

Non-Hodgkin Lymphoma

A guide for patients, families & whānau



our mission is to care, our vision is to cure

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There is a separate information booklet called 'Hodgkin Lymphoma – a guide for patients, families and whānau' available from Leukaemia & Blood Cancer New Zealand.

Introduction

This booklet has been written to help you and your family or whanau understand more about non-Hodgkin lymphoma (NHL).

If you or someone you care for 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 different treatment options with your doctor and your family. 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 doctor or specialist nurse.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

We have used some medical words and terms that you may not be familiar with. Their meaning is either explained in the text, in the glossary of terms at the back of this booklet, or in the 'Dictionary of Terms' booklet available through Leukaemia & Blood Cancer New Zealand.

Some people may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, many of you will receive written information from the doctors and nurses at your treatment centre.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your circumstances at all times with your doctor and treatment team.

We hope that you find this booklet useful. There is a feedback form in the back of this booklet, please feel free to fill this in and return it to us to assist in the production of future editions.

Acknowledgements

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Leukaemia & Blood Cancer New Zealand also gratefully acknowledges Dr Leanne Berkahn (Auckland City Hospital) and Dr Allannah Kilfoyle (Palmerston North Hospital) for their assistance with the development of this booklet.

Leukaemia & Blood Cancer New Zealand

Leukaemia & Blood Cancer New Zealand (LBC) is the only organisation in New Zealand dedicated to supporting patients and their families 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. We do not receive government funding.

LBC manages the New Zealand Bone Marrow Donor Registry, which works towards finding matched volunteer donors from New Zealand or overseas for New Zealand patients who need a bone marrow or stem cell transplant and who do not have a family donor. The registry maintains information on New Zealand donors and has access to a worldwide database of over 18 million donors.

Patient Support

Leukaemia & Blood Cancer New Zealand's Support Services provide personalised support programmes for patients and their families. This can include regular visits, phone or email contact, as well as face to face education and support programmes and an online information forum. We also provide a toll free number for advice, empathy and support.

Research

Research plays a critical role in building a greater understanding of blood cancers and conditions. LBC supports and funds investigation into these conditions. Improved treatments for patients can lead to increased survival rates.

Information

We provide vital information to patients, families, health professionals and the community to improve understanding about blood cancers and conditions.



Awareness

We work to increase public knowledge of blood cancers and conditions. This is achieved through specifically focused campaigns for the public, health professionals and health agencies.

Advocacy

We represent the needs of patients and their families to the government, related agencies and other relevant organisations.

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, but you don't have to do it alone.



Call **0800 15 10 15** to speak to a local Support Services Coordinator or to find out more about the services offered by Leukaemia & Blood Cancer New Zealand. Alternatively, contact us via email by sending a message to info@leukaemia.org.nz or by visiting www.leukaemia.org.nz.

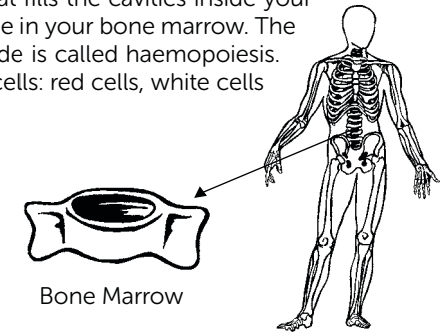
We welcome visitors to our offices in Auckland, Wellington and Christchurch. Please phone for an appointment.

Bone marrow, stem cells & blood cell formation

Bone marrow

Bone marrow is the spongy tissue that fills the cavities inside your bones. All of your blood cells are made in your bone marrow. The process by which blood cells are made is called haemopoiesis. There are three main types of blood cells: red cells, white cells and platelets.

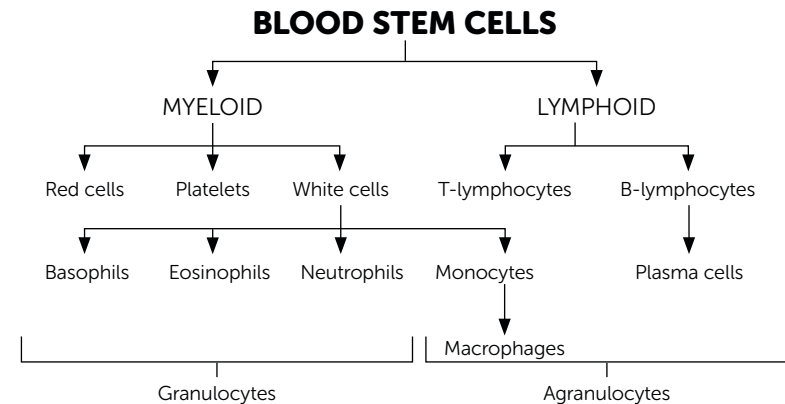
As an infant, haemopoiesis takes place at the centre of all bones. As an adult, fewer new cells are needed – the marrow space in the arms and legs is replaced by fat, and active marrow is limited to the hips, ribs and breastbone (sternum).



You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the blood stem cells. They are relatively few in number but are able, when stimulated, not only to replicate themselves, but also to grow and divide into slightly more mature stem cells called myeloid stem cells and lymphoid stem cells. These can multiply and mature further to produce all the circulating blood cells.

Myeloid ('my-loid') stem cells develop into red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets.

Lymphoid ('lim-foid') stem cells develop into two other types of white cells called T-lymphocytes and B-lymphocytes.



Blood

Blood consists of blood cells and plasma. Plasma is the straw coloured fluid part of the blood, which blood cells use to travel around your body.

Blood cells

Red cells and haemoglobin

Red cells contain haemoglobin (Hb), which transports oxygen from the lungs to all parts of the body. Haemoglobin also carries carbon dioxide to the lungs where it can be breathed out.

The normal haemoglobin range for a man is between 130 - 170 g/L

The normal haemoglobin range for a woman is between 120 - 160 g/L

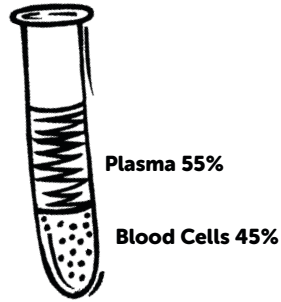
Red cells are by far the most numerous blood cell and the proportion of the blood that is occupied by red cells is called the haematocrit. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

The normal range of the haematocrit for a man is between 40 - 52%

The normal range of the haematocrit for a woman is between 36 - 46%

Anaemia is a condition caused by a reduction in the number of red cells, which in turn results in a low haemoglobin. Measuring either the haematocrit or the haemoglobin will provide information regarding the degree of anaemia.

If you are anaemic you will feel run down and weak. You may be pale and short of breath or you may tire easily because your body is not getting enough oxygen. In this situation a red cell transfusion may be given to restore the red cell numbers and therefore the haemoglobin to normal levels.



White cells

White cells, also known as leucocytes, fight infection. There are different types of white cells which fight infection together and in different ways.

Granulocytes:

| | |
|-------------|--|
| Neutrophils | kill bacteria and fungi |
| Eosinophils | kill parasites |
| Basophils | work with neutrophils to fight infection |

Agranulocytes:

| | |
|---------------|--|
| T-lymphocytes | kill viruses, parasites and cancer cells; produce cytokines |
| B-lymphocytes | make antibodies which target microorganisms |
| Monocytes | work with neutrophils and lymphocytes to fight infection; they also help with antibody production and act as scavengers to remove dead tissue. These cells are known as monocytes when they are found in the blood and macrophages when they migrate into body tissues to help fight infection |

If your white cell count drops below normal you are at risk of infection.

The normal adult white cell range is between $4.0 - 11.0 \times 10^9/L$

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1.0 ($1.0 \times 10^9/L$) you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections.

The normal adult neutrophil range is between $2.0 - 7.5 \times 10^9/L$

Platelets

Platelets are disc-shaped cellular fragments that circulate in the blood and play an important role in clot formation. They help to prevent bleeding. If a blood vessel is damaged (for example by a cut), the platelets gather at the site of the injury, stick together and form a plug to help stop the bleeding.

The normal adult platelet range is between $150 - 400 \times 10^9/L$

Thrombocytopenia is the term used to describe a low platelet count. If your platelet count is low, you are at higher risk of bleeding, and tend to bruise easily. Platelet transfusions are sometimes given to bring the platelet count back to a higher level. In certain situations, especially when patients are receiving some chemotherapy treatments, platelets may be transfused if the blood level falls below $10 \times 10^9/L$.

The normal blood counts provided here may differ slightly from the ones used at your treatment centre. You can ask for a copy of your blood results, which should include the normal values for each blood type.

Growth factors and cytokines

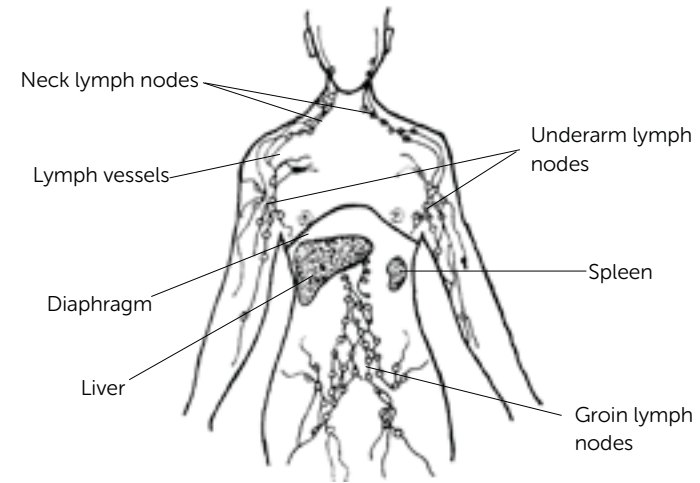
All normal blood cells have a limited survival in the circulation and need to be replaced on a continual basis. Natural chemicals in your blood called growth factors or cytokines control the process of blood cell formation. Different growth factors stimulate the blood stem cells in the bone marrow to produce different types of blood cells.

Many growth factors can be made in the laboratory (synthesised) and are available for use in people with blood disorders. For example, granulocyte-colony stimulating factor (G-CSF) stimulates the production of white cells called neutrophils, while erythropoietin (EPO) stimulates the production of red cells. Unfortunately, drugs to stimulate platelet production have been less successful, but research is continuing in this area.

