

# HODGKIN LYMPHOMA (HL)

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A guide for patients,  
families & whānau



Vision to Cure. Mission to Care.

# INTRODUCTION

**This booklet has been written to help you and your family/whānau understand more about Hodgkin lymphoma (HL).**

If you or someone you know has been diagnosed with lymphoma, you may be feeling anxious or a little overwhelmed. This is normal. Perhaps you have already started treatment, or you are discussing treatment options with your doctor and your family/whānau. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your health care team.

It is not the intention of this booklet to recommend any particular treatment to you. You need to discuss your circumstances with your doctor or treatment team.

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## Interpreter service

New Zealand's Code of Health and Disability states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family/whānau member or friend may assist. The hospital can organise a trained interpreter if needed, either in person or through a telephone interpreter service. NZ Sign Language interpreters are also available.

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## Informed consent

If you are supporting a family/whānau member who needs language support at appointments, your doctor may ask an interpreter to join meetings where informed consent is required. Interpreters are specially trained to explain medical information clearly.

# HOW TO USE THIS BOOKLET



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## Detailed information



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## Key points



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## Important information



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## More information available online

There are many resources available at [leukaemia.org.nz](http://leukaemia.org.nz) such as fact sheets, booklets and more. Most resources available on the Leukaemia & Blood Cancer New Zealand (LBC) website can be obtained in a printed version. Ask your LBC Support Services Coordinator if you would like information posted to you.

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## Space for your questions

There is space at the end of this booklet to write questions that you can ask next time you see a doctor, nurse or LBC Support Services Coordinator. They will be happy to answer your questions or explain something in more detail.

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## Glossary

On page 50 there is a glossary (word list).

In this booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases. A Dictionary of Terms booklet is also available from LBC.

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# WHAT IS LYMPHOMA?

**Lymphoma is the general name for cancers that develop in the lymphatic system.**

Lymphoma is a cancer of immune cells called lymphocytes (lim-fo-sites) (B-cells, T-cells and natural killer [NK] cells) which grow out of control and form tumours. These tumours cause swelling in the lymph nodes and other parts of the body. Over time, these cancerous lymphocytes (lymphoma cells) crowd out normal cells. Eventually the immune system becomes weakened and can no longer function properly.

## Types of lymphoma

The World Health Organization currently recognises over 70 different subtypes of lymphoma. These subtypes are usually separated into two groups – Hodgkin lymphoma and non-Hodgkin lymphoma. Each year in New Zealand around 1100 people are diagnosed with lymphoma. More than 85% of these people have non-Hodgkin lymphoma. Hodgkin lymphoma is relatively rare, with around 120 people being diagnosed with it in New Zealand each year.



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## Key points

- Lymphoma is a type of blood cancer of white blood cells called lymphocytes (B-cells, T-cells and NK cells).
- There are many different subtypes of lymphoma, which are commonly grouped together as Hodgkin or non-Hodgkin lymphomas.

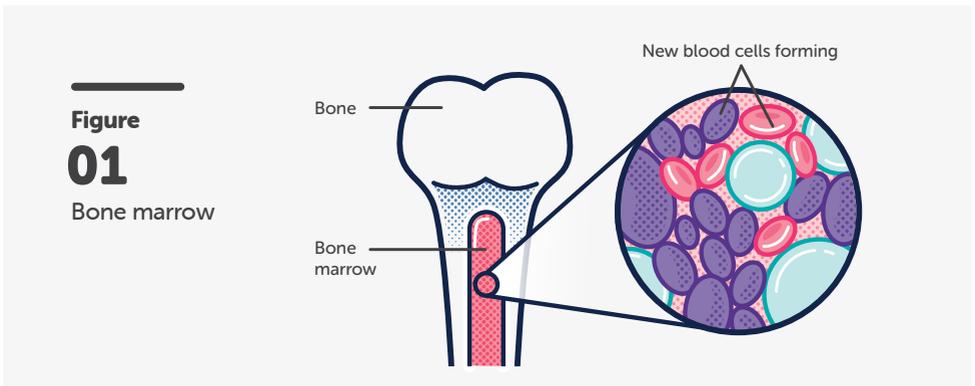
# WHAT IS HODGKIN LYMPHOMA?

Hodgkin lymphoma (HL) is the name given to lymphomas that have a special kind of cancer cell, called a Reed-Sternberg cell.

To fully understand HL it is helpful to learn about the cells in your body, your bone marrow and your lymphatic system.

## BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 01).



**Figure 01**  
Bone marrow

In your bone marrow there are cells called blood stem cells. Blood stem cells create the new blood cells in your body.

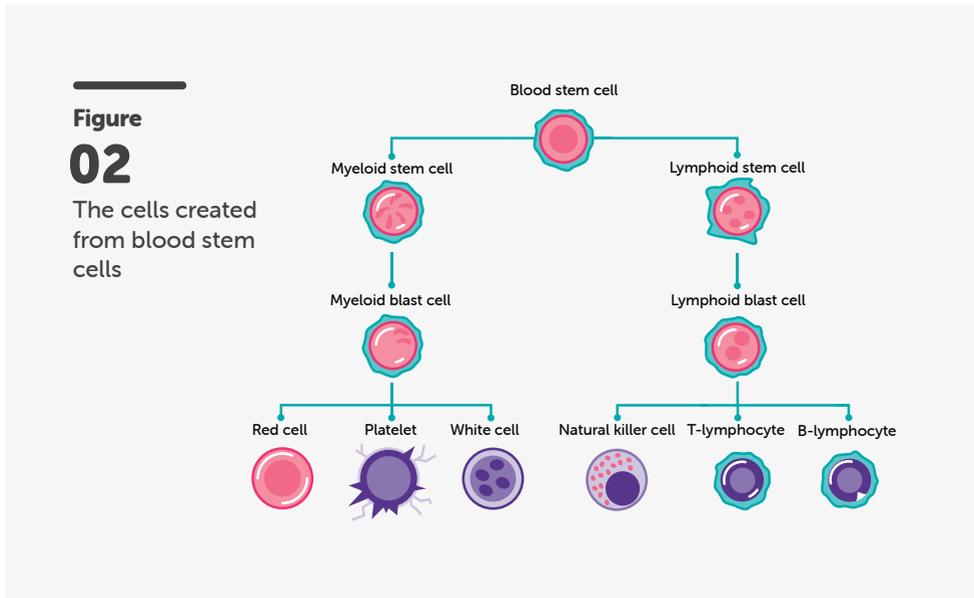
The two main functions of blood stem cells are to:

- Make exact copies of themselves.
- Divide and make two different cell groups: myeloid (my-ill-oid) stem cells and lymphoid (lim-foid) stem cells.

Myeloid and lymphoid stem cells create the blood cells for your body including white blood cells, red blood cells and platelets.

In Figure 02 (on the next page) you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create.

Lymphoma starts in the lymphoid cell line, originating in developing B-cells, T-cells and NK cells.



## Detailed information

- The medical term for blood stem cells is haematopoietic (he-ma-toe-po-ee-tick) stem cells. When a blood stem cell matures into a blood cell, this is called haematopoiesis (he-ma-toe-po-ee-sis). In adults, haematopoiesis occurs in the bone marrow of large bones such as the breastbone (sternum), thigh bone (femur) and the hip bone (iliac crest).



## Key points

- Blood stem cells in your bone marrow make exact copies of themselves, as well as divide to create myeloid and lymphoid stem cells. These cells create all the red blood cells, white blood cells and platelets for your body.
- Lymphomas form from developing lymphocytes.

# YOUR BLOOD

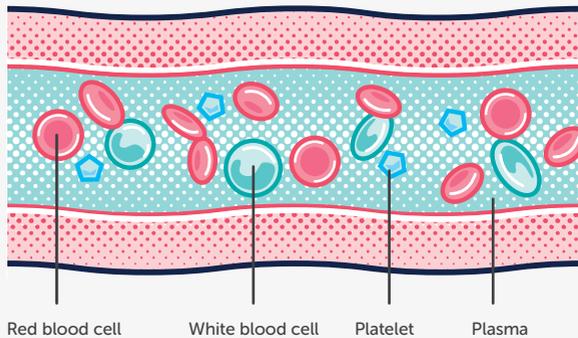
After being made in your bone marrow, the red blood cells, platelets and white blood cells are released into your bloodstream so they can function around the body.

Blood is made up of blood cells and plasma. A blood test measures the amount of each type of blood cell in your blood. Figure 03 shows the three main types of blood cells in the plasma. The role of plasma and each type of blood cell is discussed in the next section.

**Figure**

**03**

Blood vessel and cells in your blood



## Plasma

Plasma is a light-yellow coloured liquid in which blood cells travel around your body.

## Red blood cells

Red blood cells transport oxygen from the lungs to all the cells in the body. A protein called haemoglobin (heem-a-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin in your body is called anaemia (a-nee-me-a).

## White blood cells

White blood cells fight infection. For example, if bacteria enter your bloodstream through a cut, the white blood cells attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

Neutrophils (new-tra-fils) are the most common type of white blood cell. A low number of neutrophils in your body is called neutropenia (new-tra-pee-nee-a).

## Platelets

Platelets help your blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding.

A low level of platelets in your body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a) and can result in easy bruising and bleeding.



### Detailed information

There are many different types of white blood cells, all with specific jobs to do.

Below is a list with the names of different types of white blood cells and what they do.

- **Neutrophils** (new-tra-fils)  
Kill bacteria and fungi.
- **Eosinophils** (ee-o-sin-o-fils)  
Kill parasites.
- **Basophils** (bay-so-fils)  
Work with neutrophils to fight infection.
- **T-lymphocytes** (T-lim-fo-sites) (T-cells)  
Kill viruses, parasites and cancer cells.
- **B-lymphocytes** (B-lim-fo-sites) (B-cells)  
Make antibodies which can target harmful microorganisms (germs).
- **Natural killer cells** (NK cells)  
Kill viruses and cancer cells.
- **Monocytes** (mono-sites)  
Work with neutrophils and lymphocytes to fight infection. They also help act as scavengers (cleaners) to remove dead tissue.
- **Macrophages** (mac-row-far-jes)  
Monocytes are known as macrophages when they move to body tissue to help fight infection there.



### Key points

- There are three main types of blood cells (red blood cells, white blood cells and platelets), each with an important role.
- Blood cells travel around your bloodstream in a light-yellow coloured liquid called plasma.

# THE LYMPHATIC SYSTEM

The lymphatic system is a large network of tubes (like blood vessels) that branch out into all the tissues of the body.

These tubes contain lymph, a colourless watery fluid that carries lymphocytes which are white blood cells that fight infection. There are three types of lymphocytes – B-cells, T-cells and NK cells.

The lymphatic system forms part of the immune system, which protects our bodies against disease and infection. Clusters of small bean-shaped organs called lymph nodes (or lymph glands) are found throughout the lymphatic system. The lymph nodes (which are filled with lymphocytes) clean the lymph fluid as it passes through them. Bacteria, viruses and other harmful substances are removed and destroyed. When you have an infection, such as a sore throat, you may notice that the lymph nodes under your jawbone become swollen and tender. This is because the lymphocytes become activated and multiply in response to the virus or bacteria causing the infection.



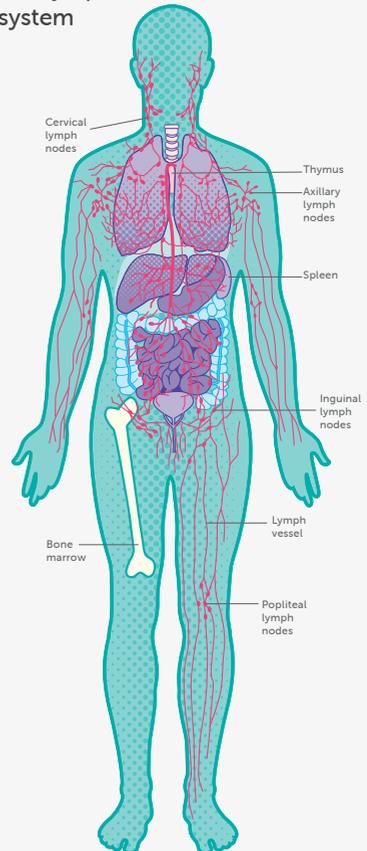
## Key points

- The lymphatic system is a network of lymph vessels and lymph nodes.
- B-cells, T-cells and NK cells are found in the lymph fluid and help to fight infection.

Figure

04

The lymphatic system



# HODGKIN LYMPHOMA

Hodgkin lymphoma (HL) is a relatively rare condition, with approximately 120 New Zealanders being diagnosed each year. HL is seen in all age groups but is more common in people aged 15–30 years and 55–70 years. HL is more common in males than in females.

