximab (MabThera®) is sometimes used to treat nodular lymphocyte-predominant Hodgkin lymphoma.

Brentuximab vedotin (Adcetris®) combines an antibody with a chemotherapy drug. This is called an antibody–drug conjugate. It is used to treat some people whose classical Hodgkin lymphoma has come back after earlier treatment (**relapsed**).

Radiotherapy

Radiotherapy uses high-energy X-rays that kill lymphoma cells. Radiotherapy is painless. You have a course of daily treatments (fractions). Each fraction takes between 5 and 20 minutes.

The side effects of radiotherapy depend on the area being treated. They tend to develop towards the end of a course of treatment. Your doctor should tell you what to expect.

If you notice any side effects, do tell your medical team as there are often things that can be done to help manage them.
After my third treatment, I began to lose my hair, something that had always been important to me. I still wanted to look myself and found that a good wig and makeup made a big difference to how I felt.

Zoe, diagnosed with Hodgkin lymphoma in 2014
Coping with side effects of treatment

Tips for coping with side effects
Tips for coping with side effects

In the previous section we covered the side effects of chemotherapy, radiotherapy and targeted therapy.

The following information suggests ways of dealing with side effects. This is only introductory information – ask your medical team for tailored advice about dealing with your side effects.

Tell your team if you feel unwell in any way at any point.

For more information about dealing with side effects please call our helpline on 0808 808 5555 or visit our website at www.lymphoma-action.org.uk

“"It was losing my eyebrows that I found most upsetting. It seemed to change my looks completely and I thought it made me look really ill.” Adam
Low white cell count (neutropenia)

Contact the hospital immediately if you develop signs of infection such as fever (temperature above 38°C), chills, shivering or sweating.

The following tips may help you lower your risk of developing an infection.

Wash yourself thoroughly and regularly. Wash your hands before meals, after using the toilet, after using public facilities. Avoid places where infection risk is increased, such as swimming pools, crowded shops and buses.

Avoid contact with people who have infections (including chickenpox).

Don’t eat anything that is past its sell-by-date and use refrigerated food within 24 hours from opening.

Avoid foods that contain lots of live bacteria. These include:
• unpasteurised cheeses
• takeaways
• raw or undercooked eggs
• undercooked meats and fish
• pâté.

Ask your nurse for information on ‘clean diets’.

Take care when handling pets – avoid bites or scratches and wash your hands after any contact with an animal. If possible, get someone else to deal with litter trays and faeces.
Wear gloves for gardening.

**Low red cell count (anaemia)**
Tell your doctor if you feel short of breath, abnormally tired, dizzy or have abnormal aches and pains.

Ask about treatment for **anaemia**.

**Low platelet count (thrombocytopenia)**
Tell your doctor about any bruising or bleeding. Contact your doctors immediately if you feel unwell, faint or clammy.

Avoid contact sports or very vigorous exercise.

Avoid injury when doing day-to-day things like cooking and gardening.

**Change in taste and loss of appetite**
Avoid big meals – eat little and often instead. Eat whenever you are hungry, whether it is your usual mealtime or not.

Avoid things you now don’t like. Try foods with a stronger flavour – marinated foods, savoury rather than sweet. Eat food warm rather than hot.

Have a ready supply of ingredients for meals that are quick and easy to prepare.

Supplement your diet with nutritious drinks, but not at mealtimes. Take drinks through a straw.
When you can, eat with others in a pleasant environment.

Rinse your mouth before meals and keep it clean after eating.

Take gentle exercise to stimulate your appetite.

**Constipation**
Ask your doctor if your treatment can cause constipation, and ask for advice about using laxatives to prevent it.

Drink plenty of fluids.

Have a hot drink in the morning.

Eat a high-fibre diet.

Take gentle exercise.

**Diarrhoea**
Tell your hospital team if you are having several episodes of diarrhoea a day, if it continues for more than 24 hours, or if you have any abdominal pain.

Make sure you have plenty to drink each day.

**Fatigue**
Take regular light exercise, such as walking.

Take regular short rests throughout the day.

Ask your doctor if you are anaemic and about treatment for **anaemia**.
Ask if any of your medicines cause fatigue and if these can be changed or stopped.

Plan the important things for when you have more energy and don’t get caught up in what is less important. Accept help with day-to-day tasks.