The lymphatic system

The lymphatic system is made up of a vast network of vessels, similar to blood vessels that branch out into all the tissues of the body. These vessels contain lymph, a colourless watery fluid that carries lymphocytes, specialised white blood cells that fight infection. There are two types of lymphocytes, B-lymphocytes and T-lymphocytes (called B-cells and T-cells). These cells protect us by making antibodies and destroying harmful microorganisms like bacteria and viruses. As such, 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 (also known as lymph glands) are found at various points throughout the lymphatic system. The lymph nodes, which are filled with lymphocytes, act as important filtering stations, cleaning the lymph fluid as it passes through them. Here bacteria, viruses and other harmful substances are removed and destroyed. When you have an infection, for example 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.



The spleen (an organ on the left side of the abdomen), thymus (a gland found behind the breast bone), tonsils and adenoids (glands in the throat) and bone marrow (spongy material inside bones) all contain lymphatic tissue and are therefore considered to be part of the lymphatic system. Lymphatic tissue is also found in other parts of the body.

What is lymphoma?

Lymphoma is the general term for cancers that develop in the lymphatic system. Lymphoma originates in developing B-lymphocytes and T-lymphocytes, which have undergone a malignant change. This means that they multiply without any proper order forming tumours, which are collections of cancer cells. These tumours cause swelling in the lymph nodes and other parts of the body. Over time, malignant lymphocytes (called lymphoma cells) crowd out normal lymphocytes and eventually the immune system becomes weakened and can no longer function properly.

The World Health Organisation currently recognises over 40 different sub-types of lymphoma, with five of these sub-types belonging to a group of diseases called Hodgkin lymphoma. All other sub-types are commonly grouped together and called non-Hodgkin lymphoma (or B- and T-cell lymphomas).

Each year in New Zealand more than 800 people are diagnosed with lymphoma, making it the sixth most common type of cancer. The majority of these people have non-Hodgkin lymphoma, which represents more than 85% of all cases.

Non-Hodgkin lymphoma is seen in all age groups, but is more common in people over the age of 50. In children, non-Hodgkin lymphoma and leukaemia (bone marrow cancer) are the most common types of cancer seen,

but few children overall are ever diagnosed with these diseases. Lymphomas in children tend to grow quickly, but are often curable.

Significant advances are continually being made in the way we manage lymphomas. This means that with treatment, many people can now be cured. Many others who are treated remain disease-free and well for a long time.

There is a separate booklet called 'Hodgkin Lymphoma – a guide for patients and whānau' available from Leukaemia & Blood Cancer New Zealand

What causes lymphoma?

Many people who are diagnosed with lymphoma ask the question “why me”? Naturally, they want to know what has happened or what they might have done to cause their disease. The number of people diagnosed with lymphoma is rising, but in the majority of cases we don't know why.

We do know lymphoma is not contagious, that is, you cannot ‘catch’ it by being in contact with someone who has it, and in most cases people who are diagnosed with lymphoma have no family history of the disease.

There are certain factors which may put some people at a higher risk of developing this disease. 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 as a result 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 the human T-cell leukaemia/lymphoma virus (HTLV-1) may damage developing lymphocytes and put people at a higher risk of developing lymphoma.

Chemicals

Some evidence suggests that farmers and other people who are 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 whom have been exposed to significant or long term radiation may also be at an increased risk of developing lymphoma.

What are the symptoms of lymphoma?

Some people do not have any symptoms when they are first diagnosed with lymphoma. In these cases the disease may be diagnosed incidentally, whilst undergoing routine medical tests or general check-ups.

Lymphoma commonly presents as a firm, usually painless swelling of a lymph node (swollen glands), usually in 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, for example a sore throat. In these cases, the glands in the neck are usually swollen and painful.

Other symptoms may include:

- regular and frequent fevers
- excessive sweating, usually at night and often drenching, known as “night sweats”
- unintentional weight loss
- persistent fatigue and lack of energy
- generalised itching

These symptoms may also be seen in other illnesses, such as viral infections, and most people with these symptoms do not have lymphoma. However, it is important to see your doctor if you have any symptoms that do not go away so that you can be examined, investigated and treated in a timely fashion.

Sometimes lymphoma starts in the lymph nodes in deeper parts of the body like those found in the abdomen (causing bloating), or the lymph nodes in the chest (causing coughing, discomfort in the chest and difficulty breathing). When it is first diagnosed, lymphoma is commonly found in several different sites in the body at once. It can spread to any organ and commonly may involve the bone marrow, spleen, liver and central nervous system.

Which doctor?

If your general practitioner (GP) suspects that you might have lymphoma you will be referred to a specialist doctor for further tests and treatment. These may include the following:

Haematologist: a doctor who specialises in the care of people with diseases of the blood, bone marrow and immune system.

Oncologist: a doctor who specialises in the treatment of cancer. A medical oncologist specialises in chemotherapy. A radiation oncologist specialises in radiotherapy and a surgical oncologist specialises in cancer surgery.

The treatment of your lymphoma will be the same regardless of which of the above specialist you see.



How is lymphoma diagnosed?

When you see your doctor about any of the symptoms above, there are a number of tests that may be taken to confirm a diagnosis of lymphoma, establish which sub-type of lymphoma you have and the stage it has progressed to.

Physical examination and medical history

The doctor will look and feel for any swelling of the glands in your neck, armpits and groin. Your abdomen and chest will also be examined for any signs of enlarged organs or fluid collection. The doctor will also ask you about any other symptoms you might have and your previous medical history.

Lymph node biopsy

If the doctor suspects that you might have lymphoma, a biopsy may need to be done to help confirm the diagnosis. A biopsy involves removing a lymph node or a sample of tissue from a suspicious lump, which is then examined in the laboratory.

There are different types of biopsies. A core biopsy or fine needle aspirate (FNA) involves inserting a needle into a lymph node or lump and removing a sample of fluid and tissue. This is usually done under local anaesthetic, while you are awake. If the affected lymph node is deep inside the body, the biopsy may be done with the help of ultrasound or specialised x-ray (imaging) guidance.

A surgical or excision biopsy involves removing the entire affected lymph node. You will need a general anaesthetic for this and you will have a few stitches afterwards.

If the swollen gland is in the abdomen or pelvis, a laparoscopy (or "keyhole" surgery) may be done to get a sample of the lymphatic tissue involved. A laparoscopy is a surgical procedure in which a narrow tube with a microscope attached, is inserted through a small cut in the skin. It allows the surgeon to see the inside of your abdomen or pelvis, and to take a biopsy if needed. This is done under general anaesthetic and you will have a few stitches afterwards.

Once the tissue samples are removed, they are examined in the laboratory by a pathologist. A pathologist is a doctor who is specially trained to examine tissue specimens and cells, to help diagnose diseases such as cancer.

It can take a few days for the final results of the biopsy to come through. This is because it takes time to process the tissue and complete various tests that are needed to make an accurate diagnosis of the exact type of lymphoma you may have.

Blood tests

Blood tests provide information on how well your bone marrow, liver, kidneys and other vital organs and systems are functioning. This is important because it provides a baseline set of results regarding your disease and general health. These results can be compared with later results to assess how well you are progressing. It is often routine to have your blood also tested for HIV (the AIDS virus), hepatitis B, C and other common viruses.

Other blood tests provide information on how fast your lymphoma is growing. A raised lactate dehydrogenase (LDH) level for example, might indicate that the lymphoma is growing quickly and needs to be treated as soon as possible.

Special tests

Special laboratory tests may be undertaken using blood, bone marrow or lymph node biopsy samples.

Immunophenotyping ('im-u-no-feen-o-typing')

Immunophenotyping, or flow cytometry tests, are commonly used to confirm a suspected diagnosis of lymphoma, and to distinguish it from other similar diseases. This technology uses the special markers, called antigens, found on the surface of cells. These antigens act like flags identifying the abnormal lymphocytes that are characteristic of lymphoma.

Antigens are commonly referred to as 'clusters of differentiation' or CD antigens followed by a number. In lymphoma certain B-cell antigens, such as CD20, are expressed on the cancerous cells. The presence of these markers helps to define the exact type of lymphoma you have and distinguish it from other diseases that can resemble lymphoma. For example, chronic lymphocytic leukaemia.

Cytogenetic ('cy-to-gen-etic') tests

Chromosomes are the organised structures of DNA inside our cells. A single piece of DNA contains many genes, which are our body's blueprint for life. Cancerous cells have developed mutations in their genetic make-up which can be detected using cytogenetic testing. The two main types of tests are chromosome analysis, which examines chromosomes under a microscope, and FISH (fluorescent in-situ hybridisation), which 'paints' the genes of interest with fluorescent dye.

Certain cytogenetic mutations, such as missing, extra or abnormal chromosomes help to confirm the sub-type of lymphoma you have, the likely prognosis of your disease and the best way to treat it. Note: these mutations develop as your cells age, so this type of chromosomal change is only found in the cancerous cells and is not inherited, that is passed down from parent to child.

Imaging tests

Computerised axial tomography (CT scan or CAT scan)

CT scans provide computer analysed, three dimensional (3D) images of cross sections of your body. This technology is able to detect tiny changes in tissue density which might indicate the presence of an infection or a tumour. The CT scan does not hurt and it usually takes less than an hour to complete. You may be surprised at the loud noise made by the CT machine. While the scan is being done you have to lie flat and still on a cushioned table that moves slowly through the CT machine. The machine itself looks like a giant ring surrounding the table. Sometimes a special dye, called contrast, is used to enhance the quality of the pictures taken. The dye may be swallowed or injected into a vein in your hand or arm before the scan. The CT scanner picks up the dye as it moves through the body, and helps to highlight structures like the blood vessels and loops of bowel.

CT scans of neck, chest, abdomen and pelvis are often used to assess the spread of lymphoma in the body.

Magnetic resonance imaging (MRI)

MRI uses very strong magnet and radio waves to produce detailed, computer analysed, three dimensional (3D) images of parts of your body. An MRI may be done when the doctor needs very clear pictures of specific areas such as the brain and spinal cord, to see if these areas are affected by cancer.

MRI is painless and usually takes about an hour to complete. It is similar to having a CT scan done.

Positron emission tomography (PET) scan

PET scanning uses radioactive glucose which is injected into a vein in your hand or arm. Special gamma cameras are then used to detect areas in the body that are affected by lymphoma.

PET scanning is similar to having a CT scan, and the two procedures may be combined at the same appointment.

PET scanning is available and funded in New Zealand for clinically specific situations, such as at the beginning of treatment to accurately stage your lymphoma, or if there are borderline lymph nodes in some areas on CT scan. The PET scan results are also used to help make decisions on radiation treatment after chemotherapy.