## What causes lymphoma?

Like other types of cancer, HL is thought to develop after DNA is damaged causing genetic mutations (errors). In day-to-day life, we are all exposed to low levels of radiation and chemicals that can damage the DNA in our bodies. Usually, this DNA damage is either fixed by the cell or the cell dies, and no harm is done. However, in some people a mutation occurs that helps a cell to divide more (proliferate), and this cell can eventually become cancerous and cause lymphoma.

HL is not contagious; you cannot 'catch' lymphoma by being in contact with someone who has it. In most cases, people who are diagnosed with HL have no family history of the disease.

There are certain factors which may put some people at a higher risk of developing HL. These are described below:

- **Immunosuppression** – A small percentage of lymphomas occur in people whose immune system has been weakened (immunosuppressed) either by a viral infection such as human immunodeficiency virus (HIV) or because of drugs which affect the function of the immune system (immunosuppressants). These drugs are commonly used when someone has a heart, lung or other organ transplant.
- **Infection** – In some cases, particularly in people who are immunosuppressed, infections with viruses such as Epstein-Barr virus (EBV) or human T-lymphotropic virus (HTLV-1) or bacteria such as *H. pylori*, may damage developing lymphocytes and increase the risk of lymphoma.
- **Chemicals** – There is some evidence that people exposed to high concentrations of agricultural chemicals such as pesticides and fertilisers may have a higher risk of developing lymphoma.
- **Radiation** – People who have been treated for cancer using ionising radiation (X-rays and some other radioactive materials) or who have been exposed to significant or long-term radiation may also be at an increased risk of developing lymphoma.



## Key points

- Errors in DNA (genetic material) are thought to contribute to the development of HL.
- Some environmental factors can increase the risk of developing HL.
- You cannot catch HL from someone else, and in most cases there is no family link.

# WHAT ARE THE SIGNS AND SYMPTOMS OF HL?

The symptoms of HL vary from person to person. Some people do not have any symptoms when they are first diagnosed, and it is discovered incidentally when they have a blood test or check-up for a different reason. Some people will have symptoms, which are explained in this section.

In HL the normal blood cells in the bone marrow, blood and lymph glands can be crowded out by large numbers of lymphoma cells. This can result in symptoms such as anaemia, bleeding or bruising and infections.

## Anaemia

Having a low haemoglobin level (because of a low number of red blood cells) can cause anaemia.

The symptoms of anaemia include:

- Lack of energy (lethargy)
- Feeling very tired all the time (fatigue)
- Shortness of breath, especially when exercising
- Dizziness
- Pale skin (pallor).

## Bleeding and bruising

Having a low platelet count (thrombocytopenia) can mean it's harder for your blood to form clots to stop bleeding.

The symptoms of thrombocytopenia include:

- Bruising easily
- Minor cuts or wounds that take a long time to stop bleeding
- Frequent or severe nosebleeds or bleeding gums

- Unusually heavy periods
- Red or purple pinhead-sized spots on your skin called petechiae (pe-tee-kee-i).

## Infections

Having a low number of white blood cells in your blood can put you at risk of getting an infection. Neutrophils are the most common type of white blood cell. A low number of neutrophils in your blood is called neutropenia.

Common signs and symptoms of infection include:

- Fever (high temperature of 38°C or above)
- Shivering or rigors
- Coughing up yellow or green phlegm
- Fatigue or extreme tiredness.

## Swollen lymph glands (lumps)

People with lymphoma commonly have firm, usually painless swelling of a lymph node (swollen glands). The most common sites are the neck, under the arms or in the groin. It is important to remember that most people who go to their doctor with enlarged lymph nodes do not have lymphoma. Swollen glands often result from an infection, e.g. a sore throat – in these cases, the glands in the neck are usually swollen and painful.

Sometimes lymphoma starts in the lymph nodes in deeper parts of the body – like the tummy (causing bloating and fullness after meals) or the chest (causing coughing, discomfort in the chest and difficulty breathing).

## B symptoms

Drenching night sweats, significant weight loss and fevers are sometimes called 'B symptoms'. If you have these symptoms when you are diagnosed, you may see the letter 'B' recorded in the staging of your lymphoma, e.g. stage 3B. See page 18 for more information on staging.

## Other symptoms

Other symptoms of lymphoma can include:

- Generalised itching
- Rash
- Loss of appetite
- Blood clots.



### Important information

- All people with HL should see their general practitioner (GP) or emergency doctor, or contact their health care team if they develop symptoms of an infection. It is important to get checked by a doctor sooner rather than later. Having HL means infections can be more severe and can develop faster.
- If you are currently receiving chemotherapy for HL, or if you are neutropenic, you must seek urgent medical care if you develop a fever or other symptoms of infection. Your health care team will tell you how to seek help and give you a list of contacts, as this varies from hospital to hospital.



### Key points

- Symptoms vary from person to person – some people will not have any symptoms, while others may have several.
- Painless lumps (swollen lymph nodes) may be present.
- HL can cause tiredness or shortness of breath as a result of a low red blood cell count.
- HL can cause increased bruising and bleeding as a result of a low platelet count.
- People with HL are at increased risk of infection.

# WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

You may meet a range of health professionals who are part of your health care team.

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will aim to give you and your family/whānau the best available treatment and support so that you can live as well as possible following a diagnosis of HL.

Some of the health professionals you may meet, in alphabetical order:

- **Cancer coordinator** – A health professional who guides and supports patients and family/whānau, and is the main point of contact through different parts of the health system in their cancer journey.
- **Charge nurse** – A senior nurse in charge of an outpatient department, day unit or hospital ward.
- **Clinical nurse specialist (CNS)** – A nurse with advanced skills in a specific area of clinical care. This person works closely with you and other members of your health care team to coordinate treatment, and help you manage the symptoms of HL and the side effects of treatment.
- **Dietitian** – A dietitian may advise you on what to eat and drink to minimise symptoms or side effects from HL or your treatment. They may also prescribe supplements to make sure you are getting the calories and nutrients you need.
- **General practitioner (GP)** – A family and community doctor. You may be monitored by your GP if you have no symptoms and do not currently need treatment. They will work together with other health professionals to support you at home, in the community and after treatment. They can also refer you to a specialist if needed.
- **Haematologist** – A senior doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist or oncologist (see below) usually oversees any treatment for HL.
- **Occupational therapist** – Helps you manage everyday activities and achieve activities you want or need to do.
- **Oncologist** – A senior doctor who specialises in cancer and cancer treatment. You may be under the care of an oncologist or a haematologist for your treatment.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in a clinic.
- **Pathologist** – A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.
- **Pharmacist** – Prepares and checks your drugs/medications. Pharmacists can advise you on how to take your medicine, possible side effects and interactions with other medications.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility.

- **Psychologist** – Specialises in helping you manage any emotional challenges such as stress, anxiety and depression.
- **Registrar** – A doctor who is in training. You may see a registrar in clinics, day units and wards. Registrars work closely with senior specialists (haematologists or oncologists).
- **Social worker** – Helps you manage the practical and emotional impact of the condition and its treatment, such as advice about managing at home, employment or school.
- **Ward clerk** – Manages the administration on the ward, including scheduling admissions, and is the first point of contact for visitors.
- **Ward nurse** – A nurse who looks after you during a stay in hospital.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.
- **Non-governmental organisations (NGOs)** – Give emotional and practical support for those affected by cancer. Leukaemia & Blood Cancer New Zealand (LBC) is an NGO.
- **LBC Support Services Coordinator** – A professional who provides education as well as practical and emotional support. They can be contacted by calling 0800 15 10 15.

Meeting so many people can sometimes be confusing and overwhelming. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit in to your health care team.

#### Other people you might meet or hear about are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of HL, helping improve quality of life and supporting people at the end of life.

# TESTS AND INVESTIGATIONS

**Your doctor will diagnose HL by talking with you about how you are feeling, looking at your blood and taking a biopsy (sample) of a lump or lymph node.**

HL affects everyone differently, so the types of tests you have may be different to what someone else has. You may need a few different tests before lymphoma is diagnosed, and to identify what subtype and stage your lymphoma is.

## Physical examination and medical history

Your doctor will look and feel for any swelling of the glands in your neck, armpits and groin. They will also check your abdomen (tummy) and chest for any signs of swelling or fluid collection. Your doctor will also ask you about any other symptoms you might have, such as 'B symptoms' (see page 9).

Your doctor will ask you about your past medical history, including any previous

illnesses, health problems or bleeding. They will also need to know about any prescribed or over-the-counter medications you take regularly.

## Lymph node biopsy

A lymph node biopsy is a procedure where all or part of a lymph node is removed and sent to be examined in the laboratory.

It can take a few days for the sample to be tested and for the results to come through. In some cases, the biopsy may not provide enough information to diagnose HL so a repeat biopsy may be needed – either by taking a larger sample or a sample from a different site. It is important that the biopsy is accurate, as this information is used to decide the best type of treatment for your lymphoma.



## Detailed information

There are different types of lymph node biopsies:

- Core biopsy/fine needle aspirate (FNA) – A needle is inserted into a lymph node or lump and a sample is removed. This is usually done while you are awake and the area is numbed with local anaesthetic. Ultrasound or X-ray may be used to find the right position. This is done in the radiology department by an interventional radiologist.
- Surgical or excision biopsy – The entire lymph node is removed under general anaesthetic. You will have a few stitches after this procedure. This is done by a general surgeon.

If the affected lymph node is deep in the body (e.g. in the tummy or pelvic area), a laparoscopy (keyhole surgery) may be needed to get a biopsy sample. This involves a tube with a camera being inserted through a small cut in the skin, so the surgeon can see inside and take a sample. This is done under general anaesthetic, and you will have a few stitches afterwards.

## Blood test

### Full blood count (FBC)

An FBC (or complete blood count [CBC]) measures the number and appearance of red blood cells, white blood cells and platelets, as these can all be abnormal in HL.

Table 01 gives you information about normal blood test results for adults. You may find this useful when you are having regular blood tests and want to compare your results with the normal range. Please note that there may be small variations compared with the data used at your hospital or clinic.

### Blood chemistry test

Blood chemistry tests measure the amounts of different chemicals in your blood. They provide important information on how well your organs and body systems are working, e.g. your liver and kidneys. This provides a baseline for your disease and general health, which can be compared to later results to see how you are progressing.

Table 01: Normal range for adults (local laboratory ranges may differ slightly)

	Adult men	Adult women
Haemoglobin (Hb)	130–175 (g/L)	115–155 (g/L)
Neutrophils	2.0–7.5 ( $\times 10^9/L$ )	2.0–7.5 ( $\times 10^9/L$ )
Platelets	150–400 ( $\times 10^9/L$ )	150–400 ( $\times 10^9/L$ )

### Other blood tests

- You may be tested for common viruses, or viruses that can affect your treatment such as hepatitis B, hepatitis C, EBV and HIV.
- Your antibody levels may also be tested as low levels may mean you are more likely to get infections.
- Lactate dehydrogenase (LDH) may be tested, which can indicate fast lymphoma growth.

### Immunophenotyping

Immunophenotyping (im-u-no-fee-no-tie-ping) is also known as flow cytometry or cell marker studies. It is used to confirm a diagnosis of HL and to separate it from other similar diseases. Flow cytometry uses lasers to detect special markers (called antigens, e.g. CD20) on the surface of abnormal cells in blood or bone marrow samples.

## Cytogenetic and molecular tests

Cytogenetic (sy-toe-gen-et-ic) and molecular tests use blood or bone marrow samples to see if the lymphoma cells have differences (mutations) in their DNA compared to normal cells.

Below are the main types of cytogenetic tests used in HL:

- **Chromosome analysis** – Chromosomes (organised structures of DNA) are examined under a microscope to see if there are any missing, extra or abnormal chromosomes.
- **Fluorescence in-situ hybridisation (FISH)** – A test which ‘paints’ important genes so they can be seen under a microscope.
- **Polymerase chain reaction (PCR)** (sometimes called quantitative reverse transcriptase PCR or qPCR) – A test which

looks for changes in your DNA. It is often done at the same time as cytogenetic/FISH tests and can check for common mutations.

## Scans and imaging

Many people require X-rays or other imaging tests for diagnosis or monitoring of HL.

