



# Hodgkin lymphoma

JASCAP

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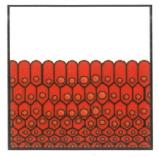
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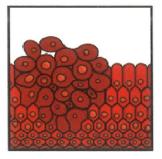
# Illustrations

# Illustration 1

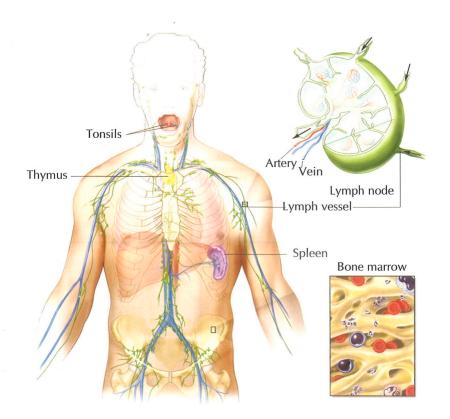
Normal cells



Cells forming a tumour



#### Illustration 2



Anatomy of the lymph system, showing the lymph vessels and lymph organs including lymph nodes, tonsils, thymus, spleen, and bone marrow. Lymph (clear fluid) and lymphocytes travel through the lymph vessels and into the lymph nodes where the lymphocytes destroy harmful substances. The lymph enters the blood through a large vein near the heart.

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\*\* JASCAP has detailed booklets on these subjects

Glossary

# **Understanding lymphoma**

#### What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

## Please see the Illustration 1 on Illustration page.

A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

# 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.

Please see the Illustration 2 on Illustration page.

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?

Lymphoma is the most common blood cancer. The two main forms of lymphoma are Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). Lymphoma occurs when cells of the immune system called lymphocytes, a type of white blood cell, grow and multiply uncontrollably. Cancerous lymphocytes can travel to many parts of the body, including the lymph nodes, spleen, bone marrow, blood, or other organs, and form a mass called a tumor. The body has two main types of lymphocytes that can develop into lymphomas: B-lymphocytes (B-cells) and T-lymphocytes (T-cells). HL, also known as Hodgkin disease

HL is characterized by the presence of very large cells called Reed-Sternberg (RS) cells, although other abnormal cell types may be present. HL usually starts in the lymph nodes; however, it often spreads from one lymph node to another and can also spread to other organs.

Hodgkins lymphoma accounts for a little less than 1% of all cancers globally. It occurs between 15 to 35 years or after 55 years of age. It occurs, more often, in two separate age groups, the first being the 15-35 years age group and the other group being those over the age of 55 years old.

In India, 21% of all Hodgkins disease was seen in children at the Tata Memorial Hospital (Bombay, India) with a marked male: female ratio of 5.5:1. Generally speaking, Hodgkins is more common in men than women the world over except the nodular sclerosis type, which is more common in women. The annual incidence of Hodgkins is 1/25,000, making it one of the rarer cancers. One in eight Lymphoma is Hodgkins type.

# 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 dving 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.

# 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.

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.

# 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).

# Diagnosis and staging

# 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.

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, IIV.

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 10 cm 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.

# More about Hodgkin lymphoma

# 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 lymphocytepredominant 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.

# Who gets Hodgkin lymphoma?

It can affect people of all ages, including children.

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 do other lymphomas 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.

# 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.

# Treatment overview for Hodgkin lymphoma

## 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.

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.

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
- advanced-stage classical Hodgkin lymphoma
- nodular lymphocyte-predominant Hodgkin lymphoma
- Hodgkin lymphoma over the age of 60.

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 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 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.

## 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 (e.g. 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 ChIVPP and VEPEMB.

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.

# 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.

## 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.

# 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.

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).

## 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.

# What happens if Hodgkin lymphoma comes back or doesn't respond to treatment?

# 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.

# 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. 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.

# More about treatments for Hodgkin lymphoma

## 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.

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.
- ChIVPP 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.

# 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.

### 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*-10days 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 lifethreatening.

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.

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 antiemetic (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.

# 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.

# 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.

# 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.

# 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 flulike 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 clinic.

### 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.

# Coping with side effects of treatment

# 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.

# 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.

# 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, e.g. 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.

# Looking after yourself

Most people feel overwhelmed when they are told they have cancer, and have many different emotions. These are part of the process you may go through when dealing with your illness. Partners, family members and friends often have similar feelings and may also need support and guidance to help them cope.

Reactions differ from one person to another - there's no right or wrong way to feel. We describe some of the common emotional effects of cancer here. However, reactions vary and people have different emotions at different times.

JASCAP also has the following booklets on topics relating to physical aspects of cancer and their management.

Dietary advice for cancer patients

Eating Hints Before During and After Cancer Treatment

Sexuality and cancer

Caring for someone with advanced cancer

Coping with advanced cancer

Controlling cancer pain

Controlling the symptoms of cancer

Other symptoms and side effects of cancer and its treatments

Life after cancer treatment

Side effects of cancer treatment

Coping with fatigue
Physical activity and cancer treatment

JASCAP has the following booklets on topics relating to emotional aspects of cancer and their management.

Talking about you cancer
Talking to children about cancer
Lost for Words - How to talk to someone-with cancer
Making or changing your Will

When Cancer Returns

Emotional effects of cancer

Please also note that all these booklets are available on our website www.jascap.org for free download. Many of them are also available in some Indian languages



We hope you found the information in this booklet helpful to you. We will appreciate if you could take some time to give feedback about the contents of the book.

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Glossary

Allogeneic transplant transplant using someone else's tissue (e.g.

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 recognized 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 (e.g.

stem cells)

**Bacteria** small oganisms, 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 types of

cells in your blood, including red blood cells, the different types of white blood cells and

platelets

**Bone marrow** spongy material at the centre of the larger

bones that makes the body's blood cells

**Bulky disease** very enlarged lymph nodes, larger than 10cm

across

Cannula small tube put into one of your veins and

used for blood tests and to give you treatment

Complete no sign of lymphoma on scans after remission treatment

CT scan computed tomography, a scan that takes X-ray pictures of the inside of your body in 'slices'

Cycle a block of chemotherapy that is followed by a rest period to allow the healthy cells to recover

**Diagnosis** finding out about and naming a condition or disease

**Diaphragm** a layer of muscle that lies below the lungs and separates your chest from your abdomen

Echocardiogram (often just called an 'echo') an ultrasound test to check how well your heart is working

**Epstein-Barrvirus** 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

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

a treatment that stimulates the body's own

body tissues that fight and prevent infections

immune system to fight a cancer

treatment given intravenously through a pump or drip

Intravenous into a vein

HIV

Immune system
Immunotherapy

Infusion

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 a manufactured protein that may be used as targeted

Antibody 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

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

lymphoma shrunk by at least half

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

a scan in which PET and CT scans are combined

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

Neutrophil

Partial remission

**Pathologist** 

PET/CT scan

PET scan

**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 l'ymphoma **Radiotherapist** a doctor who specialises in radiotherapy (also called a clinical oncologist) Red blood cell a cell that contains the pigment haemoglobin, which allows it to carry oxygen around the body an abnormal cell with a characteristic Reed-Sternberg cell appearance under the microscope of 'owl eyes'; if present in a biopsy, it indicates a Hodgkin lymphoma Refractory lymphoma that didn't respond to treatment Relapse lymphoma that comes back after treatment Spleen an organ found behind the stomach that is part of the immune system Subcutaneous underneath the skin a change in the body or how it works that is Symptom a sign that something is wrong Thromboa shortage of platelets in the blood; makes you more cytopenia prone to bleeding or bruising Virus a tiny organism that often causes disease White blood cell 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

### **Notes**

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