Bone marrow biopsy or examination

A bone marrow biopsy involves taking a sample of bone marrow, usually from the back of the iliac crest (hip bone) or from the sternum (breast bone) and sending it to the laboratory for examination under the microscope. It is done to check if there are any cancer cells present in the bone marrow and to see how well the bone marrow is functioning.

The bone marrow examination may be done in the hospital or outpatient clinic under local anaesthesia or, in selected cases, under sedation. A mild pain-killer is given beforehand and the skin is numbed using a local anaesthetic; this is given as an injection under the skin. The injection takes a minute or two, and you should feel only a mild stinging sensation.

After allowing time for the local anaesthetic to work, a long thin needle is inserted through the skin and outer layer of bone into the bone marrow cavity. A syringe is attached to the end of the needle and a small sample of bone marrow fluid is drawn out - this is called a 'bone marrow aspirate'. Then a slightly larger needle is used to obtain a small core of bone marrow which will provide more detailed information about the structure of the bone marrow and bone - this is known as a 'bone marrow trephine'.

If a sedative is used you might feel a bit drowsy afterwards, and it is advised you take a family member or friend along who can take you home. A small dressing or plaster over the biopsy site can be removed the next day. There may be some mild bruising or discomfort, which usually is managed effectively by paracetamol. More serious complications such as bleeding or infection are very rare.

Lumbar puncture (LP)

A lumbar puncture is a procedure where a small sample of the cerebrospinal fluid (CSF) that surrounds your brain and spinal cord is collected via 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 (CNS).

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

Waiting around for tests can be both stressful and tedious. Remember to ask beforehand how long the test will take and what to expect afterwards. You might like to take a book, some music or a friend for company and support.

Other tests

Once a diagnosis of lymphoma is made, other tests may be used to assess your general health. They may include:

- chest x-ray
- electrocardiogram (ECG)
- lung function tests
- 24-hour urine collection
- An echocardiogram (cardiac ultrasound), or a nuclear cardiac scan

Waiting for results can be a very distressing time for you and your family. It may help to talk about your feelings with someone you are close to or feel comfortable with.

Types of non-Hodgkin lymphoma

As mentioned earlier, lymphoma is not a single disease and knowing the exact type of lymphoma you have is important because it provides information on the most likely course of your disease and the best way to treat it.

The many different sub-types of non-Hodgkin lymphoma are broadly divided into the following two main groups:

- B-cell lymphomas (those that arise from developing B-lymphocytes)
- T-cell lymphomas (those that arise from developing T-lymphocytes)

The majority of non-Hodgkin lymphomas (over 80%) are B-cell lymphomas.

When deciding how to treat your lymphoma it is important to know how fast it is likely to grow and cause problems in your body. Some types of lymphoma grow slowly, cause few symptoms and may not need to be treated initially. These are known as:

- Indolent lymphomas (also called low-grade lymphomas)

Others grow more quickly, cause more severe symptoms and generally need to be treated soon after they are diagnosed. These are known as:

- Aggressive lymphomas and highly aggressive lymphomas (also called intermediate-grade and high-grade lymphomas)

Both the likely growth behaviour of your lymphoma, and whether it belongs to the B-cell or T-cell group, can be determined by examining the cells from your lymph node biopsy, under a microscope in the laboratory.

Below you will find some examples of B-cell and T-cell lymphomas. The more common types are written in **bold** text.

| B-Cell Lymphomas | T-Cell Lymphomas |
|---|--|
| Diffuse large B-cell lymphoma | Peripheral T-cell lymphoma |
| Follicular lymphoma | Mycosis fungoides |
| Burkitts lymphoma/leukaemia | Sezary syndrome |
| Chronic lymphocytic leukaemia/ small lymphocytic lymphoma | Angio-immunoblastic T-cell lymphoma |
| Mantle cell lymphoma | Anaplastic large cell lymphoma |
| Mediastinal (thymic) large B-cell lymphoma | Precursor T-lymphocyte leukaemia/lymphoma |
| Waldenstroms macroglobulinaemia (also called Lymphoplasmacytic lymphoma) | |
| Marginal Zone Lymphoma. 3 sub-types: * Extra nodal marginal zone B-cell lymphoma (also called mucosa-associated lymphatic tissue lymphoma or MALT lymphoma) * Nodal marginal zone B-cell lymphoma * Splenic marginal zone lymphoma | |

More information

The various types of non-Hodgkin lymphomas are distinguished from each by:

- Their cell of origin - lymphoma cells carry special marker-like 'flags' on their surface called antigens that identify them as having developed from either B- or T-lymphocytes (B-cell lymphoma or T-cell lymphoma).
- The appearance of the cell under the microscope - for example, the size of the cells (small or large cell) and how differentiated or mature they are. In general, the more immature cells are (those described as large cell, anaplastic or blastic cell lymphomas) the more aggressive in nature they tend to be, and therefore grow more quickly.
- Some lymphomas are described according to the areas within the lymph node they are found (mantle cell lymphoma, marginal zone lymphoma). While others are described according to the distinct way in which the cells are arranged within the lymph node (see follicular and diffuse large B-cell lymphoma below).
- The genetic make-up of the cells - certain genetic abnormalities, such as missing or extra chromosomes (collections of DNA) may help to distinguish one type of lymphoma from another type.

Lymphoma or leukaemia?

When lymphoma cells are found within the blood and bone marrow the cancer presents as leukaemia. When the affected cells are predominantly found in the lymphatic system however, the cancer almost always presents as lymphoma. In some cases the disease can present as either leukaemia or lymphoma and is therefore classified as both (i.e. leukaemia/lymphoma). Some people seem to have lymphoma first and then over time show signs that their disease is progressing to a type of leukaemia.

Diffuse large B-cell lymphoma

Diffuse large B-cell lymphoma is one of the most common types of lymphoma and represents about 30% of all cases. It usually affects middle aged and elderly people but it can also affect children and young adults. In this type of lymphoma the normal structure of the lymph node is disrupted and the lymphoma cells have spread widely (diffusely) throughout the lymph node. This type of lymphoma is regarded as aggressive and tends to spread over weeks or months from the lymph node to other areas of the body including the skin, gut, central nervous system and bone. Treatment is effective in the majority of cases.

Follicular lymphoma

Follicular lymphoma is another common type of lymphoma representing around 25% of all cases. Follicular lymphoma gets its name from the way in which the lymphocytes are arranged in clusters or circular structures called follicles, within the lymph node. This type of lymphoma is usually slow-growing, over months or years (indolent). They can usually be well controlled with treatment but like most indolent lymphomas, they are currently incurable.

B-cell chronic lymphocytic leukaemia (CLL)/small lymphocytic lymphoma

CLL is the most common type of leukaemia in the Western world. It usually affects older people. This disease can present as either leukaemia or lymphoma. Initially it tends to be an indolent disease, requiring little or no treatment for many years.

There is a separate booklet called 'Chronic Lymphocytic Leukaemia – a guide for patients and whānau' available from Leukaemia & Blood Cancer New Zealand

Mantle cell lymphoma

Mantle cell lymphoma is a rarer form of non-Hodgkin Lymphoma but it can be more aggressive than the other small B-cell lymphomas as it is usually more widespread when it is first diagnosed. However there are some patients who present with an asymptomatic and slow growing form of this sub-type.

Burkitts lymphoma/leukaemia

Burkitts lymphoma is a rare but highly aggressive type of lymphoma. It can also present as leukaemia. Burkitts lymphoma produces a mass of lymphoma cells often in the abdomen and can spread very quickly (over days). It is usually treated with high doses of chemotherapy.

Cutaneous T-cell lymphomas

Cutaneous T-cell lymphomas (including mycosis fungoides and sezary syndrome) primarily affect the skin and the lymph nodes. In the early stages these lymphomas are generally indolent. Redness of the skin and intense itching is common, and treatment involves the use of creams, emollients, medications to help you stop itching, and ultraviolet light. Chemotherapy and radiotherapy may also be used in more advanced stage disease.

AIDS-related lymphoma

Lymphomas that occur in people with human immunodeficiency virus (HIV) tend to be aggressive and quite advanced when they are first diagnosed.

Central nervous system lymphoma

In the more aggressive types of disease, lymphoma can spread from its original site to the brain, spinal cord or eye. In the case of primary central nervous system lymphoma, the disease is only found in these areas. Treatment usually involves radiotherapy and chemotherapy that specifically targets the lymphoma in this area.

For more information on your particular type of lymphoma contact Leukaemia & Blood Cancer New Zealand.

What is staging?

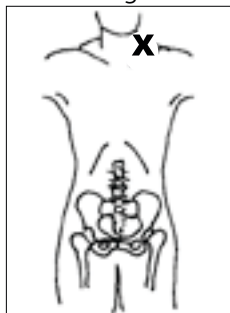
The extent to which the cancer has spread in the body is called the stage of the disease. In stages 1 and 2, lymphoma is limited to one or two areas of the body (early stage). In stages 3 and 4, the disease is more widespread in the body (advanced stage).

At the time of diagnosis it is not uncommon for both indolent and aggressive types of lymphoma to have spread to several sites in the body.

Knowing the stage of your lymphoma is important because it provides more information regarding the best way to treat your disease.

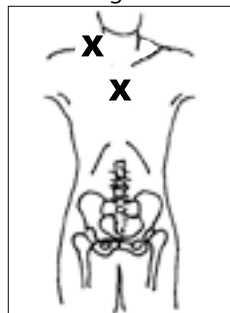
Stages of lymphoma

Stage 1



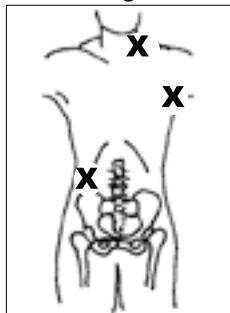
lymphoma is limited to one group of lymph nodes or one organ/area outside the lymph nodes

Stage 2



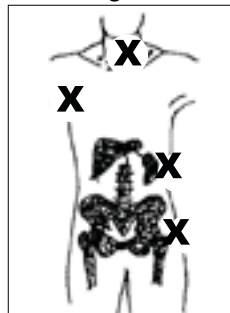
lymphoma is limited to two groups of lymph nodes or organs/areas outside the lymph nodes above or below the diaphragm (the large muscle that separates the stomach and the chest)

Stage 3



lymphoma is found in lymph nodes and/or an organ or other area both above and below the diaphragm

Stage 4



lymphoma has spread outside the lymph nodes to one or more organs, for example; the bone marrow, lungs, liver and skin

A, B or E?

Each stage is described further according to the symptoms you have when you are first diagnosed. If you have symptoms including fever, night sweats and unexplained weight loss the letter 'B' will be put after the stage of your lymphoma, for example stage 2B.