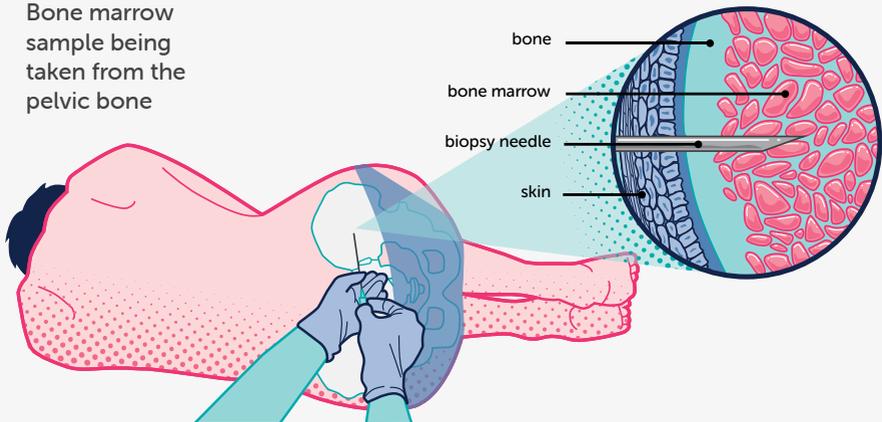
These might include:

- **Chest X-ray** – To detect a chest infection or other abnormalities.
- **Electrocardiogram (ECG) and echocardiogram (ECHO)** – To see how well your heart is working.
- **Computer-assisted tomography (CT or CAT) scan or ultrasound** – May be used if there is concern about lymphoma growing in or damaging a particular area.

**Figure**

**05**

Bone marrow sample being taken from the pelvic bone



- **Magnetic resonance imaging (MRI) scan** – May be used in diagnosis and monitoring of lymphoma to show very clear pictures of specific areas such as the brain and spinal cord.
- **Positron emission tomography (PET) scan** – A type of specialised CT scan that uses radioactive glucose to identify increased levels of tissue activity due to lymphoma.

## Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a laboratory to be looked at under a microscope. Bone marrow samples are usually taken from the back of your pelvic bone (iliac crest) (see Figure 05). You will then have an appointment with your haematologist to talk about the findings of your bone marrow biopsy.



### Detailed information

#### What is it like to have a bone marrow biopsy?

A bone marrow biopsy can be done when you are staying overnight in hospital or as an outpatient (you visit the hospital for this purpose).

Your doctor might give you a drug that makes you feel relaxed and sleepy (a sedative) before the biopsy starts. You might also be given pain relief. Your doctor will give you a local anaesthetic. This is a small injection that is put into your skin where the biopsy is going to be done, to make the area numb.

To do a bone marrow biopsy your doctor puts a long needle through your numbed skin into the bone and then into the bone marrow. Bone marrow has liquid and solid parts. A small sample of your bone marrow liquid is taken out. This is called bone marrow aspirate. A sample of the solid part of the bone marrow is also taken. This is called a bone marrow trephine (tre-fine).

Some people who have had a bone marrow biopsy say that it was painful and other people describe it as uncomfortable. Everybody is different. We recommend that you bring a support person with you when you have a bone marrow biopsy. If you have a sedative, you will still feel a bit drowsy afterwards. Your support person can make sure you get home safely.

After the biopsy, your doctor or nurse will put a plaster or small dressing over the biopsy site. You may need paracetamol to help ease some discomfort in the area afterwards. Your doctor or nurse will talk to you about this.

## Lumbar puncture

A lumbar puncture is a procedure where a small sample of the cerebrospinal fluid that surrounds your brain and spinal cord is collected through a long thin needle in the lower back. The fluid is then examined in the laboratory to check for the presence of lymphoma cells within the central nervous system.

You will be asked to lie on your side in the foetal position to help guide the spine into the optimal position. A local anaesthetic is used just like in a bone marrow biopsy. You may be asked to lie flat for a short time after the procedure to help minimise the potential side effect of a headache.

## Other tests

There may be other tests that provide your health care team with information about your general health. Your health care team will let you know when you need to have these tests and what they are for.

## Preparing for tests

Before you go for a test, ask your health care team member how long the test will take, what the test involves and how you will feel afterwards.

Things that you can do to help prepare for the test are:

- Plan your journey so that you arrive on time and do not have to rush.
- Find out about parking. Your LBC Support Services Coordinator can help.
- Ask a support person to come with you.
- Ask for an interpreter if needed. Your health care team at the hospital can organise this for you in advance.
- Take your favourite music on a device with headphones.
- Take something to read.



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## Key points

The main tests for diagnosing HL are:

- Blood test
- Lymph node biopsy
- Immunophenotyping/flow cytometry
- Imaging such as a CT scan or PET scan
- Bone marrow biopsy.

# TYPES OF HL

**HL is not a single disease. Knowing the exact type of lymphoma you have is important because it helps predict the course of your disease, and how it should be treated.**

There are 2 main types of HL: classical Hodgkin lymphoma, and nodular lymphocyte-predominant Hodgkin lymphoma. Around 95% of HL cases are classical Hodgkin lymphoma. Classical Hodgkin lymphoma can be further divided into 4 subtypes: nodular sclerosing, mixed cellularity, lymphocyte-rich and lymphocyte-depleted.

## Classical Hodgkin lymphoma

**Nodular sclerosing** – This subtype is more commonly seen in young adults. It typically involves the lymph glands of the neck and chest.

**Mixed cellularity** – This subtype is more common in older adults. It often affects a few different groups of lymph nodes when it is diagnosed, and the lymph nodes contain a mixture of different types of lymphocytes and other blood cells.

**Lymphocyte-rich** – This is a very rare subtype with the most positive outcome. It contains lots of lymphocytes and very few Reed-Sternberg cells, which makes it harder to diagnose.

**Lymphocyte-depleted** – This is a very rare subtype of classical HL. The lymph nodes may contain a lot of fibrous tissue or a lot of reticular lymphocytes. There may or may not be a lot of Reed-Sternberg cells present.

## Nodular lymphocyte-predominant Hodgkin lymphoma

This subtype is more common in older people but can also occur in young people. There tend to be very few Reed-Sternberg cells present in the lymph nodes, but other abnormal cells called popcorn cells are present.

This subtype usually grows slowly and responds well to chemotherapy and radiotherapy. It behaves very similarly to an indolent (slow-growing) non-Hodgkin lymphoma, and is often treated in the same way.



### More information available online

See the Non-Hodgkin Lymphoma booklet on the LBC website for information on the treatment of indolent NHL, which is treated similarly to nodular lymphocyte-predominant HL.

# STAGING

**How much the lymphoma has spread in the body is called the stage of the disease.**

There are 4 stages of HL (see Figure 06). In stages 1 and 2 (early stage), lymphoma is limited to one or more areas of the body, with all of the lymphoma present on one side of the diaphragm. In stages 3 and 4 (advanced stage), the disease is more widespread (both sides of the diaphragm).

Knowing the stage gives doctors more information regarding the best way to treat your lymphoma.

## **A, B, E or bulky?**

More information about the stage of your disease is given by the symptoms you have when you are first diagnosed. If you do not have any symptoms, the letter A will appear after the stage of your lymphoma, e.g. stage 2A.

If you have symptoms such as fevers, night sweats and unexplained weight loss, the letter B will appear after the stage of your lymphoma, e.g. stage 2B.

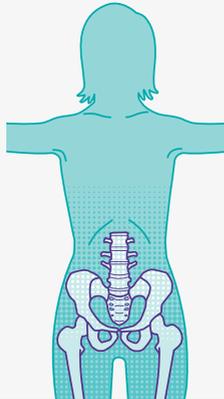
The letter E (for extranodal) is used when lymphoma has spread to an area or organ outside the lymph nodes, e.g. stage 4E. If the lymphoma cells have spread to the spleen, the letter S may be used instead.

If you have a big lymphoma, it is called bulky. Definitions of bulk vary but range from a diameter (measured across) of 7–10cm. Sometimes the letter X is added after the stage number to indicate bulky disease, e.g. stage 3X.

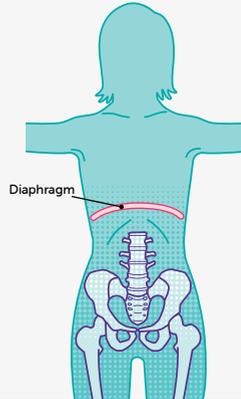
Figure

06

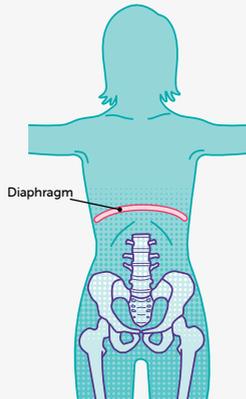
Stages of lymphoma



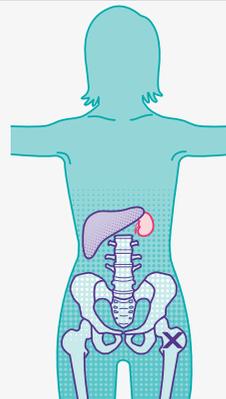
**Stage 1:**  
Lymphoma is only in one group of lymph nodes or one organ/area outside the lymph nodes.



**Stage 2:**  
Lymphoma is in two or more lymph node areas or extends from one lymph node area into a nearby organ.  
All affected areas are either above or below the diaphragm (a large muscle that separates your stomach and chest).



**Stage 3:**  
Lymphoma is in lymph nodes or an organ/area both above and below the diaphragm.



**Stage 4:**  
Lymphoma has spread widely to one or more organs outside the lymphatic system, e.g. bone marrow, lungs, liver.

# INFORMED CONSENT FOR TREATMENT AND PROCEDURES

**You will be asked to give your informed consent for all treatments or procedures suggested by a health professional in your health care team.**

Consent means that you agree. Informed consent means that you understand the information and accept the possible risks and benefits of the treatment or procedure. Informed consent also means that you have had other treatment or procedure options explained to you.

If you have any doubts or questions or need more information about a procedure or treatment, it is important you speak to your doctor or nurse again. You may need to sign a consent form (written consent) or you may just say you agree to treatment or a procedure (verbal consent).

If someone is not able to give informed consent, a legal guardian, welfare guardian or person with enduring power of attorney (EPOA) can give consent on behalf of the patient.

Generally, a person over the age of 16 can give informed consent if the doctor feels they are able to do so.

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 23.



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## Key points

- Informed consent means that you understand the information about a treatment or a procedure.
- Speak to your health care team if you have any doubts or need more information about a treatment or a procedure.

# MAKING TREATMENT DECISIONS

There are two main goals of treating HL:

- Destroy the lymphoma cells and stop any progression.
- Improve quality of life by treating the symptoms and complications associated with lymphoma.

No two people are the same. To help you make the best treatment decision, your doctor will consider all the information available.

**The treatment your doctor will recommend depends on things like:**

- The type of HL you have
- Where it has spread within your body
- Your age
- Your general health.

Many people feel overwhelmed when they are diagnosed with HL. Waiting for test results and discussing treatment options can be very stressful. Some people do not feel that they have enough information to make decisions, while other people feel that they have too much information. Some people feel that they are being rushed into making a decision. If treatment is recommended to start immediately, it can be difficult when you feel like you don't have time to consider all options and process the treatment information.

Your doctor will spend time with you and your family/whānau discussing what they feel is the best option for you. Ask as many questions as you need to, at any stage. You should feel that you have enough information to make the important decisions you are facing.

## Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist or oncologist about your diagnosis and/or treatment. You can ask any member of your health care team, including your current specialist, about getting a second opinion.

## Questions to ask your health care team

Before going to see your GP or specialist, or another member of your health care team, make a list of the questions you would like to ask.

In appendix A on page 55 there are some examples of questions you could ask your GP, haematologist or oncologist. You could write your questions and answers at the back of this booklet or in the LBC Haematology Patient Diary available from your LBC Support Services Coordinator. On page 13 of the Haematology Patient Diary there is also a list of questions that you might like to ask your doctor.

## Bring a support person

We recommend that you bring a support person along to your appointments. Your support person can write down the answers to your questions, remind you of questions you want to ask and help you remember information.

The LBC Haematology Patient Diary is useful for writing down your questions, making notes from appointments, and recording details of treatment.

## Prognosis

Prognosis means an estimate of the likely course of a disease. It provides a guide of how long your HL might be controlled or the likelihood that it will progress and get worse.

The prognosis of your HL will depend on several factors, including the subtype of HL and any other medical conditions. Your doctor is the best person to indicate prognosis and tell you how well your lymphoma is likely to respond to treatment. HL usually responds well to therapy and most patients are cured with treatment. The treatment aims to treat any symptoms you may have and to prevent them coming back. If your lymphoma does come back (relapses), you are likely to need more treatment to get you well again and back into remission.

When doctors and other members of the health care team talk about prognosis, they

might use the terms complete remission, partial remission, stable disease, relapse or refractory disease.