Get a good night’s sleep as often as you can.

Eat well. If you are struggling, ask your doctor about meal-in-a-drink supplements.

Make time to see friends and take part in normal social activities.

**Feeling sick**
Take anti-sickness drugs regularly as prescribed – don’t wait until you feel sick.

Tell your medical team if the drugs don’t work.

Get travel sickness wristbands from the pharmacy. These help to stop you feeling sick by using acupressure points.

Explore relaxation techniques.

Avoid cooking food that has a strong smell and ask someone else to prepare meals, if you can.

Eat small meals. Have them cold or at room temperature.

Some people find that sipping a fizzy drink can help to relieve sickness. Try ginger ale as ginger is an old remedy
for nausea.

Keep surroundings as peaceful and as clean as possible, and get some fresh air regularly.

**Hair loss**
Have your hair cut short before treatment starts.

Talk to your medical team about getting a wig as soon as you know you are going to lose your hair. Try hats or scarves if you prefer.

Don’t use heated rollers, hair dryers or chemical treatments such as perms and hair dyes. Avoid things that pull at your hair such as rollers and tight elastics.

Use wide-toothed combs and soft-bristled hairbrushes.

Protect the skin of your scalp from becoming dry. Avoid exposure to heat and cold.

Wearing a hairnet or towelling turban to bed will help to collect hair lost overnight.

Use make up, jewellery and accessories to give you more confidence.

**Nerve damage**
Tell your doctors if you have ‘pins and needles’ or loss of feeling in your fingers or toes, loss of balance, abdominal pain or constipation.

Take care to avoid injury to fingers and toes – they are
less sensitive than they used to be. Avoid extreme temperatures, wear gloves for gardening, and take care when cooking.

Keep your feet and hands warm. Cold can make symptoms worse.

Try gentle massage and exercise of fingers and toes by flexing and stretching for a few minutes, 4 times a day.

Wear comfortable shoes – avoid high heels or tight shoes.

Inspect your feet regularly to check for damaged skin in parts that are numb, particularly on the soles of your feet and around toenails.

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**Sore mouth, sore throat**
See your dentist before starting treatment and tell a member of your hospital team if you need dental work during your treatment.

Avoid smoking and drinking alcohol as these can make soreness worse.

Practise good mouth hygiene – the hospital may give you special mouthwashes to use at home. Avoid mouthwashes containing salt or alcohol.

Ask your hospital team for advice about taking painkillers.

Use a soft-bristled toothbrush.

Rinse your mouth after meals.
Keep your lips moist with lip creams or Vaseline™.

Avoid hot, spicy foods or foods that are coarse in texture. Cool foods that are easy to swallow, such as ice cream and yoghurt, can alleviate your discomfort.

Sip drinks through a straw.

**Sore skin**
Ask for painkillers or other medication to help.

Ask your team how best to look after your skin.

Do not use creams unless recommended by your specialist. Don’t use soaps, talcum powder or deodorants on sore areas, or areas treated with radiotherapy.

Avoid rubbing the skin. If bathing, use lukewarm water and pat yourself dry with a towel.

Use electric razors rather than wet shaving, or avoid shaving altogether.

Keep out of the sun and wind.

**Chemo brain**
Don’t attempt several demanding activities at once, eg talking on the phone while carrying out chores.

Use a calendar, diary or lists to remind you what you need to do, when and where you need to do it.

Rest when you are tired – without feeling guilty about it!
If an activity becomes overwhelming, try taking a step back and break the activity down into smaller steps that you can take one at a time.

Prioritise activities and tasks every day or every week and do the most important or urgent things first.

Ask for help with any daily activities that can be delegated.

Keep your mind active by playing games, reading or solving problems.

Have a healthy diet and take up some regular light exercise.
Both my wife Maria and I developed a healthy lifestyle after my treatment finished. We looked more closely at our diet and introduced more exercise. For me, I have a more positive mindset and feel much better physically.

John, diagnosed with Hodgkin lymphoma in 2008
Looking after yourself

Your feelings 114
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Your feelings

No one can tell exactly how you will feel when you are diagnosed with Hodgkin lymphoma, when you have treatment or afterwards. You will probably have different feelings at different times. This is natural. There is no right or wrong way to handle being diagnosed with cancer.