If you do not have these symptoms, the letter 'A' will appear after the stage of your lymphoma, for example stage 2A.

The letter 'E' is used when lymphoma has spread to an area or organ outside the lymph nodes.

What is prognosis?

A prognosis is an estimate of the likely course of a disease and the possibility of relapse in the future. It provides a guide regarding the chances of curing or controlling the disease for a given timeframe.

Your doctor is the best person to give you an accurate prognosis regarding your lymphoma as he or she has the necessary information to make this assessment.

The particular sub-type is crucial in estimating a prognosis. While the vast majority of lymphomas respond well to therapy, some sub-types are currently incurable and the aim of treatment for this group is disease control. Treatments for lymphoma continue to improve and many people remain disease-free and well for a long time - this is also known as being in remission. If your lymphoma comes back or relapses, more treatment may be required to get you well again and back into remission.

Commonly used prognostic terms

The following terms may be used to describe how well your disease has responded to treatment:

Cure - This means that there is no evidence of cancer and no sign of cancer reappearing even many years later. With treatment, many people with lymphoma can be cured of their disease.

Complete remission (CR) - This means that the treatment has been successful and that so much of the cancer has been destroyed that it can no longer be detected on the tests repeated after treatment. The length of time that a remission lasts varies from person to person. The cancer may reappear even after a long time so regular check-ups are necessary while you are in remission.

Partial remission - This term is used when the cancer shrinks to less than half its original size following treatment, but there is still some lymphoma present.

Stable disease - When the cancer is stable and is not getting any worse or any better with treatment.

Relapse - The cancer has reappeared.

Resistant or refractory disease - This means that the cancer is not responding to treatment.

Disease progression - This is when the lymphoma is getting worse, on or off treatment.

How is lymphoma treated?

The treatment chosen for your disease depends on several factors including the particular type of lymphoma you have, where it has spread within your body, your age and your general health.

Information gathered from thousands of other people around the world who have had the same disease helps to guide the doctor in recommending the best treatment for you.

Remember that no two people are the same. In helping you to make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

Treatment for lymphomas may involve the use of chemotherapy, radiotherapy and immunotherapy, or combinations of these treatments. Blood stem cell transplantation may also be used.

Informed consent

Giving your informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you feel you have adequate information to make such a decision.

Your informed consent is also required if you agree to take part in a clinical trial, or if information is being collected about you or some aspect of your care (data collection).

If you have any doubts or questions regarding any proposed procedure or treatment, please do not hesitate to talk to the doctor or nurse again.

Standard therapy

Standard therapy refers to a type of treatment which is commonly used in particular types and stages of disease. It has been tried and tested (in clinical trials) and has proven to be safe and effective in a given situation.

Clinical trials

Your specialist doctor may ask you to consider taking part in a clinical trial (also called a research study). Clinical trials test new treatments, or existing treatments given in new ways to see if they work better. Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side effects.

Participation in a trial may also involve giving blood or bone marrow samples in order to contribute to a better understanding of the disease. Clinical trials often give people access to new therapies not yet funded by governments.

Taking part in a clinical trial is entirely voluntary and you are under no obligation to participate. If you are considering taking part in a clinical trial, make sure that you understand the reasons for the trial and what it involves for you. You should always take time to consider all the implications of a trial and discuss this thoroughly with your specialist doctor and other support people before giving your informed consent. Your specialist doctor can guide you in making the best decision for you.

There is a separate booklet called 'Clinical Trials' available from Leukaemia & Blood Cancer New Zealand.

Indolent lymphomas (low grade)

Many low-grade lymphomas take years to grow, cause few (if any) symptoms, and do not necessarily need to be treated initially. In these cases the doctor may recommend regular check-ups to carefully monitor your health.

If the disease is limited to a small group of lymph nodes, radiotherapy alone may be able to cure some low-grade lymphomas, or control them for a long time. If the low-grade lymphoma is more widespread in the body, the decision to treat the disease or not, depends on a number of factors such as: where the lymphoma has spread to, how large the areas of lymphoma are, and your general condition. If treatment is warranted chemotherapy (either in tablet form or intravenously) and/or immunotherapy is usually given. This is very effective in the majority and puts many patients into a remission that lasts a variable length of time.

In some cases, low-grade lymphomas develop over time into more aggressive or high grade lymphomas which require more aggressive treatment.

Aggressive and highly aggressive lymphomas (intermediate and high-grade)

Intermediate-grade and high-grade lymphomas grow quickly, and treatment is needed when they are diagnosed. Chemotherapy and immunotherapy are the treatment of choice in these cases, and if these diseases respond well to initial treatment they can often be cured.

Central nervous system treatment

Lymphoma cells are sometimes found in the CNS (brain and spinal cord) at the time of diagnosis. In other cases lymphoma can appear or relapse within this area at a later stage. Because the blood supply to the CNS is different from the blood supply to other parts of the body, this area can act as a 'sanctuary site' or hiding spot for lymphoma cells. Here the cells can grow and multiply beyond the reach of standard chemotherapy drugs which normally travel throughout the rest of the body in the blood stream.

If you have CNS involvement with your lymphoma there are three possible forms of treatment.

1. Treatment involving injections of chemotherapy drugs directly into the spinal fluid (intrathecal injection), through a lumbar puncture.
2. Administration of high dose intravenous chemotherapy (methotrexate) for which you need to be an in-patient at hospital.
3. Radiotherapy to the brain can be given, which can be a very effective treatment for lymphoma in the CNS or in prevention of CNS relapse.

Relapsed or resistant lymphoma

Finding out that your cancer has relapsed or is resistant can be devastating; however there are usually several options for treating the disease and getting it back under control. A relapse does not necessarily mean treatment needs to start again immediately, some indolent lymphomas can be observed for quite long periods before treatment is required. Sometimes a recurrence in just one area is managed by radiotherapy alone.

The treatment of relapsed disease depends on a number of factors including the duration of the remission, the speed at which the disease has reappeared, and the number of times the cancer has been treated. Your age and general health are also taken into account when considering which treatment is suitable for you.

Similar drugs to those used to initially treat your lymphoma or in some cases different drugs may be used to treat relapsed disease. You may also be invited to take part in a clinical trial to test new and experimental treatments. Younger patients who respond to chemotherapy for relapse may be considered for a transplant in some circumstances.

Palliative care

Palliative care is aimed at relieving any symptoms or pain you might be experiencing as a result of your disease or its treatment, rather than trying to cure or control it. Palliative care is not purely aimed at end of life care. The palliative care team may be involved in your care throughout treatment, to help with any symptoms you may experience that are problematic.

If a decision is made to discontinue curative treatment for your lymphoma, there are still many things that can be done to help you to stay as healthy and comfortable as possible for as long as possible. This may involve receiving palliative chemotherapy or radiotherapy to control symptoms, but at much lower doses to reduce side effects.

Types of treatment

Treatment for lymphoma may involve the use of:

- Chemotherapy
- Corticosteroid therapy
- Immunotherapy
- Radiotherapy
- Stem cell transplant
- Experimental treatments with drugs not yet available for general use (e.g. clinical trials)

Chemotherapy

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxic drugs (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells.

Chemotherapy is the main form of treatment given for lymphoma. The dose, timing and types of the drugs used will vary depending on the particular disease involved, your age and general health, and the treatment protocol (plan of treatment) you are following.

Chemotherapy is usually given as a combination of drugs (combination chemotherapy). Each drug acts together to target the cancer in a different way, and also has different side effects. Therefore a combination may be more effective than a single drug in controlling your disease and the side effects are kept to a minimum. Chemotherapy is usually given in several cycles (or courses) with rest periods in between. This is to allow your body time to recover from the side effects.

Chemotherapy is given in many different ways in the treatment of lymphoma. Some drugs are given in tablet form (orally) or are injected into a vein (intravenously or IV) in your hand or arm. For some types of lymphoma, chemotherapy may also be given intrathecally (into the spinal fluid) to prevent or treat any CNS disease.

If you are having several cycles of chemotherapy your doctor may recommend that you have a central venous catheter (also called a central line) inserted. A central venous catheter is a special line inserted through the skin, into a large vein in your arm, neck or chest. Once in place, chemotherapy and any other IV drugs can be given through the line and blood tests can usually be taken from the line, without the need for frequent needle pricks. There are several different kinds of central lines used; some are intended for short term use while others remain in place for months and even years. These lines require special care to prevent infection. If necessary, the nurses at your treatment centre will teach you how to look after your line.

In most cases you don't need to be admitted to hospital for chemotherapy, which is usually taken at home or given in the hospital's day treatment centre. Sometimes, depending on the type of chemotherapy being given and your general health, you may need to be admitted to the ward for a short while.

There are a variety of initial chemotherapy approaches. In general some approaches are better tolerated with lower response rates overall, but excellent responses in some individuals. Others, especially combination therapies, have more side effects but better overall response rates. The choice of treatment for you depends on the preferences of you and your doctor, and the behaviour of your cancer cells.

The names of the different regimes used are commonly derived from the first letters of each of the drugs given. Some examples of combinations of drugs used to treat lymphoma are listed below. A typical chemotherapy regime for non-Hodgkin lymphoma involves six to eight cycles of a combination of drugs, given every 2 or 3 weeks over a period of several months.

| | |
|---------------|--|
| R-CHOP | R ituximab (an immunotherapy) C yclophosphamide H ydroxydaunorubicin (doxorubicin) O ncovin® (vincristine) and P rednisone (a corticosteroid) |
| CVP | C yclophosphamide V incristine P rednisone |
| ICE | I fosfamide C arboplatin E toposide |

Corticosteroid therapy

Corticosteroids are hormones produced naturally by the body. They can also be made in the laboratory. These drugs play an important role in the management of lymphoma. Prednisone and dexamethasone are examples of corticosteroids commonly used in the treatment of lymphoma. These drugs work by directly killing lymphoma cells as well as enhancing the effects of chemotherapy.

Immunotherapy

Immunotherapy refers to medications which work with your immune system to target specific cells, such as monoclonal antibodies like rituximab (MabThera). Monoclonal antibodies are specifically engineered to lock on to specific proteins found on the surface of abnormal cells like lymphoma cells.

Rituximab works by binding to a specific B-cell antigen, named CD20, found on the surface of some types of the lymphoma cells. This helps the patient's own immune system to recognise these cells as foreign and kill them. Because this type of therapy specifically targets one type of cell, they tend not to affect other healthy cells, which is why they are usually well tolerated with few side effects.