Here is what these terms mean:

- **Complete remission** – The treatment has successfully killed the lymphoma cells so they can no longer be detected in the blood or bone marrow, and there are no remaining enlarged lymph glands.
- **Partial remission** – The number of lymphoma cells has reduced, but there are still some lymphoma cells present in the blood, lymph nodes or bone marrow.
- **Stable disease** – The lymphoma has not improved or worsened with treatment.
- **Relapse** – The lymphoma has come back again. Some people's HL may never relapse while others may have a higher chance of relapse.
- **Refractory disease** – The lymphoma is not responding to treatment (it is 'resistant' to treatment).



### Key points

- Your doctor will recommend a course of treatment to you, and will give you the opportunity to discuss your treatment and ask questions.
- You will be given information so that you can understand the risks and benefits of treatments and procedures. You will be asked to give your written or verbal consent for treatments and procedures.
- We recommend you bring a support person to your appointments if possible.
- Clinical trials (research studies) help find new treatments or aim to improve current treatments. Clinical trials are voluntary – you can choose whether or not you take part.

## Being in a clinical trial

Your doctor might ask you to take part in a clinical trial. Clinical trials are also called research studies. Clinical trials help find out if a new treatment or different ways of giving treatment are better than treatments that are already available. Participation in a clinical trial can provide an opportunity to access these latest treatments, or to use existing treatments for lymphoma in a new way.

Taking part in a clinical trial is voluntary, which means that you do not have to take part in the trial if you do not want to. If you do not want to be part of the trial, your decision will be respected. You do not have to give a reason why you don't want to be part of the trial and there will be no change in the way you are treated by the hospital or your health care team.

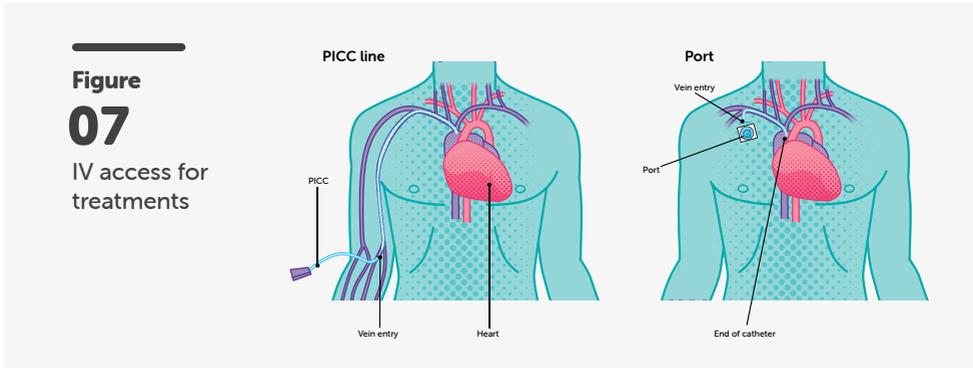
Make sure you understand the reasons for the trial and what is involved. You need to give informed consent for a clinical trial. Take time to talk through the trial with your haematologist or oncologist and other members of the health care team before signing the consent form.

# TREATMENT FOR HL

## Intravenous (IV) access for treatments

Many treatments are given through your veins (IV). This can be through the peripheral veins in your arms or into the larger central veins in your chest through a peripherally inserted central catheter (PICC) line or port. A line (tube) is inserted through the skin and into

a large vein in your arm (PICC line) or chest (port). Once in place, chemotherapy and any other IV drugs can be given through the line and blood tests can be taken from the line, without the need for lots of needle pricks.



## Detailed information

Types of lines for IV access (see Figure 07):

- **Peripheral IV line/catheter** – This is a short thin tube attached to a needle that is inserted into a vein in your arm or the back of your hand. It is held in place with a dressing and can be removed after your treatment, or stay in place for a few days.
- **PICC (peripherally inserted central catheter) line** – This is a long silicone tube that is put into your arm just above the inside of your elbow. One end of the tube travels up the vein in your arm and ends in a large vein in your chest. The other end is just above your elbow and taped up with a dressing; this is where treatment or blood products are attached. It is usually inserted by a nurse specialist on the day ward or in clinic and can stay in place for up to two years.
- **Port (also called a portacath)** – This is a thin silicone disk placed under the skin on your chest that is attached to a tube which feeds into a central vein. Once the skin heals, you will be able to see and feel the shape of the port under your skin, but there are no external tubes. Treatments can be given by inserting a short needle into the disk. Ports are easy to care for and can stay in place for years.

## Types of treatment

### Chemotherapy

Chemotherapy (or cytotoxic) drugs affect cells that multiply quickly, including cancer cells. They work by killing the cells or stopping them from dividing and reproducing. Normal cells that multiply quickly (such as hair follicles and cells on the inside of your mouth) can also be affected, causing side effects, but these cells usually recover.

Chemotherapy is the main form of treatment given for HL. The amount (dose), timing and type of chemotherapy given will depend on the type of lymphoma, your age and your health.

Chemotherapy is usually given as a combination of drugs. Each drug works in a different way, and together they are more effective (usually with less side effects) than a single drug. Chemotherapy is usually given as several cycles, with rest periods of 1-4 weeks between each dose. These rest periods are to allow your body to recover from the side effects.

Chemotherapy can be given by mouth (orally, as a tablet) or into your vein (IV). Chemotherapy can often be given in the hospital day ward or taken at home (if you are taking tablets). In some cases, you might need to be admitted to the hospital ward for a short stay to have your chemotherapy. Your health care team will be able to give you more information about what to expect.



## Detailed information

The names of the different treatment regimens usually come from the first letters of the drugs they contain. Some examples of combinations of drugs used to treat HL, as well as how long each cycle takes, are listed below.

ABVD	IV infusions on days 1 and 15 6 cycles completed (usually over 6 months)	<b>A</b> driamycin (doxorubicin) <b>B</b> leomycin <b>V</b> inblastine <b>D</b> acarbazine
BEACOPP	IV infusions and tablets on days 1–3 Oral tablets on days 1–14 One IV infusion on day 8 4–6 cycles completed	<b>B</b> leomycin <b>E</b> toposide <b>A</b> driamycin (doxorubicin) <b>C</b> yclophosphamide <b>O</b> ncovin (vincristine) <b>P</b> rocarbazine <b>P</b> rednisone
ChIVPP	14 days of oral tablets IV infusions on days 1 and 8 6 cycles completed	<b>C</b> hlorambucil <b>V</b> inblastine <b>P</b> rocarbazine <b>P</b> rednisone

### Side effects of chemotherapy

Healthy cells that multiply quickly in your body can also be killed or damaged because of chemotherapy. Examples of these cells are those in your mouth, stomach, bowel, bone marrow and hair. The dead or damaged cells can cause side effects.

The side effects for each drug or drug combination are different. Most people will have some side effects, but some people do not. Side effects may vary depending on the dose of chemotherapy you are having. Most side effects of chemotherapy begin to go away when your treatment is finished.

When you receive chemotherapy, there are breaks during the treatment so that your body (the bone marrow in particular) has time to recover from the side effects of the chemotherapy. Side effects of treatment may be short-term or long-term (sometimes called 'late effects'). Short-term side effects should go away a few weeks after treatment finishes, once the damaged cells recover. Long-term means that you may experience side effects for months after treatment.

Here is a list of the most common side effects of chemotherapy, in alphabetical order:

- Anaemia (from a low red blood cell count)
- Bruising and bleeding (from a low platelet count)
- Constipation
- Diarrhoea
- Difficulty concentrating or remembering (chemo brain)
- Early menopause
- Fatigue (extreme tiredness)
- Fertility changes
- Hair loss
- Increased risk of infection (from a low white blood cell count)
- Low mood, anxiety or depression
- Nausea and vomiting
- Organ damage
- Pain
- Peripheral neuropathy
- Poor appetite and taste changes
- Skin changes
- Sore mouth (mucositis)
- Weight loss or gain.

These side effects, and what you can do if you have them, are discussed in the section called 'Living with HL' on page 31.



### Key points

- There are many different chemotherapy drugs, and combinations of drugs. They can be given as a tablet or into your veins (IV).
- Chemotherapy can be given in hospital, in the day unit, or taken at home depending on the type of chemotherapy and how well you are.

### Steroid therapy

Corticosteroids (or steroids) such as prednisone (prednisolone) and dexamethasone are commonly used in HL treatment. They work alongside chemotherapy drugs to kill lymphoma cells, make the chemotherapy drugs more effective and reduce the risk of allergic reactions to some chemotherapy drugs. Steroids can be taken as a tablet or given by IV/drip.

Steroid treatment commonly has side effects, these can be different for every person.

**Below are some common side effects, and suggestions for how to deal with them:**

- **Mood changes (mood swings, anxiety, irritability, tearfulness)** – Ask your treatment team about what support is available, and speak to your local LBC Support Services Coordinator.
- **Difficulty sleeping** – Talk with your doctor about whether you can take the steroid at a different time. Some people find taking them in the morning helps, others prefer to take them right before going to bed so they are asleep by the time the steroid starts working.
- **Stomach pain** – Take with food and speak to your treatment team if this continues, there may be medications you can take to help.
- **High blood sugar** – If you are diabetic, check your blood sugars more often. You may need to speak to your doctor about adjusting your insulin or other medications.
- **Increased appetite and weight gain** – This can be common with long-term steroid use. If you are concerned, ask your treatment team if you can speak to a dietitian.
- **Muscle weakness** – Steroids may cause muscle weakness or wasting in some people. Continue regular gentle exercise. You may also find it useful to see a physiotherapist.
- **Increased risk of infection** – Monitor for signs of infection such as a high temperature, swelling, red skin or unexplained pain, and speak to your doctor immediately.

### Immunotherapy and targeted treatments

Immunotherapy helps a person's own immune system to fight lymphoma. Unlike other lymphomas, immunotherapy is not currently a part of the standard treatment for HL. This may change in the future, as immunotherapy is a part of some clinical trials.

### Radiotherapy

Radiotherapy (also called radiation therapy) uses high-energy X-rays to kill cancer cells and shrink tumours. Radiotherapy is called a 'local therapy' because it only destroys cancer cells in the treated area (the radiation field).

Radiotherapy can be used in the treatment of HL to shrink enlarged lymph nodes or an enlarged spleen, to kill lymphoma cells that are in a small area, or to reduce bone pain when lymphoma is affecting the bone.

### Before you start radiotherapy

The radiation oncologist (a doctor who specialises in treating people with radiotherapy) will calculate how much radiotherapy you need (the dose). You will have scans to work out the best position to be in, and the areas of your body that need to be treated will be marked with tiny ink dots on your skin using a special pen. Your doctor will treat the smallest area possible to avoid affecting the normal tissue.

### During treatment

Radiotherapy is usually given in small doses (also known as fractions) in the radiotherapy department of the hospital. You usually do not need to be admitted to hospital for this treatment, but if you live far away you may need to organise closer accommodation for this time. The social worker or nurses can assist you with this.

During radiotherapy you will be positioned on a table underneath the radiotherapy machine, which will deliver the planned dose of radiation. Radiotherapy sessions are usually short (15–30 minutes) and you will need to stay perfectly still while the treatment is taking place. You will hear a buzzing sound as the machine moves around you. If necessary, important structures like your heart and lungs are shielded as much as possible to ensure that they are not affected by the treatment given. Radiotherapy is painless – you will not see or feel anything during the actual treatment. If you are feeling anxious, you might like to bring along some music to help you relax.



### Important information

Radiotherapy treatment does not make you radioactive, as the radiation passes through your body. It is okay to interact with other people during and after your treatment.

### After radiotherapy

Side effects can develop after receiving radiotherapy. These vary from person to person, and can be short term or last for a while after treatment.

### Side effects include:

- Fatigue (see more about fatigue on page 33).
- Skin irritation – skin can become red, dry, painful or warm in the area that has been treated. Skin changes will be worst just after treatment has ended and should heal in 4–6 weeks. Stay out of the sun and avoid scented soaps and moisturisers or skin products that contain metals during this time.
- Mouth pain.
- Parotitis – inflammation of the saliva glands in the mouth, which can cause a dry mouth and jaw pain.
- Feeling sick (nausea) and vomiting.
- Bowel changes – gas/wind, loose stools, diarrhoea, bloating or cramping.
- Hair loss in the area of radiation treatment.

After your radiotherapy has finished, you may have scans to see how the lymphoma has responded. This will help your treatment team make decisions about your treatment.

If you have had radiotherapy to your mediastinum (chest) area, you may be advised to have earlier or more frequent mammograms, to monitor for breast cancer.



### Important information

Excessive friction, heat or washing should be avoided on areas that have just been treated with radiotherapy. The health care team in the radiotherapy department will be able to advise you on the best way to care for your skin.