You might be feeling:
• shocked – you may feel numb and find it hard to accept things at first
• sad – your life and plans, at least for a while, are going to have to change
• scared – often this is fear of the unknown, so finding out more about what to expect can help
• angry – you may feel you’ve lost all control of your life and resent the fact that this has happened to you.

These feelings are natural. It is important to accept them and deal with them. It can help to talk about your feelings, especially during times when you are finding it harder to cope.

Talking to people closest to you can sometimes be difficult – particularly if they are dealing with their own feelings about your illness. Your nurse specialist is a good person to talk to if you’re looking for help through it – they know the kind of feelings people often have and how to approach them.
My Mum coped by talking about my lymphoma to everyone. My Dad and I coped by shutting down. 
Natalia

Depression
You may feel that there are times when you don’t want to talk to anyone and just want to be alone. This is normal, but if you feel like this all the time for more than 2 weeks, it could be a sign of depression.

People who are affected by depression may feel hopeless, guilty or worthless. They may lose interest in hobbies or normal activities. They can also have trouble sleeping; this can include difficulties falling asleep, waking up early or sleeping all the time.

If you, or those around you, think you might be affected by depression, talk to someone about it. Depression will get worse if you don’t do anything about it, but it can be successfully treated.

For an information pack about depression, contact the Depression Alliance on 0845 123 23 20 or visit their website at www.depressionalliance.org
After treatment
Many people have mixed feelings when they finish treatment. This can come as a surprise, if you’re expecting to feel happy and relieved. Occasionally, people can feel more anxious and down once their treatment has finished, even if they are in remission. If this happens to you, it may be because you:
• start to think deeply about what has happened only once your treatment is finished
• have had to make changes to your life because of the lymphoma or its treatment
• miss the reassurance of frequent contact with your hospital team
• are worried about the future and find it difficult to plan ahead.

“Instead of being delighted to finish treatment, it was at this stage that I began to feel angry, asking ‘Why me?’ I also felt like I was being left behind.”
Adam

It is important to realise that these feelings are all natural, even if others expect you to feel happy. Talk to people, including your GP and medical team, about how you are feeling.

“Our helpline team are here to listen. They may also be able to put you in touch with one of our buddies, who have all been affected by lymphoma, and whose experience you might relate to. Please call us on 0808 808 5555. Our website has forums for people to post questions and discuss topics.”
Now that I feel I am through it, I get a lot more emotional. Before, I don’t recall crying, and was just focused and determined. Perhaps that was my coping mechanism. But now I get tearful about lots of things. Carol

Helping yourself

There are many things you can do to help yourself if you have Hodgkin lymphoma. Here are a few suggestions.

Looking after your general health and fitness

Many people find that having a serious illness makes them reassess their lifestyle. Changes that you make after your diagnosis may help you to live a longer and healthier life after treatment.

It is important that you:
• drink plenty of liquids, especially if you are having chemotherapy
• eat a healthy diet; if you are having problems eating or are losing weight because of your treatment, ask for advice at the hospital
• keep your body at a healthy weight
• stop smoking; lung infections are more common with chemotherapy and with smoking; your risk of developing long-term treatment side effects is also higher if you smoke
• exercise regularly; exercise can help to reduce fatigue and make you feel better in general.
You may want to look at other aspects of your life, too, such as your responsibilities, your job or finances and how you spend your free time. Many people find having lymphoma makes them value the simple things in life, such as spending time with family and friends and doing the activities they enjoy.

We have more practical advice in our booklet Living with lymphoma. For a copy, please call 0808 808 5555 or visit www.lymphoma-action.org.uk/about-lymphoma/our-printed-information

Finding out about your lymphoma
Knowing more about your illness and your treatments can help by:
• easing some of the fears and anxieties you may have
• learning how to avoid or limit problems during and after treatment
• knowing how to deal with any side effects
• knowing when to call the hospital if a problem occurs
• helping you feel more in control of what is happening to you.

When someone close to you has lymphoma

When someone close to you has lymphoma, it can be a difficult time for you, too. You may feel helpless watching the person you love go through all the tests and treatments. You may feel you don’t know what to do or how to help.
There are many things you can do – you can find some suggestions below. Don’t forget to take care of yourself, too. If you become run down or ill, you will not be able to support your loved one. Look after your own health, particularly if you have any illnesses, eat well and get plenty of rest.