Further monoclonal antibodies continue to be developed and trialled which target specific antigens found in other types of lymphomas and also in different types of cancers.

Monoclonal antibodies are given as intravenous infusions, usually in the outpatient department of the hospital. They are usually used in combination with chemotherapy, but can be given alone or continued after the chemotherapy has been completed (called maintenance therapy). Side effects are generally mild and can generally be easily managed. They may include fever, chills and mild skin reactions.

Radiotherapy

Radiotherapy is a type of treatment that uses high energy x-rays to kill cancer cells and shrink tumours. Radiotherapy is generally regarded as local therapy because it only destroys cancer cells in the treated area.

Radiotherapy is used in the treatment of lymphoma to shrink very enlarged lymph nodes or a very enlarged spleen which are causing symptoms, or to treat lymphoma that is localised to only a small area of lymph nodes.

The radiation field is the area of the body which is being treated. Common fields include the mantle field (treating the lymph nodes of the neck, chest and armpit), the upper abdominal field (abdomen and sometimes spleen) and the pelvic field (hips and groin). 'Involved Field Radiotherapy' is the term sometimes used to describe radiotherapy being given to the local area where lymph nodes are found to be involved. The area of normal tissue encompassed by the radiotherapy field is kept to the smallest area possible to avoid affecting the normal tissues.

Before you start radiotherapy, the radiation oncologist (doctor who specialises in treating people with radiotherapy) will carefully calculate the correct dose of radiation therapy for you. The area or areas of your body that need to be treated will be marked with tiny ink dots on your skin using a special indelible pen.

Radiotherapy is usually given in small doses (also known as fractions) each weekday (Monday to Friday) over a week or more in the radiotherapy department of the hospital. You 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.

When you are having radiotherapy you usually lie on a table underneath the radiotherapy machine, which delivers the planned dose of radiation. 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. In fact you do not see or feel anything during the actual treatment. You will however need to stay perfectly still for a few minutes while the treatment is taking place. You might like to bring along some music to help you relax.

Stem cell transplant

For some people very high doses of chemotherapy or radiotherapy are needed to effectively treat their lymphoma. A transplant will only be offered

if your doctor feels that it will be of benefit to you. You will be able to discuss with your doctor if a transplant is a suitable treatment option in your case.

There are two main types of transplant, allogeneic and autologous. These are discussed below:

Allogeneic

Younger patients who have a suitably matched donor may be offered an allogeneic (donor) transplant. However, it is rare for an allogeneic or sibling transplant to be used to treat relapsed lymphoma in a younger patient as autologous transplant is usually the preferred option.

Allogeneic transplant involves the use of very high doses of chemotherapy, with or without radiotherapy, which kills the normal marrow cells (as well as, hopefully, any cancerous cells that have survived thus far). The term used for this intense treatment is 'myeloablative'. This is then followed by infusion of blood stem cells or bone marrow, which have been donated by another person; a suitably matched donor, usually a sibling or sometimes an unrelated donor from worldwide donor registries. Whether you will be offered a transplant will depend on a number of factors, predominantly the risk of relapse you are estimated to have if treated with chemotherapy alone together with your tolerability of the chemotherapy you will receive. This risk will vary between different patients so the advice from your doctor will be very specific to your circumstances. Due to the potential toxicities of this type of treatment it is not generally suitable for older patients (over 50 - 60 years).

An alternative approach involves using lower and therefore less toxic doses of chemotherapy and radiotherapy. This is called a reduced intensity, non-myeloablative, or miniallogeneic (mini-allo) transplant. This may be suitable for selected older patients and those with certain health problems who would benefit from, but might not be able to tolerate a conventional donor transplant. Using this approach less intensive doses of chemotherapy are used to treat disease in the bone marrow and suppress the patient's immune system sufficiently for it to accept the new, donated healthy stem cells. Meanwhile it is hoped that the donor's immune system will attack and destroy any leftover disease.

Autologous

Another option involves collecting your own stem cells, usually from your blood stream, storing them and then giving them back after you have received high doses of chemotherapy. This type of treatment is called an autologous stem cell transplant and this is commonly used for relapsed lymphoma. In general, your bone marrow has to be clear of lymphoma to be eligible for this type of transplant.

There are separate booklets about stem cell transplants available from Leukaemia & Blood Cancer New Zealand.

Common side effects

The type of side effects and their severity varies from person to person, depending on the type of treatment used and how an individual responds to it. There is no doubt that side effects can be very unpleasant at times, but it's good to remember that most of them are temporary and reversible.

It is important that you report any side effects you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

It is important that you contact your doctor or the hospital for advice immediately (at any time of the day or night) if you are feeling very unwell, or if you experience any of the following:

- a temperature of 38°C or over and / or an episode of shivering
- bleeding or bruising, for example blood in your urine, faeces, sputum, bleeding gums or a persistent nose bleed
- nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- diarrhoea, stomach cramps or constipation
- coughing or shortness of breath
- the presence of a new rash, reddening of the skin, itching
- a persistent headache
- a new pain or soreness anywhere
- if you cut or otherwise injure yourself
- if you notice pain, swelling, redness or pus anywhere on your body

Fatigue

Most people experience some degree of tiredness in the days and weeks following treatment for lymphoma. Having plenty of rest and a little light exercise each day may help to make you feel better during this time. Getting out into the fresh air and doing some gentle exercise is important for your general feeling of wellbeing and it also may help to reduce your fatigue. It is also important to listen to your body and rest when you are tired. Fatigue is a common side effect of lymphoma treatments and a symptom of lymphoma itself.

Effects on the bone marrow

Treatment for lymphoma will affect your bone marrow's ability to produce normal blood cells. As a result, your blood count (the number of blood cells circulating in your blood) will generally fall within a week of treatment, increasing the risk of infection and bleeding.

Platelets - Your platelet count may also be affected by your disease and by the chemotherapy you are receiving and you may become thrombocytopenic (a reduction in the number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time it is helpful to avoid sharp objects in your mouth such as toothpicks, as these can cut your gums. Using a soft toothbrush also helps to protect your gums. Common bleeding sites include gums, nose and in women prolonged menstruation. If the level drops too low or you are experiencing bleeding you will be given an infusion of platelets. Sometimes other medications or minor procedures will be required to stop any bleeding. Do not take aspirin or ibuprofen in any form as this can increase the risk of bleeding if your platelets are low.

Red cells - If your red blood cell count and haemoglobin levels drop you will probably become anaemic. When you are anaemic you feel more tired and lethargic than usual. If your haemoglobin level is very low, your doctor may prescribe a blood transfusion.

White cells - The point at which your white blood cell count is at its lowest is called the nadir. This is usually expected 10 to 14 days after having your chemotherapy. During this time you will be at a higher risk of developing an infection. At this stage you will also be neutropenic, which means that your neutrophil count is low. Neutrophils are important white blood cells that help us to fight infection.

Sometimes your doctor may decide to use a growth factor such as G-CSF to help the recovery of your neutrophil count. This drug works by stimulating the bone marrow to increase the production of neutrophils. G-CSF is given as an injection under the skin (subcutaneous). This is quite a simple procedure and the nurse will teach you or a family member (or friend) to do this at home. Major side effects are uncommon, but occasionally aching bones may occur.

Side effects of chemotherapy

Chemotherapy kills cells that multiply quickly, such as lymphoma cells. It also causes damage to fast-growing normal cells, including hair cells, and cells that make up the tissues in your mouth, gut and bone marrow. The side effects of chemotherapy occur as a result of this damage.

Chemotherapy in tablet form is tolerated well by most people and side effects tend to be few and mild. Intravenous chemotherapy can have more side effects, the type and severity of which will vary from one person to another, depending on what chemotherapy is used and how an individual responds to it.

There is no doubt that side effects can be very unpleasant at times but it's good to remember that most of them are temporary and reversible. It is important that you report any side effects you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

Nausea and vomiting

Nausea and vomiting are often associated with chemotherapy and some forms of radiotherapy. These days however, thanks to significant improvements in anti-sickness (anti-emetic) drugs, nausea and vomiting are generally very well controlled. You will be given anti-sickness drugs before your treatment, and for a few days after your treatment has finished. Be sure to tell the nurses and doctors if the anti-emetics are not working for you and you still feel sick. There are many different types of anti-emetics that can be tried. A mild sedative may also be used to help stop you feeling sick. This will help you to relax but it might make you a little sleepy. Be sure to tell the nurse if you have a history of travel sickness or nausea and vomiting with pregnancy as more medication may be required.

Some people find that eating smaller meals more frequently during the day, rather than a few large meals, helps to reduce nausea and vomiting. Many find that eating cool or cold food is more palatable, for example jelly or custard. Drinking ginger ale or soda water and eating dry toast may also help if you are feeling sick. Getting plenty of fresh air, avoiding strong or offensive smells, and taking the prescribed anti-sickness drugs as recommended by the nurse and doctor should also help.

Changes in taste and smell

Both chemotherapy and radiation therapy can cause changes to your sense of taste and smell. This is usually temporary but in some cases it lasts up to several months. During this time you may not be able to enjoy the foods and drinks that you used to love and this can be very disappointing, but it will pass. Some people find that adding a little more sugar to sweet foods and salt to savoury foods can help.

Mucositis (sore mouth)

Mucositis is an inflammation of the lining of the mouth, throat or gut and is a common and uncomfortable side effect of chemotherapy, and some forms of radiotherapy. It usually starts about a week after the treatment has finished and goes away once your blood count recovers. During this time your mouth and throat could get quite sore. Soluble paracetamol and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger pain killers might be needed. Having ice chips or an ice block to suck on can be other ways of relieving the discomfort caused by mucositis. Ask your doctor or nurse for help if mucositis is a problem for you.

It is important to keep your mouth as clean as possible while you are having treatment to help prevent infection. It is particularly important to attend to mouth care regularly while your mouth is sore. Your nurse will show you how to care for your mouth during this time. This may include using a soft toothbrush and mild toothpaste. Avoid commercial mouthwashes, like the ones you can buy at the supermarket as these are often too strong, or they may contain alcohol which will hurt your mouth. Your doctor will supply an

appropriate gentle mouth wash. Keep your lips moist with a lip balm or chapstick to avoid cracking.

Occasionally mouth pain or mouth ulcers may develop as a result of infection. For example, thrush or cold sores. These need specific treatment which will be prescribed by your doctor.

Bowel changes

Chemotherapy and radiotherapy can cause damage to the lining of your bowel wall. This can lead to cramping, wind, abdominal swelling and diarrhoea. Be sure to tell the nurses and doctors if you experience any of these symptoms. If you develop diarrhoea, a specimen will be required from you to ensure that the diarrhoea is not the result of an infection. After this you will be given some medication to help stop the diarrhoea and/or the discomfort you may be feeling.