### Stem cell transplant

If your HL comes back (relapses) or does not respond well to your initial treatment, then a stem cell transplant (also called haematopoietic stem cell transplant or bone marrow transplant) may be recommended as further treatment. Your treatment team will weigh up the risks and side effects against the benefit of having a transplant. It is usually only offered to people who are under 75 years old and otherwise in reasonably good health, based on tests such as heart and lung function tests. There are two main types of transplant – autologous and allogeneic.

#### Autologous

Most transplants for HL are autologous stem cell transplants (or autografts). You will be given chemotherapy to kill off as many lymphoma cells as possible. You will then have your own stem cells collected (usually from your blood), which are given back to you via IV/drip after more high-dose chemotherapy.

The stem cell collection (also known as a stem cell harvest) involves having a drug called granulocyte colony stimulating factor (GCSF) that helps your body grow lots of stem cells for the collection. The collection is similar to giving blood, but you will have two IV lines that connect you to a big machine, which spins the stem cells out of your blood.

The infusion of stem cells allows the bone marrow to recover after an intensive dose of chemotherapy, which means higher doses can be given. Autologous transplants are often used for relapsed lymphoma and are more common than allogeneic transplants.

#### Allogeneic

An allogeneic stem cell transplant (or allograft) uses stem cells from a healthy donor. This is not usually required for HL, unless you have had a previous autologous stem cell transplant and your lymphoma has still come back. Allogeneic stem cell transplants usually have more intense side effects than autologous transplants.



### More information available online

See the Autologous Stem Cell Transplants and Allogeneic Stem Cell Transplants fact sheet and information booklets on the LBC website.

#### Supportive care

Supportive care (also called palliative care) is aimed at relieving any symptoms you may have due to your lymphoma or your treatment. Supportive care may happen with or without other treatment. Below are some examples of supportive care.



### Key points

- A stem cell transplant is when you are given high-dose chemotherapy followed by stem cells through IV/drip.
- There are two types of stem cell transplants – autologous and allogeneic. Autologous transplants are more common for HL and may be recommended if your lymphoma relapses after treatment.
- Stem cell transplants allow you to have much higher doses of treatment to improve your chances of remission.

### Transfusions

You may need a blood or platelet transfusion when you have symptoms of anaemia or a low platelet count. Transfusions are given by a nurse, usually on the day ward or outpatient clinic. The blood or platelets are given via IV/drip into your arm, which takes 1–2 hours.

### Growth factors

Growth factors are chemicals that help your bone marrow make more blood cells. They can be given to increase low blood counts. For example, if you have a low white blood cell count during treatment, you may be given a growth factor called GCSF to make the body produce more neutrophils. This is given as an under-the-skin (subcutaneous) injection.

### Antibiotic, antimicrobial and antiviral treatments

You may be at higher risk of infection, due to either your lymphoma or treatment. If you get an infection, you may be given antibiotics, antivirals or other antimicrobials to help treat it. These are usually given as a tablet or an infusion into your veins. You may also be given these treatments to prevent an infection – this is called prophylaxis.

### Vaccines

Vaccines help prevent infections. Only inactivated vaccines are safe if you have HL – you should not have any live vaccines. Some treatments can 'reset' your immune system, so you may need to have some vaccines you have already had again. Talk to your medical team about which vaccines they recommend for you, and when you should have them.

### Complementary therapies

Complementary therapies can be very useful to help people feel better emotionally and physically. There are lots of different therapies and some people find it helpful to try more than one.

Examples of complementary therapies are:

- Acupuncture
- Aromatherapy
- Art therapy
- Homeopathy
- Journaling
- Massage
- Meditation
- Mindfulness techniques
- Music therapy
- Reflexology
- Reiki
- Relaxation
- Tai chi
- Visualisation
- Yoga.

If you are not sure what some of these therapies are, ask a member of your health care team. If you plan to use complementary therapies, including any supplements, make sure they are a safe option for you by asking your haematologist first.

# LIVING WITH HL

**There are a number of symptoms of HL or side effects of treatment. Some are more common than others.**

Each person's experience will be different. Some people feel very unwell, while others have milder or no symptoms. Side effects can be unpleasant, but most of them are temporary and reversible.

This section helps you manage the more common symptoms of HL and the side effects of treatment. They are listed below in alphabetical order.

Remember to report any side effects to your doctor or nurse. Your LBC Support Services Coordinator can give you support and more information.

## Anaemia

A low red blood cell count is called anaemia. Anaemia is described in more detail on page 8.

If you have a low red blood cell count, you may be given red blood cells via IV/drip, which is called a blood transfusion.

## Bruising and bleeding

You may bruise easily, or bleed more than usual from minor cuts if you have a low platelet count (thrombocytopenia), or as a side effect of some medicines. Symptoms of thrombocytopenia are described on page 8.

**Things you can do to help or prevent bruising and bleeding include:**

- Use a soft toothbrush.
- Don't floss your teeth.
- Don't shave with a razor blade.

- Move about carefully so you don't bump into things or trip.
- Don't play contact sports such as rugby or hockey.
- Wear protective gloves when doing work around the home or garden.
- Don't eat food with sharp edges, e.g. potato chips.
- Let your doctor or nurse know if you are constipated.

If you have a very low platelet count, you might be given a transfusion of platelets via IV/drip to help stop bruising and bleeding.



### Important information

Call the hospital straight away if you have:

- Nosebleeds
- Bleeding gums
- Tiny red or purple spots on the skin that look like a rash.

## Constipation

Constipation means that you cannot pass a bowel motion easily – usually because your bowel motions are hard. Tell your nurse or doctor if you are constipated or sore.

Hard bowel motions can damage the lining of your bowel and cause bleeding or infection.

**Things you can do to help:**

- Drink plenty of water.
- Eat more fibre such as cereals, raw fruit and vegetables (while still following your neutropenic/low-risk diet, if you are on one).
- Do some gentle exercise.
- Tell your doctor or nurse, as they can give you something to soften your bowel motions.
- Talk to a dietitian.

**Diarrhoea**

Sometimes treatment (e.g. chemotherapy) damages the lining of your bowel wall.

This might cause diarrhoea (die-a-rea) (loose bowel movements) and other symptoms such as:

- Cramping (pains in the lower abdomen or gut)
- Abdominal swelling (swollen tummy).

If you have diarrhoea, the health care team will do a test to see if you have an infection.

**Things you can do to help:**

- Take the drugs that your doctor or nurse give you to stop the diarrhoea.
- Wipe your bottom with soft toilet paper or flushable wipes.
- Apply a barrier cream around your bottom to protect and soothe the skin.
- Drink plenty of fluids.
- If you are unable to drink fluids, tell your doctor or nurse as you may need to have a drip/IV.

**Important information**

Call the hospital if you have more than four episodes of diarrhoea in a day.

**Difficulty concentrating or remembering (chemo brain)**

Chemo brain is another symptom of HL or side effect of treatment such as chemotherapy.

Chemo brain is also called mild cognitive impairment. It can also affect people with cancer who have not had chemotherapy. The exact cause of chemo brain is not known.

**The symptoms of chemo brain are:**

- Difficulty concentrating
- Difficulty remembering things, including finding the right word
- Feeling very tired.

**Chemo brain can be frustrating and it can make everyday life difficult. Some things you can do to help are:**

- Keep a diary of your symptoms.
- Make lists, take notes, and use sticky pads or your phone for reminders.
- Keep a calendar or diary.
- Do mental exercises such as crosswords and puzzles.
- Try to keep calm.
- Do some regular exercise.
- Get plenty of rest and sleep.
- Read short articles rather than books and watch episodes of programmes rather than films.

**More information available online**

See the Chemo Brain fact sheet on the LBC website.

## Difficulty eating or drinking

You may find it harder than usual to eat or drink due to the effects of lymphoma or your treatment. Sometimes people can lose weight or strength as a result. Having small, frequent meals or snacks and sipping fluid throughout the day can make it easier to get enough in. Speak to your treatment team if you have pain or nausea that is stopping you from eating and ask to speak to a dietitian for further support.



### More information available online

See the Eating Well fact sheet on the LBC website.

## Early menopause

Some chemotherapy drugs can lower the amount of hormones that the ovaries make. This can lead to early menopause and menopausal symptoms.

Menopause usually starts any time after 40 years of age when, due to hormonal changes, women's periods stop and they can no longer have children.

Your doctor will be able to tell you if you are having a type of chemotherapy that might cause you to experience early menopause.

## Fatigue (extreme tiredness)

Fatigue is very common for people with HL or having lymphoma treatment.

Extreme tiredness can be caused by:

- Lymphoma itself
- Chemotherapy and targeted therapies

- Emotional stress
- Poor sleep
- Low blood counts (especially anaemia caused by a low red blood cell count)
- Muscle loss
- Loss of appetite or dehydration.

Extreme tiredness can have a huge impact on your life. If you have chemotherapy, it can sometimes be several months before you feel your energy levels are back to normal. Some people feel tired for a year or more afterwards.

Things you can do to help:

- Have a regular night sleep routine.
- Have regular rest periods throughout the day.
- Don't try to do too many things in a day, just do the important things.
- Note the times in the day when you have the most energy and set goals to do your main activities at these times.
- Do some light exercise each day.
- Keep a diary so you can look back and see your improvements in energy levels over time.

In hospital your sleep can be interrupted. Speak with your health care team if you are finding this is making you very tired during the day. Also speak with the team about emotional support if you are having trouble coping due to fatigue.



### More information available online

See the Managing Cancer-related Fatigue fact sheet on the LBC website.

## Feelings of isolation

A diagnosis of lymphoma can make you feel isolated or alone for a number of reasons, including:

- Being unable to continue working, studying or doing the things you usually do.
- Symptoms and side effects (such as fatigue or risk of infection) can make it hard to be with other people or attend social events.
- A lack of support from family/whānau or friends who may not know what to say or do.
- Financial difficulties can make it hard to maintain social activities or visit family/whānau and friends.

Feeling isolated can have an impact on your physical and mental well-being. It is important to speak to your doctor, nurse, social worker or LBC Support Services Coordinator if you feel isolated or alone.

## Hair loss (alopecia)

Hair loss is a common side effect of chemotherapy and some forms of radiotherapy. It is usually only temporary. Hair loss usually occurs 3–6 weeks after you begin treatment. You should start to feel and see new hair growing back 6–12 weeks after you finish treatment, although the colour and/or texture may be different. Each person is different and some might take longer for their hair to fall out or grow back.

Hair loss can happen on all parts of your body including your head, eyebrows, eyelashes, beard or moustache, underarms, pubic hair and legs. You may experience hair thinning, or it may fall out completely.

Your scalp may feel sensitive, sore or itchy when your hair is falling out.

### Things you can do to help:

- Pat your hair gently with a towel to dry it.
- Don't use heat, such as a hair dryer or straighteners.
- Don't use chemicals, such as hair dye.
- Use a soft brush – some people find baby brushes are best.

Unfortunately, there is nothing you can do to prevent your hair from falling out. Stopping brushing or washing your hair will not stop your hair from falling out.

### Emotional support

Some people find losing their hair upsetting. Hair, including facial hair, can be an important part of a person's identity. It is important to acknowledge how you feel about hair loss. If you are struggling with hair loss, talk to your health care team. They can give you information and support.

Other people's reactions to your hair loss can sometimes be difficult to cope with. It can be helpful for you to talk to them about it first. Children will generally cope well if you talk to them about it and explain why it happens.

There is support for family/whānau members who are struggling to cope with your hair loss. Talk to your health care team to find out about the support available to them.

### Shaving your head and head wear

Some people let their hair fall out naturally. Other people have their hair cut off in stages or shave it off before treatment begins as they find this easier than watching their hair fall out.

**Things you can do that can help:**

- Speak to other people who have experienced hair loss.
- Wear a wig, baseball cap, beanie or woolly hat, scarf or turban. This can make you feel more comfortable. In winter you will probably find it very cold without a head covering.
- In summer you are more prone to sunburn. Your skin is more sensitive to the sun after chemotherapy so it's important to apply sun block and wear a hat.

**Increased risk of infection**

Lymphoma itself, and treatments for HL, including chemotherapy and radiotherapy, can increase the risk of infection.

If you are receiving chemotherapy, you may be at risk of a very low white blood cell count (neutropenia). If this is the case, your health care team will tell you what to do if you develop a fever or other symptoms of infection. Infections during chemotherapy can be very serious and even fatal if you do not seek medical advice quickly for an assessment and antibiotics.