You probably have many of the same feelings as your loved one. You need to deal with them, too. Talk to someone – friends, family, or a specialist – if you are finding it difficult to cope.

People sometimes worry that they don’t know what to say to the person affected by an illness or that they will say the wrong thing. In fact, you don’t need to say anything. Let the person with lymphoma know that you love them and then care for them in whatever way you can. Remember that a smile or a hug can say much more than any words.

Practical things that may help your friend or loved one include:
• providing transport to hospital
• going to hospital appointments with them
• helping with shopping or preparing meals
• taking care of other family members
• encouraging them to spend time with other people or doing things they enjoy
• organising fun things to do when they feel up for it.
Summary

There is no right or wrong way to feel about having Hodgkin lymphoma. You will probably feel a mixture of shock, sadness, fear and anger at different times.

If you, or the people around you, think you may be affected by depression, talk to someone about this. Depression is an illness that can be treated.

Finding out more about your illness and treatments can help you know what to expect and how to deal with problems that occur. It can also help you feel more in control of your situation.

Many people find having a serious illness makes them reassess their lifestyle. Some changes could help you to live a longer and healthier life after your treatment.

If someone close to you has lymphoma, there are lots of practical things you can do to help, as well as ways to offer support. Make sure to take care of yourself, too, and talk to someone if you are finding it difficult to cope.
**Glossary**

**Allogeneic transplant**
transplant using someone else’s tissue (eg stem cells)

**Anaemia**
shortage of red blood cells in the blood

**Anaesthetic**
a drug given to make a part of the body numb (a local anaesthetic) or the whole body numb (a general anaesthetic)

**Antibody**
an immune system protein that kills disease-causing organisms such as bacteria

**Antigen**
the part of a ‘foreign’ substance that has entered the body that is recognised by the immune system, which then stimulates a defensive response in the form of an antibody; the foreign substance is usually a protein

**Autologous transplant**
transplant using a person’s own tissue (eg stem cells)

**Bacteria**
small organisms, some of which can cause disease

**Biopsy**
a test that takes some cells to be looked at under a microscope

**Blood count**
a blood test that counts the different
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>types of cells in your blood</td>
<td>including red blood cells, the different types of white blood cells and platelets</td>
</tr>
<tr>
<td>Bone marrow</td>
<td>spongy material at the centre of the larger bones that makes the body’s blood cells</td>
</tr>
<tr>
<td>Bulky disease</td>
<td>very enlarged lymph nodes, larger than 10cm across</td>
</tr>
<tr>
<td>Cannula</td>
<td>small tube put into one of your veins and used for blood tests and to give you treatment</td>
</tr>
<tr>
<td>Complete remission</td>
<td>no sign of lymphoma on scans after treatment</td>
</tr>
<tr>
<td>CT scan</td>
<td>computed tomography, a scan that takes X-ray pictures of the inside of your body in ‘slices’</td>
</tr>
<tr>
<td>Cycle</td>
<td>a block of chemotherapy that is followed by a rest period to allow the healthy cells to recover</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>finding out about and naming a condition or disease</td>
</tr>
<tr>
<td>Diaphragm</td>
<td>a layer of muscle that lies below the lungs and separates your chest from your abdomen</td>
</tr>
</tbody>
</table>
**Echocardiogram** (often just called an ‘echo’) an ultrasound test to check how well your heart is working

**Epstein-Barr virus** a commonly occurring herpes virus that causes glandular fever; has been discovered to be associated with some lymphomas

**Haematologist** a doctor specialising in diseases of the blood and blood cells

**HIV** human immunodeficiency virus, a virus that causes AIDS and affects how well your immune system works

**Immune system** body tissues that fight and prevent infections

**Immunotherapy** a treatment that stimulates the body’s own immune system to fight a cancer

**Infusion** treatment given intravenously through a pump or drip

**Intravenous** into a vein

**Irradiated blood** blood (or platelets) that has been treated with X-rays before transfusion to destroy any white cells; done to prevent transfusion-associated graft-versus-host disease

**Late effects** side effects that can develop months
or years after treatment has finished

**Lymph** the clear fluid that carries white blood cells (lymphocytes) through the lymphatic system

**Lymph node** gland that acts like a filter in the lymphatic system; involved in fighting infection

**Lymphocyte** a type of white blood cell that normally helps to fight infections caused by viruses; the cell that becomes cancerous in lymphoma