It is also important to tell the nurse or doctor if you are constipated or if you are feeling any discomfort or tenderness around your anus when you are trying to move your bowels as haemorrhoids can be a problem. You may need a gentle laxative to help soften your bowel motion.

Hair loss

For most of us, the thought of losing our hair is very frightening. Hair loss is unfortunately a very common side effect of chemotherapy and some forms of radiotherapy. It is, however, usually only temporary. The hair starts to fall out within a couple of weeks of treatment and tends to grow back three to six months later. In the meantime there are lots of things that you can do to make yourself feel more comfortable. Hair loss will affect all bodily hair in varying degrees; from thinning out to complete loss.

Avoiding the use of heat or chemicals and only using a soft hair-brush and a mild baby shampoo can help reduce the itchiness and scalp tenderness which can occur while you are losing your hair. When drying your hair, pat it gently rather than rubbing it with a towel. Some people find it more comfortable to simply have a short hair cut when they notice their hair starting to fall out.

You need to avoid direct sunlight on your exposed head (by wearing a hat or similar head covering) because chemotherapy (and radiotherapy) makes your skin even more vulnerable to the damaging effects of the sun (such as sunburn and skin cancers). Remember that without your hair, your head can get quite cold, so a beanie might be useful, especially if you are in an air-conditioned environment like a hospital. Hair can also be lost from your eyebrows, eyelashes, arms, legs and pubic area.

Side effects of corticosteroids

The types of side effects seen with corticosteroids depend largely on how long they are used for, and the dose given. If you are using them for a short time you may notice that your appetite increases or you may feel more

restless than usual. Some people find it more difficult to get to sleep at night and sleeping tablets or other natural therapies are sometimes recommended. Sometimes corticosteroids can affect your mood and concentration as well.

Corticosteroids can cause a rise in the blood sugar. Diabetics may find they need more of their diabetes medication while they are taking these drugs and some people who are not normally diabetic may require treatment to keep their blood sugar at acceptable levels. It is important to keep a check on the blood sugar and keep a diary of the levels and the amount of diabetic medication being taken. Diabetics will already know how to do this. People whose blood sugar only goes up when they are on corticosteroids may be given information on diet and taught how to measure their blood sugar and adjust their medication. Blood sugar levels usually return to normal once the steroids are finished.

Many of the side effects of corticosteroids are temporary and should pass once you finish taking them. Long-term use of corticosteroids may cause some other effects such as fluid retention and an increased susceptibility to infections. Aching joints such as the knees and hips have also been reported.

Remember to tell your doctor and nurses about any side effects you are having as they can usually suggest ways to help you.

Side effects of radiotherapy

Radiotherapy can cause similar side effects to those caused by chemotherapy including nausea and vomiting, increased sun sensitivity (especially on the site radiated), hair loss and fatigue.

In general, however, the side effects experienced with radiotherapy depend on the area of the body which has been treated. For example, radiotherapy to the abdomen is more likely to cause nausea and vomiting while hair loss is usually confined to the areas of the body being treated.

Skin reactions

Radiotherapy can cause a reddening of the skin which may also flake and become itchy. The staff at the radiotherapy department will advise you on how to care for your skin while you are having treatment. Gentle washing (avoiding perfumed products like scented soaps) and drying (patting rather than rubbing) is often recommended. You should also avoid any creams or moisturisers that contain traces of metals. Check with the radiotherapy department staff if you are unsure. Also, it is best to avoid direct sunlight on any area of skin that has received radiotherapy, even after the therapy has finished. This is because radiotherapy makes your skin more vulnerable to the damaging effects of the sun such as sunburn and skin cancers.

Parotitis

Parotitis is an inflammation of the saliva-producing glands in the mouth which can occur if these glands are within the treatment field used. These

include the parotid or submandibular glands which are situated at the top of the jaw line, in front of the ears. Parotitis causes dryness of the mouth and jaw pain which usually settles down within a few days once the inflammation subsides.

Supportive care

Supportive care plays an important role in the treatment of many people living with lymphoma. This involves making every effort to improve your quality of life, by relieving any symptoms you might have and by preventing and treating any complications that arise from your disease or treatment.

Blood transfusions, antibiotics, intravenous fluids and similar treatments, can all be important elements of medical supportive care.

Non-medical supportive care may involve complementary therapies, nutrition support, exercise, counselling and similar services.

Inform your haematologist if any surgery or treatment is planned by another practitioner, as advice may be required from your haematologist as to the best supportive treatment, such as transfusions, blood tests or other monitoring, to ensure that your treatment happens successfully without problems due to your disease, current or previous treatment.

Infection precautions

Infections are a common complication of lymphoma and its treatment, which can result for a number of reasons including lower levels of normally functioning white cells circulating in the blood stream. While infections can occur anywhere in the body; common sites include upper and lower respiratory infections (chest infections), urinary tract infections (kidney infections) and skin infections. While most are caused by bacteria and viruses; fungal and opportunistic infections (infections caused by microorganisms that are normally harmless in healthy people) are also seen. You may be prescribed preventive (prophylactic) antibiotics especially during and after particular types of treatment.

While your white blood cell count is low you should take sensible precautions to help prevent infection. These include washing your hands frequently and using alcohol hand gel. Tell your friends and family, especially those with small children, that you are at risk of infection and ask them to ring before visiting if they have coughs and colds. Avoid crowds and other close contact with people who may have infections that are contagious (for example colds, flu, chicken pox). Only eat food that has been properly cooked and stored, and avoid sharing food and utensils.

If you do develop an infection you may experience a fever which may or may not be accompanied by an episode of shivering, where you shake uncontrollably. Infections while you are neutropenic can be quite serious and need to be treated with antibiotics as soon as possible.

It is important you do not use any drugs to bring your temperature down (i.e. paracetamol) until you are reviewed by your doctor. This could mask an infection which could lead to serious life threatening complications. Do not take aspirin or ibuprofen in any form as this can increase the risk of bleeding if your platelets are low. Always check with your doctor first.

Blood and platelet transfusions

If symptoms of anaemia are interfering with your normal daily activities, your doctor may recommend that you have a red blood cell transfusion. Platelet transfusions are sometimes given to prevent or treat bleeding (for example a persistent nose bleed). You do not need to be admitted to hospital for a red blood cell or platelet transfusion and they are usually given in the outpatient department. Transfusions don't usually cause any serious complications; nevertheless you will be carefully monitored throughout the transfusion. Alert your nurse if you are feeling hot, cold, and shivery or in any way unwell, as this might indicate that you are having a reaction to the transfusion. Steps can be taken to minimise these effects and ensure that they don't happen again.

Growth factors

As mentioned earlier, growth factors are natural chemicals in your blood that stimulate the bone marrow to produce different types of blood cells. Some of them can be made in the laboratory and used to help manage your lymphoma.

Erythropoietin (EPO) is an example of a growth factor which is used to stimulate the production of more red blood cells, and can in some cases reduce the need for frequent blood transfusions. Granulocyte-colony stimulating factor (G-CSF) may be given to stimulate the bone marrow to produce more white cells, particularly neutrophils. These white cells help fight bacterial and fungal infections in particular.

Growth factors are given as an injection under the skin (subcutaneous). They don't usually cause any major side effects but some people experience fevers, chills, headaches and some bone pain while using G-CSF. Your doctor may recommend that you take paracetamol to relieve any discomfort you may be feeling.

Complementary therapies

Complementary therapies are therapies which are not considered standard medical therapies. Many people find that they are helpful in coping with their treatment and recovery from disease. There are many different types of complementary therapies. These include yoga, exercise, meditation, prayer, acupuncture, relaxation and herbal and vitamin supplements.

Complementary therapies should 'complement' or assist with recommended medical treatment. They are not recommended as an alternative to medical treatment. It is important to realise that no complementary or alternative treatment alone has proven to be effective against lymphoma.

It is also important to let your doctor or nurse know if you are using any complementary or alternative therapies in case they interfere with the effectiveness of chemotherapy or other treatments you may be having.

Nutrition

A healthy and nutritious diet is important in helping your body to cope with the condition you've been diagnosed with, and its treatment. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a nutritionist or dietician who can advise you on planning a balanced, safe and nutritious diet.

If you are thinking about using herbs or vitamins it is very important to talk this over with your doctor first. Some of these substances can interfere with the effectiveness of chemotherapy or other treatment you are having.



Potential late effects of treatment

Many people enjoy long and healthy lives after being successfully treated for cancer. However, sometimes the treatment can affect a person's health months or even years after it has finished, these effects are called 'late effects'.

People who have been treated with high-dose chemotherapy and radiation therapy may be at a higher risk than normal of developing other diseases such as myelodysplastic syndrome and other (secondary) cancers including leukaemia, and melanoma in the future.

Regular medical check ups will help monitor your health and help to identify any late effects you may develop from your treatment. It is important to tell any health care professional treating you in the future about your past medical history.

Reproductive health

Fertility

Fertility is the ability to produce a child. In males, fertility means having enough healthy sperm to get a female pregnant. In females, fertility is the ability to become pregnant.

Some types of chemotherapy and radiotherapy may cause a temporary or permanent reduction in your fertility. It is very important that you discuss any questions or concerns you might have regarding your future fertility with your doctor, if possible, before you commence treatment.

In women, some types of chemotherapy and radiotherapy can cause varying degrees of damage to the normal functioning of the ovaries. In some cases this leads to menopause (change of life) earlier than expected. In men sperm production can be impaired for a while but the production of new sperm may become normal again in the future.

There are some options for preserving your fertility, if necessary, while you are having treatment. These are described below.

Protecting your fertility - Men

Sperm banking is a relatively simple procedure whereby the man donates semen, which is then stored at a very low temperature (cryopreserved), with the intention of using it to achieve a pregnancy in the future. You should discuss sperm banking with your doctor before starting any treatment that might impact on your fertility. In some cases, however, people are not suitable for sperm banking when they are first diagnosed because they are too unwell and therefore unable to produce the sperm in sufficient quantity or quality.

If possible, semen should be donated on more than one occasion. It is important to realise that there are many factors that can affect the quality and quantity of sperm collected in a semen donation and its viability after it is thawed out. There is no guarantee that you and your partner will be able to achieve a pregnancy and healthy newborn in the future. You should raise any concerns you have with your doctor who can best advise you on your fertility options.

The use of donor sperm might be another option for you and your partner. The sperm is donated from another male to achieve a pregnancy.