Even if you are not receiving chemotherapy, and do not have a low white blood cell count, you should consider yourself at increased risk of infection due to HL. The most common infections in people with HL are chest infections (including pneumonia), skin infections (including cellulitis and shingles) and urinary tract infections (UTIs, including



**Important information**

- Make sure you have a thermometer at home and you know how to check your temperature correctly.
- All people with HL are at increased risk of infection. You should promptly see your GP or an emergency doctor if you develop a fever or other symptoms of infection. Infections can rapidly get worse if left untreated.
- If you are currently receiving chemotherapy or if you have been told you are at risk of, or have, neutropenia, you should contact your hospital immediately if you have a temperature over 38°C. Do not wait to see if your temperature goes away as you could deteriorate very quickly. Your health care team will provide you with instructions and/or emergency telephone numbers if you are in this risk group.
- Do not use any drugs to bring your temperature down (e.g. paracetamol) without checking with your health care team. This could hide an infection, which can lead to serious life-threatening complications.
- Be cautious about using aspirin or ibuprofen in any form. These drugs can increase your risk of bleeding if your platelet count is low. Always check with a doctor or nurse first.
- Ask a member of your health care team for the phone numbers of the hospital and write them here:

Monday to Friday (during office hours) ph.....

Evenings/nights/weekends ph.....

kidney and bladder infections). You should contact your haematology service quickly if you develop a fever or other symptoms of an infection, as you are more likely to need antibiotic or antiviral treatment than someone who does not have lymphoma. You may also be prescribed preventative (prophylactic) antibiotics to prevent infection, especially during and after some types of treatment.

The following actions can help prevent infections.

### Avoiding food-related infections

You need to be careful when preparing and cooking food.

#### Be sure to:

- Always wash your hands before preparing or eating food.
- Tell your family/whānau to wash their hands before preparing food.
- Prepare food in a clean place.
- Prepare raw meat on a separate chopping board from other foods.
- Wash fresh fruit and vegetables well.
- Cook food well and makes sure it is very hot.
- Make sure reheated food is very hot.
- Eat food before its best before/ use-by date.
- Do not reheat food more than once.

### Avoiding viral infections

People with HL may be at increased risk of viral infections, particularly during and for the first year after finishing treatment.

#### If possible, you should:

- Try to avoid people, including children, who are currently unwell with a cold, flu or another infection.

- Try to avoid people who have, or have been near others who have, active chicken pox, shingles or measles.
- Try to avoid people who currently have Covid-19, who have recently had Covid-19 and are still symptomatic and/ or returning positive tests, or are currently isolating due to Covid-19 exposure.

The annual influenza vaccines and Covid-19 vaccinations are recommended for most people with HL, but might be less effective if you are currently having or have recently had HL treatment. Check with your doctor about what vaccinations you should have, and the best time to have them.



### Important information

People with HL should avoid live vaccines, including the MMR vaccine. If you are unsure, check with your doctor. If you have been in contact with someone with chicken pox or shingles, contact your doctor immediately, as you may need a medicine to help protect you.

It is important that you maintain your usual social activities when you are able. Touching, hugging and kissing your close family/ whānau and friends is important. It is fine if they are well.

### Pets

#### You need to:

- Wash your hands after touching pets.
- Avoid letting a pet lick your face.
- Keep pets clean and treat them for worms and fleas.

- Keep pets away from areas where food is prepared.
- Wash your hands carefully if you touch a litter tray or animal poo.

### Gardening

Garden soil can cause infections in people with a low white blood cell count.

#### You need to:

- Wear gloves, as soil or potting mix can have harmful germs in it.
- Thoroughly wash any cuts you receive from gardening.
- Check cuts for signs of infection.
- Wear a mask when working with manure, compost or soil to avoid breathing in particles.

Talk to your health care team if you would like more information about preventing or treating infection.

## Low mood, anxiety, depression or difficulty coping

It can be common to have a low mood, feel anxious or depressed, or find it difficult to cope after diagnosis with HL or during treatment. There can be a lot of things that cause these feelings.

#### Things you can do to help:

- Talk about how you're feeling with someone you feel comfortable with, e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger long-term goals.

- Make a list of things that make you feel better such as your favourite TV show, talking to someone on the phone or doing a hobby.
- Try to keep socialising by staying in touch with friends and family/whānau.
- Try to spend time each day relaxing, e.g. meditating, listening to music.
- Exercise regularly.
- Try to keep a regular sleep pattern.
- Keep a diary. This can help you express how you feel without needing to talk to anyone.
- Cry if you need to.
- Try complementary therapies such as massage, aromatherapy or reflexology. Information on complementary therapies can be found on page 30.

It is important to tell a member of your health care team if you continue to have feelings of low mood, anxiety, depression or difficulty coping. They can help you get the support you need.

## Nausea, vomiting and dehydration

Some chemotherapy can make you feel sick (nausea) or be sick (vomiting). Feeling anxious can also cause nausea and vomiting.

There are drugs (medicines) called antiemetics which can help treat nausea and vomiting. Different antiemetic drugs work in different ways and you may have one or more types to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch.

Tell your doctor or nurse if you still feel sick because they might be able to try a different antiemetic or give it to you in a different way.

Controlling your nausea and vomiting is important so you can keep eating and drinking enough to fuel your body. If you have bad nausea and vomiting and are unable to drink or keep fluid down, it is important you speak with your doctor or nurse to make sure you don't become dehydrated.

#### Things you can do to help:

- Eat smaller meals or snacks, more frequently throughout the day.
- Don't eat foods with a strong smell or taste.
- Don't eat hot or fatty foods.
- Try fizzy drinks.
- Try ginger tea or ginger ale.

Complementary therapies such as relaxation, aromatherapy or massage might help some people.

## Organ damage

Sometimes chemotherapy can cause damage to cells in organs such as your kidneys, liver, heart and lungs. This damage can be temporary (short term) or less likely, permanent. Some types of chemotherapy are more likely to cause organ damage than others. Examples include doxorubicin (which can cause heart damage), cyclophosphamide (heart damage), methotrexate (kidney damage) and vincristine (damage to nerve ends). Your treatment team will be able to give you more information about whether organ damage is a likely side effect of the chemotherapy you are having.

#### Things you can do to help:

- Have all recommended blood tests – these are often used to monitor organ

function, so your treatment team can see if damage is occurring.

- Ask your treatment team if there is any regular follow up you should have after you have finished treatment (such as regular heart checks or lung function tests).

## Pain

Some people may experience pain as a result of HL or its treatment, e.g. with mucositis (sore mouth) or heartburn.

It is important to tell your health care team if you have pain.

#### Your health care team will ask you about the pain, for example:

- What the pain feels like, e.g. dull, sharp, burning?
- How bad is the pain?
- What makes the pain worse and what makes it better?

Pain can be caused, or made worse, by your emotions or how you are coping with your diagnosis and treatment. This is called 'total pain'. Total pain can be psychological, social and/or spiritual. Examples of things that might contribute to total pain are anxiety, worries about your family/whānau or a crisis of faith. It is important that total pain is managed as well as physical pain. Ask your health care team for the support you need.

## Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves in the hands, feet, arms and legs. Some people might experience numbness, tingling, pain, hot or cold sensations, or increased sensitivity.

This can be caused by the lymphoma itself, but more commonly from some of the drugs used to treat lymphoma.

The best way to prevent peripheral neuropathy is to be aware of any changes and report symptoms to your doctor or nurse as soon as possible. The doctor might decide to reduce your drug dose or change you to a different drug with less side effects. There are some pain-relief options that may be beneficial, but they don't always work for everyone.

#### Things you can do to help:

- Take care of your feet by wearing covered shoes that fit well. Keep hands and feet warm.
- Be careful when getting into baths and showers to make sure the water isn't too hot and could burn your skin.
- Eat a well-balanced diet and try to include as many essential vitamins and minerals as possible.
- Keep your home tidy to reduce the risk of tripping and falling.
- Stop smoking as this can affect your peripheral blood flow.
- Use ice packs or hot-water bottles to provide short-term relief of symptoms.

### Poor appetite and taste changes

You may not feel like eating, and you may experience taste changes. This may be because of the chemotherapy, other drugs, the worry of having lymphoma, or doing less physical activity.

#### Low appetite

Having a low appetite (not feeling like eating) can be disappointing for people who usually

enjoy eating. It is important to keep eating to help maintain your weight and energy levels. It is also important to drink plenty of fluids, especially if you are not eating very much.

It can be common for people to really feel like eating certain foods but then by the time it has been made, they cannot eat it. Choose meals that can be made quickly and are easy to eat.

If you are finding it difficult to eat, or are worried about your weight, ask to speak with a dietitian who will be able to help you.

#### Things you can do to help:

- Eat small amounts of food as often as possible.
- Keep snacks handy such as nuts, cheese and dried fruit (as long as it is allowed, if you are on a neutropenic diet).
- Add extra energy and protein to your diet by using full-fat products or nutritional supplements.
- Eat what you feel like – you can return to your normal diet when your appetite returns.

#### Taste changes

Your sense of taste may change or the texture of food may seem different. This may mean that you no longer enjoy food, that all food tastes the same, or food has a metallic taste. Your sense of smell can also be affected.

#### Things you can do to help:

- Choose cold foods as they often taste better and smell less.
- Suck boiled sweets or drink fruit juice, as they leave a nicer taste in the mouth.

- Try different seasonings such as herbs and spices on your food.

If you are in hospital and don't feel like eating the hospital food, ask your nurse about suitable foods that family/whānau or friends can bring in for you.



### More information available online

See the Eating Well fact sheet on the LBC website.

## Sex and fertility

Fertility is a person's ability to get pregnant or father a child. Infertility means that you may not be able to become pregnant or father a child. Some chemotherapy or other treatments for HL may cause infertility. Even though chemotherapy can cause infertility, it does not make all people infertile.

It is important that you ask any questions or discuss concerns you might have about your fertility with your doctor and nurse as soon as possible. There may be some things you can do before you start treatment that mean you might be able to have a baby or father a child in the future.

For some people, the possibility of losing their fertility can be very upsetting. There is practical and emotional support available. Talk to a member of your health care team. They will help you get the support you need.

LBC has a 'Fertility' fact sheet for both men and women available on the LBC website or from an LBC Support Services Coordinator.



### More information available online

See the men's and women's Fertility fact sheets on the LBC website.

Chemotherapy can affect a developing foetus, so use a condom when you have sex in the months before, during and after chemotherapy to avoid a pregnancy.

More information on contraception, sex and relationships can be found on pages 44–46.

## Skin and nail changes

Chemotherapy can affect your skin and nails. Your skin may become dry or oily, and can also become red, sore, itchy and more sensitive. Nails may become brittle and flaky. Ridges or lines may appear on your nails and they can also become painful or swollen.

### Things you can do to help:

- Don't use soap and perfumed products, or products that contain alcohol.
- Moisturise dry skin once a day, or more if needed.
- Use lip balm regularly.
- Don't scratch.
- Don't shave with razor blades.
- Use oil-free moisturiser on oily skin.
- Use hand cream regularly.
- Use nail-strengthening cream.
- Wear gloves when doing chores.

### Sun protection

After chemotherapy, you might find that the sun burns your skin much quicker than it used to.

**Things you can do to help:**

- Wear sunscreen with a high sun protection factor (SPF) and reapply regularly.
- Don't go outdoors during the hottest part of the day.
- Cover exposed skin with clothing.

You should protect your skin from the sun for the rest of your life.

If you are having problems with your skin or nails and none of the above suggestions are helping, get support and advice from a member of your health care team or your LBC Support Services Coordinator.

**Sore mouth (mucositis)**

A sore mouth can be an uncomfortable side effect of chemotherapy. Chemotherapy can cause damage to the cells in the lining of your mouth and digestive system. The medical name for this side effect is mucositis (mew-co-site-is).

You will usually notice symptoms of mucositis a couple of days after you start chemotherapy.

**The symptoms of mucositis can include any of the following:**

- Mild soreness of the mouth, especially the insides of your cheeks, the sides and underneath of your tongue and the back of your throat.
- Taste changes.
- White, rough-feeling patches on the inside of your mouth.
- Red and inflamed patches on the inside of your mouth.
- Painful ulcers (sores) on the inside of your mouth.

- Difficulty or pain eating, drinking and taking tablets.
- Thick saliva (spit).
- Sore throat.
- Sore and cracked lips.

**Mouth care**

Regular mouth care is important for comfort and to prevent infection, especially from mouth ulcers.

It is recommended that you do mouth care five times a day: when you wake up, after each meal and before bed. Doing mouth care can be painful, however it is very important to do it regularly and carefully. Mouth care reduces the risk of infection, especially from mouth ulcers.

**How to do mouth care:**

- Brush your teeth with a soft or baby toothbrush, or use a mouth sponge if a toothbrush is too painful.
- Rinse with mouthwash or water, as instructed by your health care team.
- Use a lip balm or petroleum jelly (Vaseline) on your lips.
- Don't use dental floss as this increases the risk of bleeding gums.