**Lymph vessels** the tubes that carry lymph and connect with the lymph nodes

**Monoclonal antibody** a manufactured protein that may be used as targeted treatment to kill cancer cells

**MRI** magnetic resonance imaging, a scan that uses magnetic waves to give a picture of the body

**Neutropenia** a shortage of white blood cells called neutrophils in the blood, which makes you more prone to infection

**Neutrophil** a type of white blood cell that is important in fighting infections caused by bacteria and fungi
Oncologist  a doctor specialising in treatment of cancer

Partial remission  lymphoma shrunk by at least half

Pathologist  a doctor who diagnoses disease by looking at tissues removed from the body

PET/CT scan  a scan in which PET and CT scans are combined

PET scan  positron-emission tomography, a scan that uses a radioactive form of sugar to look at how active cells are; often combined with a CT scan (a PET/CT scan), it shows which bits of the body contain lymphoma

Platelets  the tiny fragments of cells in your blood that help form blood clots and stop any bleeding

Radiographer  a person who takes X-rays or gives radiotherapy

Radiologist  a doctor who can analyse X-rays and scans and may take biopsies to diagnose lymphoma

Radiotherapist  a doctor who specialises in radiotherapy (also called a clinical oncologist)
<table>
<thead>
<tr>
<th>Term</th>
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<tbody>
<tr>
<td>Red blood cell</td>
<td>a cell that contains the pigment haemoglobin, which allows it to carry oxygen around the body</td>
</tr>
<tr>
<td>Reed-Sternberg cell</td>
<td>an abnormal cell with a characteristic appearance under the microscope of ‘owl eyes’; if present in a biopsy, it indicates a Hodgkin lymphoma</td>
</tr>
<tr>
<td>Refractory</td>
<td>lymphoma that didn’t respond to treatment</td>
</tr>
<tr>
<td>Relapse</td>
<td>lymphoma that comes back after treatment</td>
</tr>
<tr>
<td>Spleen</td>
<td>an organ found behind the stomach that is part of the immune system</td>
</tr>
<tr>
<td>Subcutaneous</td>
<td>underneath the skin</td>
</tr>
<tr>
<td>Symptom</td>
<td>a change in the body or how it works that is a sign that something is wrong</td>
</tr>
<tr>
<td>Thrombocytopenia</td>
<td>a shortage of platelets in the blood; makes you more prone to bleeding or bruising</td>
</tr>
<tr>
<td>Virus</td>
<td>a tiny organism that often causes disease</td>
</tr>
<tr>
<td>White blood cell</td>
<td>a cell found in the blood and in many other tissues that helps our bodies to fight infections; several different types exist, including lymphocytes and neutrophils</td>
</tr>
</tbody>
</table>
Information and support

If you’d like to talk to someone about anything to do with lymphoma (including how you feel) get in touch.

Call our Freephone helpline Monday to Friday on 0808 808 5555. You can also use Live Chat on our website

Come to one of our support groups. Find one near you at www.lymphoma-action.org.uk/support-groups

Join our online forum to chat with others who are affected by lymphoma

Get in touch with a buddy, someone affected by lymphoma

Like us on Facebook

Follow us on Twitter

Check out our YouTube channel

Follow us on Instagram
On our website, you’ll find a list of other organisations you may find helpful. There are many other organisations offering specialised help.

**How you can help us**

We continually strive to improve our resources for people affected by lymphoma and are interested in any feedback you might have about this booklet. Please visit our website at www.lymphoma-action.org.uk/feedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our helpline on 0808 808 5555.

**We produce other publications that give information about lymphoma and what to expect from treatment. Visit our website at www.lymphoma-action.org.uk or call our Information and Support Team on 0808 808 5555 for more information.**

**References**

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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Lymphoma Action is the UK’s only charity dedicated to lymphoma, and have been providing in-depth, expert information and support for over 30 years.

To make a gift towards our work, please visit www.lymphoma-action.org.uk/donate

Thank you
This booklet will help you understand more about Hodgkin lymphoma. It describes how Hodgkin lymphoma typically affects people, how it is treated and what to expect during and after treatment.

Lymphoma Action has been providing information and support to people affected by lymphoma for over 30 years. We’re here for you.

Freephone helpline 0808 808 5555
information@lymphoma-action.org.uk
www.lymphoma-action.org.uk

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