Protecting your fertility - Women

There are several approaches that may be used to protect a woman's fertility. These are outlined below.

Embryo storage - this involves collecting your eggs, usually after taking drugs to stimulate your ovaries to produce a number of eggs, so that more

than one egg can be collected. This process takes at least several weeks and this can be a problem if your treatment needs to start immediately. Once the eggs are collected they are then fertilised with your partner's sperm and stored to be used at a later date. Your unfertilised eggs can also be collected and stored in a similar manner (egg storage).

Ovarian tissue storage - this is still a fairly new approach to protecting your fertility and to date there is very little experience with this technique in New Zealand. It involves the removal and storage at a very low temperature of some ovarian tissue (cryopreservation). It is hoped that at a later date the eggs contained in this tissue can be matured, fertilised and used to achieve a pregnancy.

To date, these first two approaches have unfortunately shown little success in cancer patients.

The use of donor eggs might be another option for you and your partner. These eggs could be fertilised using your partner's sperm and used in an attempt to achieve a pregnancy in the future.

It is important to understand that these methods are still quite experimental and for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of them. In addition, some are time consuming and costly while others may simply not be acceptable to you or your partner.

Because of the need to start treatment without delay and the problems associated with the lymphoma itself, it is often not possible to collect eggs or ovarian tissue prior to the first cycle of chemotherapy.

Early menopause

Some cancer treatments can affect the normal functioning of the ovaries. This can sometimes lead to infertility and an earlier than expected onset of menopause, even at a young age. The onset of menopause in these circumstances can be sudden and, understandably, very distressing.

Hormone changes can lead to many of the classic symptoms of menopause including menstrual changes, hot flushes, sweating, dry skin, vaginal dryness and itchiness, headache and other aches and pains. Some women experience decreased sexual drive, anxiety and even depressive symptoms during this time.

It is important that you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you or refer you to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

Menstruation

Cancer treatment can also affect your periods; you may find your periods stop, become irregular or sometimes much heavier and longer in length. You may be prescribed a birth control pill to stop your periods. This prevents heavy bleeding and blood loss when your platelets are low. If you are having chemotherapy, it is best to use pads instead of tampons if you are menstruating as this will reduce the risk of infections. Always let your doctor know if you are having your period.

Body image, sexuality and sexual activity

It is likely that the diagnosis and treatment of lymphoma will have some impact on how you feel about yourself as a man or a woman and as a 'sexual being'. Hair loss, skin changes and fatigue can all interfere with feeling attractive.

During treatment you may experience a decrease in libido, which is your body's sexual urge or desire, sometimes without there being any obvious reason. It may take some time for things to return to 'normal'. It is perfectly reasonable and safe to have sex while you are on treatment or shortly afterwards, but there are some precautions you need to take. Men may sometimes experience some degree of erectile dysfunction during treatment and in the stages of recovery. Please discuss this with your doctor so any help can be initiated.



It is usually recommended that you or your partner do not become pregnant as some of the treatments given might harm the developing baby. As such, you need to ensure that you or your partner uses a suitable form of contraception. Condoms (with a spermicidal gel) offer good contraceptive protection as well as protection against infection or irritation. Your partner may be worried that sex might in some way harm you. This is not likely as long as your partner is free from any infections and the sex is relatively gentle. It is important to be extra careful when your white cell count or platelet levels are low as you may be more prone to infection and bleeding/spotting. Finally, if you are experiencing vaginal dryness, a lubricant can be helpful. This will help prevent irritation. Using a condom is also important to protect your partner from chemotherapy drugs that can be excreted in body fluids in the first few days after they are administered.

If you have any questions or concerns regarding sexual activity and contraception don't hesitate to discuss these with your doctor or nurse, or ask for a referral to a doctor or health professional who specialises in sexual issues.

Making treatment decisions

Many people feel overwhelmed when they are diagnosed with lymphoma. In addition to this, waiting for test results and then having to make decisions about proceeding with the recommended treatment can be very stressful. Some people do not feel that they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given. It is important that you feel you have enough information about your illness and all of the treatment options available, so that you can make your own decisions about which treatment to have.



Anxiety, shock, denial or grief can make it difficult, at times, to absorb or remember discussions you have had with your doctor and it is common for people not to remember much of the information given to them at diagnosis. Before going to see your specialist doctor make a list of the questions you want to ask. It may be useful to keep a notebook with you and write questions down as you think of them, as often questions are forgotten between appointments.

Sometimes it is hard to remember everything the doctor has said. It may help to bring a family member or a friend along who can write down the answers to your questions or prompt you to ask others, be an extra set of ears or simply be there to support you.

Your doctor will spend time with you and your family discussing what he or she feels is the best option for you. Feel free to ask as many questions as you need to, at any stage. You are involved in making important decisions regarding your wellbeing.

You should feel that you have enough information to do this and that the decisions made are in your best interests. Remember, you can always request a second opinion if you feel this is necessary.

The 'Haematology Patient Diary', available from Leukaemia & Blood Cancer New Zealand, may be useful for recording details of treatment and making notes from clinic appointments.

Interpreting services

New Zealand's Health and Disability Code states that everyone has the right to have an interpreter present during a medical consultation. Family or friends may assist if you and your doctor do not speak the same language, but you can also ask your doctor to provide a trained interpreter if using a family member is not appropriate.

Social and emotional effects

People cope with a diagnosis of lymphoma in different ways, and there is no right or wrong or standard reaction. For some people, the diagnosis can trigger any number of emotional responses ranging from denial to devastation. It is not uncommon to feel angry, helpless and confused. Naturally people fear for their own lives or that of a loved one.

It is worth remembering that information can often help to take away the fear of the unknown. It is a good idea for you and your family to speak directly to your doctor regarding any questions you might have about your disease or treatment. It can also be helpful to talk to other health professionals including social workers or nurses who have been specially educated to take care of people with haematological diseases. Some people find it useful to talk with other patients and family members who understand the complexity of feelings and the kinds of issues that come up for people living with blood cancers and conditions.

In some areas there may be patient group meetings, and there is also an online support and information forum run by Leukaemia & Blood Cancer New Zealand – LifeBloodLIVE. This is available at www.lifebloodlive.org.nz.

Many people are concerned about the social and financial impact of the diagnosis and treatment on their families. Normal family routines are often disrupted and other members of the family may suddenly have to fulfil roles they are not familiar with, for example, cooking, cleaning, and taking care of children. The social worker attached to your treatment centre is available for you to talk through and discuss these issues with you and your family.

If you have a psychological or psychiatric condition, please inform your doctor and don't hesitate to request additional support from a mental health professional.

There is a variety of assistance available to help ease the emotional and financial strain created by a diagnosis of a blood cancer or condition. In some cases a travel allowance may be available. Support Services staff at Leukaemia & Blood Cancer New Zealand are available to provide you and your family with information and support to help you cope during this time. Contact details for Leukaemia & Blood Cancer New Zealand are provided on the back of this booklet.



Finishing treatment – Looking to the future

Once treatment has finished most people are followed up on a regular basis by their haematologist and are advised to see their general practitioner (GP) for any necessary medical care. This can make some people nervous because they may fear that their GP may not be aware of the latest developments in lymphoma. It is important to remember that your treating specialist will send information to your GP to keep him or her informed regarding your progress and what needs to be followed up on a regular basis, for example blood tests.

Even though you have been treated successfully for cancer it is normal to continue to experience feelings of vulnerability, uncertainty about the future and fear that your illness could return. The fear of a recurrence or relapse of your lymphoma may cause some people to become over protective or cautious. Being more aware of any physical signs and symptoms than previously, for example a bruise, sustained in normal activity, may cause great anxiety and fear of relapse. Follow-up appointments after treatment has finished are often times of great anxiety as people wait for an 'all clear' from their doctor. As time passes and as more distance is allowed between appointments anxiety reduces. Everyone gradually becomes more and more engaged in the activities of daily living rather than concentrating most of their attention on the experience of illness.

Looking after yourself

Focusing on the things you can do to help yourself recover both physically and emotionally is important. Enjoying simple pleasures every day, looking to better times in the future, making plans and having hope are all important in maintaining a sense of control in a time of uncertainty.

Maintain a healthy lifestyle by:

- Avoiding smoking
- Eating a healthy diet
- Taking regular exercise
- Drinking alcohol sensibly
- Maintaining a healthy weight
- Wearing appropriate sun protection

Useful internet addresses

The value of the internet is widely recognised; however, not all the information available may be accurate and up to date. For this reason, we have selected some of the key sites that people living with lymphoma might find useful.

With the exception of our own website, Leukaemia & Blood Cancer New Zealand does not maintain these listed sites. We have only suggested sites we believe may offer credible and responsible information, but we cannot guarantee the information on them is correct, up to date or evidence based medical information.

Leukaemia & Blood Cancer New Zealand

www.leukaemia.org.nz
www.lifebloodlive.org.nz

Cancer Society of New Zealand

www.cancernz.org.nz

American Cancer Society

www.cancer.org

International Lymphoma Coalition

www.lymphomacoalition.org

Leukemia & Lymphoma Society of America

www.leukemia-lymphoma.org

Leukaemia & Lymphoma Research Fund (UK)

www.llresearch.org.uk

Lymphoma Association (UK)

www.lymphoma.org.uk

Lymphoma Research Foundation (USA)

www.lymphoma.org

MacMillan Cancer Support (A UK cancer information site)

www.macmillan.org.uk

National Cancer Institute (USA)

www.cancer.gov/cancerinfo

Grief Centre

www.griefcentre.org.nz

Glossary of terms

Alopecia

Hair loss. This is a side effect of some kinds of chemotherapy and radiotherapy. It is usually temporary.

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.

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 substances such as bacteria, viruses and some cancer cells and cause their destruction.

Antiemetic

A drug which prevents or reduces feelings of sickness.

Antigen

A substance, usually on the surface of a foreign body such as a virus or bacteria that stimulates the cells of the body's immune system to react against it by producing antibodies.

Blood count

Also called a full blood count (FBC). A routine blood test that measures the number and type of cells circulating in the blood.

B-lymphocyte

A type of white cell normally involved in the production of antibodies to combat infection.

Bone marrow

The tissue found at the centre of our bones. Active or red bone marrow contains stem cells from which all blood cells are made and in the adult this is found mainly in the bones making up the axial skeleton – hips, ribs, spine, skull and breastbone (sternum). The other bones contain inactive or (yellow) fatty marrow, which, as its name suggests, consists mostly of fat cells.