**Things you can do to help:**

- Suck on ice cubes or ice blocks.
- Suck on hard-boiled lollies if your mouth is dry.
- Drink fizzy water.
- Spit your saliva into a bowl. If you are in hospital, ask the nurse how to use the suction.
- Your doctor may prescribe a saliva substitute.

- Avoid acidic foods if they are causing you pain, e.g. lemon, orange, mandarin, grapefruit, tomato.

### Managing mouth pain

Let your health care team know if your mouth is painful, especially if it stops you from eating.

### Your health care team can advise you on how to use pain relief, for example:

- Take painkillers regularly as directed.
  - Take stronger painkillers 20 minutes before eating or doing mouth care, as directed.
- Use a mouthwash with local anaesthetic to numb the pain.

Unfortunately, painkillers might not get rid of all the pain.

Sometimes mucositis can also affect the oesophagus (food pipe) and bowel (gut). This can cause discomfort, pain, indigestion and heartburn or diarrhoea. Tell your doctor or nurse if you have any of these symptoms. Mucositis should start to get better when your white blood cell count begins to increase.



## Important information

### When to contact your doctor or the hospital for help.

Contact your doctor or the hospital straight away (night or day) if you are feeling unwell or have any of these symptoms:

- A temperature of 38°C or over and/or shivering.
- Bleeding or bruising, e.g. blood in your urine, bowel motion or sputum (spit), bleeding gums or a nosebleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or severe constipation.
- Coughing or shortness of breath.
- A new rash, reddening of the skin or itching.
- A headache that won't go away, confusion or blurry vision.
- A new pain or soreness anywhere.
- A cut or injury.
- Pain, swelling, redness or pus anywhere on your body.

## Contacting the hospital after-hours

If you are feeling unwell, ring the hospital contact number you were given and ask for advice, no matter what time it is. Your health care team and the hospital would prefer that you ring to discuss how you feel, rather than not ring and feel worse. If in doubt, make the call. The emergency department (ED) at the closest hospital will always be open. A list of haematology centres in New Zealand can be found on page 59.

It can also be useful to keep a letter from your doctor that has important information about your diagnosis and treatment and take it with you to the ED or hospital. This is especially useful if you are going on holiday and have to go to a different hospital.

## Coping with isolation while in hospital

There may be periods of time that you have to stay in hospital. This may be for treatment, a complication or monitoring. If you are on treatment and have a low white blood cell count, you might be in a single room, which may be referred to as 'protective isolation'.

Isolation means that you are in a hospital room by yourself and visitors may be limited. This is to protect you from serious infections while your white blood cell count is very low. Being separated from family/whānau can be a challenging time for everyone, especially children. Each hospital has a policy around protective isolation, and they will tell you if you are allowed to leave your room, who is allowed to visit, and what precautions visitors should take – such as hand hygiene and wearing a mask.

### Things you can do to help:

- Set yourself daily goals. Your physio, occupational therapist or nurse could help you with this.
- Have special photos in your room.
- Maintain regular contact with family/whānau via phone and video calling.
- Shower and get dressed in day clothes each day.
- Do light exercise and relaxation.
- Write in a diary about your thoughts and feelings.
- Do things you enjoy such as watching favourite TV shows, listening to music, playing games or doing puzzles, contacting friends, and keeping up with world news and events.
- Ask your visitors to come at different times throughout the day.

Contact your LBC Support Services Coordinator if you need support while you are in isolation.

## Moving to a main centre hospital for treatment

If your local hospital cannot provide the treatment you require, you may need to move to another hospital in a main centre.

A social worker can help you with information and practical support such as advice on how to get accommodation, transport and financial assistance.

Moving to another hospital for treatment can be stressful for you and your family/whānau.

Contact your LBC Support Services Coordinator to obtain a relocation booklet with practical information about moving to a main centre hospital.

# RELATIONSHIPS

**A diagnosis of HL can have both positive and negative impacts on relationships with your partner, family/whānau and friends.**

## Relationship with your partner

A diagnosis and the treatment of HL can put a lot of strain on a relationship, but some couples grow closer as they go through this experience together. Good communication is essential to supporting your relationship, including sharing how you feel with your partner.

### Other things you can do to help:

- Plan activities together such as meals out. If you are in hospital and feel well enough, you and your partner could eat together. Talk to your nurse about the possibility of having some uninterrupted time together in your room.
- Tell your partner how they can support you.
- Get support from a counsellor or psychologist. Ask your health care team or LBC Support Services Coordinator for more information or a referral.

There are other practical things you might want to discuss with your partner, such as setting up your partner, or another trustworthy person, to be your 'power of attorney'. A power of attorney is where you give a person the authority to act on your behalf if you are not well enough to do so yourself.

You could complete an Advanced Care Plan (ACP) and discuss this with your partner. An ACP gives you the opportunity to say what is important to you. Your doctor, nurse or LBC Support Services Coordinator can explain what an ACP is and how to get a copy of the booklet.

## Talking to your children

Helping children to understand HL and how this will affect them can help them to cope with the changes and challenges of your diagnosis and treatment.

You can encourage younger children in your treatment journey to use an LBC sticker journal. Your children can record your treatments and write and share journal entries with you. Ask your LBC Support Services Coordinator for more information about the LBC sticker journal.

Counselling or psychological support is available if you are concerned about how your child or children are coping. Ask your health care team or LBC Support Services Coordinator for more information.

For pre-school or school-age children, it is a good idea to speak with their teachers to let them know about your diagnosis and treatment, and how this is affecting family/whānau routines and relationships.

Regular LBC Kids' Club events are held throughout the country and online to support children who have a loved one diagnosed with a blood cancer. These sessions are run by a trained facilitator who is experienced in supporting children through these situations.



## More information available online

See the Supporting a Child Through a Loved One's Cancer Diagnosis fact sheet on the LBC website.

## Talking to friends and colleagues

It can sometimes feel difficult to talk to friends and work colleagues about your HL diagnosis, and they may also find it difficult to discuss with you. Sometimes people, without realising it, make comments that can be hurtful or make suggestions that are unhelpful.

Most people are very keen to offer support but just don't know how.

Here are some suggestions to help you build your own support team:

- Let people know what you need – such as a regular phone call, text or visit.
- Share how you are feeling and any worries you have with someone who is a good listener.
- Encourage people to read this booklet or speak to your LBC Support Services Coordinator to learn more about HL.
- Either you or a friend could make a list of practical tasks others can do to help you. You might like to include things like cooking meals, picking a child up from school or cleaning the house.

You may not always feel well enough to answer phone calls or respond to texts. Some people find it helpful to have one person who updates friends and colleagues on how you are doing. That person can set up an email or social media group to share information.

Your journey with lymphoma may look different to other types of cancer. You may have periods of time when you are quite unwell, or when your condition is well managed and you can continue to work and socialise as you normally would have before your diagnosis.

Some people find that after a year or so of having HL, others don't ask how they are doing or understand that they might still be having ongoing treatment and appointments for their HL. Try and find a support network to help you feel validated and cared for.

This might be a variety of people like close friends, family/whānau, a colleague, counsellor or psychologist, or your LBC Support Services Coordinator.

## Financial worries

A diagnosis of HL can cause money worries, maybe due to earning less or having to spend more. If you are working, keep in touch with your employer to discuss sick leave and your plans for returning to work. Information about your employment rights while undergoing cancer treatment can be found on the LBC website or by asking your LBC Support Services Coordinator.

Ask a social worker for advice and support about money worries.



### More information available online

See the Blood cancer and your job section of the LBC website.

## Sexual relationships

People who receive a diagnosis of HL and have treatment can experience changes in their sex life.

The reasons for this can include:

- Extreme tiredness
- The side effects of treatment, e.g. nausea

- Changes in mood, e.g. anxiety
- Changes to body image, e.g. due to hair loss, weight change
- Changes to libido
- Vaginal dryness or difficulty getting an erection.

It is important to talk to your partner about sex and how your diagnosis and treatment are making you feel. If you are having problems with sex and it is affecting your relationship, or you are worried about starting a new relationship, speak with someone in your health care team. They can give you more information or refer you to someone who can help.

You cannot give cancer to another person when you have sex with them.

### Contraception

It is recommended that you do not try to get pregnant while on some treatments for HL. This is because some drugs may harm a developing baby. It is important to use contraception (such as condoms, the pill etc) during treatment and for several months afterwards.

If you are having or recently finished treatment, always use a condom when having sex. Even if you are beyond childbearing age or no longer need birth control, it is still important to use condoms until after your treatment has finished, for two main reasons:

1. To protect yourself from getting an infection. A low white blood cell count puts you at a higher risk of infection.
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, bowel motions and

sperm and vaginal secretions. The small amounts of chemotherapy that come out this way can cause irritation (a rash or itching) to your partner's skin.

Talk to your health care team if you have any questions about contraception or getting pregnant.

### Sex when you have a low platelet count

Speak with your doctor or nurse about having sex if your platelet count is low as you may need to be careful due to the risk of bleeding. It is often a good idea to use a lubricating gel (lube) such as KY Jelly.

### New relationships

Some people feel worried about starting a new relationship following a diagnosis of HL. It can be difficult to know what to say. Being open and honest about your experience will make it easier for you. Talk to your friends, family/whānau or health care team if you have concerns about what to say.

### Information for people supporting someone with HL

As the partner, parent or carer of someone with HL, it is quite common to experience feelings of stress, anger, fear, anxiety or depression. Speak with your health care team or LBC Support Services Coordinator if you are feeling this way. There is a lot of support available to you, including an online forum to meet other people in similar situations.

### Other things you can do:

- Look after yourself by eating well, getting enough sleep, doing regular exercise and relaxing.
- Keep doing your normal social activities.

- Join a support group and/or see a counsellor.
- Write down a list of things that have helped you get through a tricky situation previously. Use these tips to assist you now. Some ideas might include talking to friends or writing in a diary.

A diagnosis and the treatment of HL can put a lot of strain on a relationship. However, some people find that they feel closer because of what they go through together.

Remember that your health care team and LBC Support Services Coordinator are there to support you at any time throughout your diagnosis, treatment and beyond.

# KEEPING IN GOOD HEALTH AFTER YOUR HL DIAGNOSIS

**After a diagnosis of HL, it is important to look after your health. When you feel well enough, regular exercise and eating a variety of healthy foods are very important.**

The following health changes can reduce complications from your treatment or any long-term side effects:

- Stop smoking
- Protect your skin from the sun
- Stop drinking alcohol, or reduce the amount you are having.

Your health care team is available to help you to keep well:

- A physiotherapist can advise you about the exercise that is right for you.
- A dietitian can give you advice about eating well, especially if your treatment is making you feel sick or you have taste changes.
- Ask your doctor or nurse about support to help you stop smoking and stop or reduce drinking alcohol.

Contact your LBC Support Services Coordinator if you would like more information about exercise options in your area.



## More information available online

See the Follow-up Care After Lymphoma Treatment fact sheet on the LBC website.

# THE FUTURE

**A diagnosis of HL can affect many areas of your life, such as work or school, your emotions, relationships and finances.**

For some people, a diagnosis of HL can mark a turning point in their lives. For other people, a diagnosis means they feel their life has been put 'on hold'. The length of time it takes to recover emotionally and physically from an HL diagnosis and/or treatment is different for everyone. For example, getting back to your previous routine of work, school or childcare may be a goal, or it may not be what you want any more. You may need or want to make a few changes to your life.

**Your health care team and LBC Support Services Coordinator can help you manage:**

- Day-to-day practical problems including work, travel and travel insurance.
- Relationships and communication with family/whānau, friends and colleagues.
- Emotional effects of HL and treatment, including fear of relapse and feeling uncertain about the future.

There is a lot of support available to help you and those around you cope.

Some people find it helpful to speak to someone else who has been diagnosed with HL, or their support person. Your nurse, specialist or LBC Support Services Coordinator may be able to put you in contact with someone you can talk to.

## Travelling overseas

If you are thinking of travelling overseas, speak to your doctor before making any bookings to check if they have any concerns about you travelling.

It can sometimes be difficult to get travel insurance when you have been diagnosed with cancer. Speak with your LBC Support Services Coordinator, who will be able to help you.

## After treatment

Once your treatment has finished, you will have regular check-ups with your haematologist or oncologist and health care team. You will also be encouraged to go back to see your GP. Your health care team will send regular letters to your GP to tell them about your progress and what needs to be followed up, e.g. blood tests and vaccinations. If your GP has any questions, they are able to contact your haematologist or oncologist for advice.



### More information available online

See the Follow-up Care After Lymphoma Treatment fact sheet on the LBC website.

# GLOSSARY

**Alopecia** – Hair loss, which can occur temporarily following treatments for HL such as chemotherapy.

**Anaemia** – A reduction in the haemoglobin level in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

**Antibiotics** – Drugs that kill or stop the growth of bacteria, e.g. penicillin

**Antibodies** – Naturally produced substances in the blood, made by white blood cells called B-lymphocytes or B-cells. Antibodies target antigens on foreign or abnormal cells such as bacteria, viruses and some cancer cells and cause their destruction.

**Antiemetic** – A drug which prevents or reduces feelings of sickness (anti-sickness) or vomiting.

**Antigen** – A substance that can stimulate white blood cells to get rid of the antigen or attack it directly. This is called an immune response. Also see Immune system in this glossary.

**Anxiety** – An ongoing worry or concern that doesn't go away. Feelings of worry that a person does not seem to be able to control or seem greater than they should be for a situation.

**Biopsy** – A small sample of fresh tissue, e.g. lymph node or bone marrow, removed for testing under a microscope in a laboratory, to establish the exact diagnosis or to monitor treatment response.

**Blood count** – Also called a full blood count (FBC) or complete blood count (CBC). A routine blood test that measures the number and types of cells circulating in the blood.

**B-lymphocyte** – A type of white blood cell that produces antibodies to fight infection. Also called a B-cell.

**Bone marrow** – The tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

**Bowel** – Also known as intestines or guts. After your stomach has finished with the food you eat it goes into your small bowel, which absorbs nutrients that the body needs. What is left after this moves into your large bowel and eventually moves out of your body as waste, known as a bowel motion or, as it is commonly known, poo.

**Cancer** – A malignant disease where abnormal cells grow, divide and accumulate uncontrollably and can invade other tissues from the original site where the cancer started. Cancer cells can grow and multiply to form a lump or swelling (a tumour). Not all tumours are due to cancer; tumours that are not cancer are called non-malignant or benign tumours.

**Cannula** – A plastic tube that is inserted into a vein (intravenously or IV) to allow fluid to enter the bloodstream.

**Central line** – Also known as a central venous catheter (CVC) or central venous access device (CVAD). A tube passed through the large veins of the arm, neck, chest or groin and into the central blood circulation. It can be used to take blood samples, or give IV fluids, blood or medications including chemotherapy.

**Chemotherapy** – Single drugs or combinations of drugs which may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some common side effects including hair loss (alopecia) and a sore mouth (mucositis). Nausea and vomiting are also common, but nowadays are largely preventable with modern antiemetic medication. Most of the side effects of chemotherapy are usually temporary and reversible.

**Chromosomes** – Your body is made up of cells. Inside most cells are chromosomes which, under a microscope, look like threads. These threads contain hundreds to thousands of genes. Genes determine things like what colour your hair and eyes are and how your body develops. You have 23 pairs of chromosomes and you get half from your mother and the other half from your father.

**Chronic** – An illness or disease that persists for a long time or is constantly recurring (coming back).

**Complementary therapies** – Therapies used alongside your medical treatment that can help you feel better or help you cope with your diagnosis and treatment, e.g. massage, yoga.

**Complete remission** – Anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology.

**CT scan, also known as CAT scan (computerised axial tomography)** – A specialised scan that produces detailed 3D images of cross sections of the body.

**Cure** – This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

**Cytogenetic tests** – Commonly carried out on samples of blood and bone marrow to detect chromosomal abnormalities (things that are wrong with the chromosomes) associated with disease. This information helps in the diagnosis and selection of the best treatment.

**Digestive system** – The system in your body that deals with food. Starts at your mouth and ends at your bottom. Turns food and fluids into fuel for your body.

**Disease progression** – This means that the disease is getting worse despite treatment.

**DNA (deoxyribonucleic acid)** – The cell's hereditary material which contains instructions for development, growth and reproduction. DNA is located in nearly every cell of the human body. DNA is found in chromosomes.

**Foetus** – An unborn child.

**Genes** – Genes are made up of DNA. Each chromosome contains many genes. Every person has two copies of each gene, one inherited from each parent.

**Granulocyte colony stimulating factor (GCSF)** – A growth hormone given to stimulate the bone marrow to produce certain types of blood cells. It is often used to treat neutropenia, or before a stem cell harvest for a stem cell transplant.

**Haematologist** – A doctor who specialises in the diagnosis and treatment of diseases of the blood, bone marrow and immune system.

**Haematopoiesis (or haemopoiesis)** – The processes involved in blood cell formation.

**Immature** – Not fully developed, e.g. a cell that is immature is still at a baby stage. It will mature (or develop) over time to an adult stage.

**Immune suppression** – The use of drugs to reduce the function of the immune system.

**Immune system** – The body's defence system against infection and disease.

**Immunocompromised** – When the function of the immune system is reduced.

**Immunoglobulin** – See Antibodies in this glossary.

**Immunophenotyping** – A specialised laboratory test used to detect markers on the surface of cells. These markers identify the origin of the cell.

**Incurable** – A disease or illness that is unable to be completely removed or treated. Unable to be cured.

**Indolent** – Slow-growing.

**Laparoscopy** – An operation done through a small keyhole incision in the skin, often assisted by camera views. The spleen and gallbladder are often removed using this technique.

**Leukaemia** – Cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and immature blood cells. These cells crowd the bone marrow and spill out into the bloodstream.

**Leukaemic cells** – Abnormal cells which multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the bloodstream and can build up in other organs.

**Lymph nodes or glands** – Small structures found throughout the body, e.g. in the neck, groin, armpit, chest and abdomen, which contain both mature and immature lymphocytes. There are hundreds of lymph nodes throughout the body.

**Lymphatic system** – An large network of vessels that carries a fluid called lymph through almost all tissues in the body. Lymph moves through the body in a similar way to blood. The lymphatic system is part of the immune system.

**Lymphocytes** – Specialised white blood cells involved in defending the body against disease and infection. There are three types of lymphocytes: B-lymphocytes (B-cells), T-lymphocytes (T-cells) and natural killer cells (NK cells).

**Lymphoid** – Term used to describe a pathway of maturation of blood cells in the bone marrow. Some white blood cells (including B-lymphocytes and T-lymphocytes) are derived from the lymphoid stem cell line.

**Malignancy** – See Cancer in this glossary.

**Markers** – A gene or DNA sequence with a known physical location, and where it has come from. In genetics, markers act as chromosomal landmarks. They are used to trace or identify a specific region of a gene on a chromosome.

**Menopause** – The time in a woman's life when her period stops and she is no longer able to have children. Hormones produced by the ovaries decrease after menopause. Also see Ovaries in this glossary.

**Mucositis** – An inflammation of the lining of the mouth, throat or gut.

**Myeloid** – A term used to describe a pathway of maturation of blood cells in the bone marrow. Red blood cells, some white blood cells (neutrophils, eosinophils, basophils and monocytes) and platelets are derived from the myeloid stem cell line.

**Neutropenia** – A low number of circulating neutrophils, an important type of white blood cell. Neutropenia is associated with an increased risk of infection.

**Neutrophils** – Neutrophils are the most common type of white blood cell. They are needed to fight effectively against infection.

**Oncologist** – General term used for a specialist doctor who treats cancer, e.g. medical, radiation, surgical oncologist.

**Ovaries** – Small organs that produce and then release eggs into a woman's reproductive system and produce female hormones.

**Partial remission** – The tumour shrinks to less than half its original size after treatment. There are still some lymphoma cells present.

**Petechiae** – Tiny purple or red spots on the skin caused by bleeding into the skin. They commonly appear in clusters and may look like a rash. They are usually flat to the touch and don't lose their colour when you press on them.

**Plasma** – A light-yellow coloured fluid in the blood. This fluid carries blood cells, nutrients, hormones and proteins to different parts of the body.

**Platelets** – Type of blood cells produced in the bone marrow that circulate in the blood, involved in clotting and the control of bleeding.

**Popcorn cells** – Abnormal cells sometimes found in nodular lymphocyte-predominant HL.

**Power of attorney** – One person gives another person permission to act on their behalf, such as making decisions about their health or operating their bank account. You usually see a lawyer to arrange this.

**Prognosis** – An estimate of the likely course of a disease.

**Psychological** – Relating to your mental and emotional well-being.

**Radiotherapy (radiation therapy)** – The use of high-energy X-rays to kill cancer cells and shrink tumours.

**Red blood cells** – Transport oxygen from the lungs to all the cells in the body.

**Relapse** – The return of the original disease.

**Resistant or refractory disease** – This means that the disease is not responding to treatment.

**Rigors** – A chill (feeling cold), usually with shivering, at the onset of having a high fever (temperature).

**Spleen** – An organ that accumulates lymphocytes, acts as a reservoir for red blood cells for emergencies, and destroys red blood cells, white blood cells and platelets at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It is often enlarged in diseases of the blood or bone marrow.

**Splenomegaly** – Enlargement of the spleen.

**Stable disease** – When a disease is stable, it is not getting any worse or any better with treatment.

**Stem cells** – Stem cells are primitive cells that can give rise to more than one cell type. There are many different types of stem cells in the body. Bone marrow (blood) stem cells have the ability to grow and produce all the different blood cells including red blood cells, white blood cells and platelets.

**Stem cell transplant (haemopoietic or blood stem cell transplant)** – The general name given to bone marrow and peripheral blood stem cell transplants. These transplants are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of cancers including leukaemia, lymphoma, myeloma and other diseases.

**Supplements** – Tablets or liquids you take as well as the food you eat. Supplements include vitamins, minerals, herbs and other plants.

**T-lymphocyte** – A type of white blood cell involved in controlling immune reactions. Also called a T-cell.

**Tumour** – An abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

**Ultrasound** – Pictures of the body's internal organs built up from the interpretation of reflected sound waves.

**Urinary tract infection (UTI)** – An infection in any of the parts of your body which make or store urine or take urine out of your body, e.g. bladder or kidneys.

**White blood cells** – Specialised cells of the immune system that protect the body against infection. There are five main types of white blood cells: neutrophils, eosinophils, basophils, monocytes and lymphocytes.

# APPENDIX A

**The following are sample questions to ask your doctor when you are diagnosed with HL, referred to a haematologist or are considering treatment.**

Place a tick alongside the questions you would like to ask. You could add your own questions in the space provided. Record the answers to your chosen questions in your Haematology Patient Diary or on the 'Questions and notes' page that follows.

- Which doctor will be managing my lymphoma?
- How often do I need to have a blood test? Will my GP or haematologist review my blood tests and who will contact me with the results?
- How do I arrange an appointment if I develop new symptoms?
- What should I do if I develop an infection during the night or at the weekend?
- Is there anything I can do to help my general health?
- What exactly does the treatment involve? How long will the entire treatment take? What are the alternatives to this treatment?
- How ill might I feel before, during and after treatment?
- What are the potential side effects, how long might they last and how serious are they? Why are you recommending this treatment for me?
- What is the expected outcome of this treatment for me? For example, complete remission, prolonged remission, symptom management.
- If the HL comes back (relapses), what are the options for me?
- How can I prepare myself for starting treatment?

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# ACKNOWLEDGEMENTS

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## **Leukaemia & Blood Cancer New Zealand**

LBC is the leading organisation in New Zealand dedicated to supporting patients and their families/whānau living with leukaemia, lymphoma, myeloma and related blood conditions.

Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants.

LBC is committed to improving the quality of life for patients and their families/whānau living with these blood cancers and conditions by providing patient support services, investing in and supporting research, providing information, raising awareness and advocating on behalf of patients and their families/whānau.

# HAEMATOLOGY CENTRES IN NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
North Shore Hospital	Shakespeare Road, Takapuna, Auckland	09 486 8900
Auckland City Hospital	Park Road, Grafton, Auckland	09 367 0000
Starship Hospital	Park Road, Grafton, Auckland	09 367 0000
Middlemore Hospital	Hospital Road, Otahuhu, Auckland	09 276 0044
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
Thames Hospital	Mackay Street, Thames	07 868 0040
Tauranga Hospital	Cameron Road, Tauranga	07 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	07 348 1199
Hastings Hospital	Omahu Road, Hastings	06 878 8109
Whakatane Hospital	Stewart Street, Whakatane	07 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	06 356 9169
Wellington Hospital	Riddiford Street, Newtown, Wellington	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
Christchurch Hospital	Riccarton Avenue, Christchurch	03 364 0640
Dunedin Hospital	Great King Street, Dunedin	03 474 0999
Invercargill Hospital	Kew Road, Invercargill	03 218 1949

## Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with leukaemia, lymphoma, myeloma or a related blood condition is not easy, and our Support Services Coordinators are here to help.

**Freephone** 0800 15 10 15

**Telephone** 09 638 3556

**Facsimile** 09 638 3557

**Email** [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz)

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