Cancer

A malignant disease characterised by uncontrolled growth, division, accumulation and invasion into other tissues of abnormal cells from the original site where the cancer started. Cancer cells can grow and multiply to the extent that they eventually form a lump or swelling. This is a mass of cancer cells known as a tumour. Not all tumours are due to cancer; in which case they are referred to as non-malignant or benign tumours.

Cannula

A plastic tube which can be inserted into a vein to allow fluid to enter the blood stream.

Central venous catheter (CVC)

Also known as a central venous access device (CVAD) or central venous line (CVL). A line or tube passed through the large veins of the arm, neck, chest or groin and into the central blood circulation. It can be used for taking samples of blood, giving intravenous fluids, blood, chemotherapy and other drugs without the need for repeated needles.

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 and a sore mouth (mucositis). Nausea and vomiting are also common, but nowadays largely preventable with modern anti-nausea medication. Most of the side effects of chemotherapy are usually temporary and reversible.

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 or CAT scan (computerised axial tomography)

A specialised x-ray or imaging technique that produces a series of detailed three dimensional (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

The study of the structure of chromosomes. Cytogenetic tests are carried out on samples of blood and bone marrow to detect chromosomal abnormalities associated with disease. This information helps in the diagnosis and selection of the most appropriate treatment.

Disease progression

This means that the disease is getting worse despite treatment.

Echocardiogram (echo)

A special ultrasound scan of the heart.

Electrocardiogram (ECG)

Recording of the electrical activity of the heart.

Growth factors and cytokines

A complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some are now available as drugs and may be used to stimulate normal blood cell production following chemotherapy or bone marrow/peripheral blood stem cell transplantation.

Haemopoiesis (or haematopoiesis)

The processes involved in blood cell formation.

Haematologist

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

Hairy cell leukaemia

A rare sub-type of chronic lymphoid leukaemia in which abnormal B-lymphocytes accumulate in the bone marrow, liver and spleen. Under the microscope, these cells are seen to have tiny hair-like projections on their surface.

High dose therapy

The use of higher than normal doses of chemotherapy to kill off resistant and / or residual (left over) cancer cells that have survived standard-dose therapy.

Hodgkin lymphoma

A type of lymphoma – cancer of the lymphatic system. All other types of lymphoma come under the heading of non-Hodgkin lymphoma.

Immune system

The body's defence system against infection and disease.

Immunocompromised

When someone has decreased immune function.

Immunotherapy

Immunotherapy refers to the administration of monoclonal antibodies such as rituximab (also known as MabThera). This has been shown to be effective when used alone or in combination with chemotherapy for B-cell lymphomas, in many clinical trials.

Leukaemia

A cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal blood cells. These cells take over the bone marrow often causing a fall in blood counts. If they spill out into the bloodstream however they can cause very high abnormal white cell counts.

Leucopheresis

A procedure that uses a special machine called a 'cell separator' to remove the excess white cells in the blood while returning the rest of the blood to the patient.

Localised disease

Disease that is confined to a small area or areas.

Low grade lymphoma

A slow growing lymphoma

Lymph nodes or glands

Structures found throughout the body, for example in the neck, groin, armpit, chest and abdomen, which contain both mature and immature lymphocytes. There are millions of very small lymph glands in all organs of the body.

Lymphatic system

A vast network of vessels, similar to blood vessels, that branch out into all the tissues of the body. These vessels carry lymph, a colourless watery fluid that carries lymphocytes, specialised white cells that protect us against disease and infection. The lymphatic system is part of the body's immune system.

Lymphoid

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

Lymphocytes

Specialised white blood cells involved in defending the body against disease and infection. There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. They are also called B-cells and T-cells.

Lymphomas

General name given to cancers of the lymphatic system.

Malignancy

A term applied to tumours characterised by uncontrolled growth and division of cells (see cancer).

MRI

A body scanning technique which uses very strong magnetic and radio waves to produce very clear and detailed three dimensional (3D) images of internal organs and structures.

Mucositis

Inflammation of the lining of the mouth and throat, which also can extend to the lining of the whole of the gastro-intestinal tract (stomach and intestines).

Neutropenia

A reduction in the 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 mount an effective fight against infection, especially bacteria and fungi.

Non-Hodgkin lymphoma

A group of lymphomas (cancer of the lymphatic system) that differs in important ways from Hodgkin lymphoma and are classified according to the appearance of the cancer cells under the microscope. Non-Hodgkin lymphoma can be slow growing (low grade/indolent) or fast growing (intermediate or high grade/aggressive) and may be treated in a variety of ways depending on the exact diagnosis.

Oncologist

General term used for a specialist doctor who treats cancer by different means, e.g. medical, radiation, surgical oncologist.

Partial remission

The tumour shrinks to less than half its original size after treatment.

Pathologist

A doctor who specialises in the laboratory diagnosis of disease, and how disease is affecting the organs of the body.

Peripherally inserted central venous catheter (PICC)

A type of central venous catheter which is inserted into a large vein in the arm.

PET scan

Newer imaging technique where glucose is injected into a vein in your hand or arm. Special gamma cameras are then used to detect areas in the body that are affected by lymphoma.

Pro-lymphocytic leukaemia (PLL)

A rare sub-type of chronic lymphocytic leukaemia in which abnormal lymphocytes known as prolymphocytes are found in the bone marrow and blood stream.

Prognosis

An estimate of the likely course of a disease.

Radiotherapy (radiation therapy)

The use of high energy x-rays to kill cancer cells and shrink tumours.

Relapse

The return of the original disease.

Resistant or refractory disease

This means that the disease is not responding to treatment.

Remission (or complete remission)

When there is no evidence of disease detectable in the body; note this is not always equivalent to a cure as relapse may still occur.

Spleen

An organ that accumulates lymphocytes, acts as a reservoir for red cells for emergencies, and destroys blood cells at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It cannot normally be felt on examination unless it is enlarged. It is often enlarged in diseases of the blood – this is known as hypersplenism.

Splenomegaly

Another term used to describe an enlarged spleen.

Stable Disease

When the disease is stable it is not getting any worse or any better with treatment.

Stage

The extent or spread of disease in the body.

Staging

An assessment of the extent or spread of disease in the body.

Standard therapy

The most effective and safest therapy currently being used.

Stem cells

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

Stem cell transplant (peripheral blood stem cell or bone marrow transplant)

These treatments are used to support the use of high-dose chemotherapy and / or radiotherapy in the treatment of a wide range of blood cancers including leukaemias, lymphomas, myeloma, certain solid tumours, and other serious diseases.

T-lymphocyte

A type of white cell involved in controlling immune reactions.

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.

White blood cells (white 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.

X-ray

A form of electronically produced radiation used in diagnosis and treatment.

Please refer to the 'Dictionary of Terms' booklet for further definitions.

Please send me a copy of the following patient information booklets:

- | | |
|--|--|
| <input type="checkbox"/> Dictionary of Terms | <input type="checkbox"/> Acute Lymphoblastic Leukaemia in Adults |
| <input type="checkbox"/> Haematology Patient Diary | <input type="checkbox"/> Acute Lymphoblastic Leukaemia in Children |
| <input type="checkbox"/> Clinical Trials | <input type="checkbox"/> Acute Myeloid Leukaemia |
| <input type="checkbox"/> Autologous Stem Cell Transplants | <input type="checkbox"/> Chronic Lymphocytic Leukaemia |
| <input type="checkbox"/> Allogeneic Stem Cell Transplants | <input type="checkbox"/> Chronic Myeloid Leukaemia |
| <input type="checkbox"/> Myeloproliferative Disorders | <input type="checkbox"/> Hodgkin Lymphoma |
| <input type="checkbox"/> Myelodysplastic Syndromes | <input type="checkbox"/> Non-Hodgkin Lymphoma |
| <input type="checkbox"/> Myeloma | |
| <input type="checkbox"/> My Guide to Blood Cancer - for adolescents and young adults | |

Or information on:

- Leukaemia & Blood Cancer New Zealand's Support Services
 How to make a bequest to Leukaemia & Blood Cancer New Zealand

Newsletters:

- | | |
|---|--|
| <input type="checkbox"/> LifeBlood | <input type="checkbox"/> Leukaemia Today |
| <input type="checkbox"/> Lymphoma Today | <input type="checkbox"/> Myeloma Today |

Name: _____

Address: _____

Postcode: _____ Phone: _____

Email: _____

Send to: Leukaemia & Blood Cancer New Zealand
 PO Box 99182, Newmarket, Auckland 1149
 Phone: 09 638 3556 or 0800 15 10 15
 Email: info@leukaemia.org.nz

Leukaemia & Blood Cancer New Zealand will record your details to facilitate services and keep you informed about leukaemia and related blood disorders. We value your privacy and take all the necessary steps to protect it. You can access, change or delete this information by contacting us at info@leukamia.org.nz

Notes

Notes

Notes

**Non-Hodgkin Lymphoma**

We hope that you found this information booklet useful. We are interested in what you thought of the booklet – whether you found it helpful or not. If you would like to give us your feedback, please fill out this questionnaire and send it to Leukaemia & Blood Cancer New Zealand, at the address at the bottom of the following page.

1. Did you find this booklet helpful?

Yes No

Comments _____

2. Did you find this booklet easy to understand?

Yes No

Comments _____

3. Where did you get this booklet from?

4. Did you have any questions that were not answered in the booklet?

Yes No

If yes, what were they?

5. What did you like the most about this booklet?

6. What did you like least about this booklet?

7. Any other comments?

Thank you for helping us review this booklet. We will record your feedback and consider it when this booklet is reviewed for the next edition.

Please return to: Leukaemia & Blood Cancer New Zealand
PO Box 99182 Newmarket, Auckland 1149



Important information for haematology patients

It is important that you contact your doctor or the hospital for advice immediately (at any time of the day or night) if you are feeling very unwell, or if you experience any of the following:

- a temperature of 38°C or over and / or an episode of shivering
- bleeding or bruising, for example blood in your urine, faeces, sputum, bleeding gums or a persistent nose bleed
- nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- diarrhoea, stomach cramps or constipation
- coughing or shortness of breath
- the presence of a new rash, reddening of the skin, itching
- a persistent headache
- a new pain or soreness anywhere
- if you cut or otherwise injure yourself
- if you notice pain, swelling, redness or pus anywhere on your body



our mission is to care, our vision is to cure

Freephone 0800 15 10 15
Telephone 09 638 3556
Facsimile 09 638 3557
Email info@leukaemia.org.nz

National Office:
6 Claude Road, Epsom 1023
PO Box 99182, Newmarket 1149
Auckland, New Zealand

leukaemia.org.nz

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