ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL) – ADULTS

A guide for patients,
families & whānau

leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

INTRODUCTION

This booklet has been written to help you and your family/whānau understand more about acute lymphoblastic leukaemia (ALL) in adults.

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

It is not the intention of this booklet to recommend any particular form of treatment to you. Always discuss your circumstances with your doctor and health care team.

Interpreter service

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

Informed consent

Your doctor may ask an interpreter to join meetings where informed consent is required. Interpreters are specially trained to explain the information clearly.

ALAN
Acute Leukemia Advocates Network

This revised edition was made possible by a grant from ALAN – Acute Leukaemia Advocacy Network.

HOW TO USE THIS BOOKLET

Detailed information

Key points

Important information

More information available online

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

Space for your questions

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

Glossary

On page 50 there is a glossary (word list). In this booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases.

A Dictionary of Terms booklet is also available from the LBC website, or you can ask your LBC Support Services Coordinator for a printed version.

CONTENTS

WHAT IS LEUKAEMIA?

Leukaemia is a type of blood cancer. Blood is made up of red blood cells, white blood cells and platelets. These are made in the bone marrow, which is the spongy tissue found in the centre of some bones in the body.

Leukaemia is a cancer of the white blood cells. White blood cells are an important part of the immune system and help fight infection. Normally, immature (baby) white blood cells divide and then mature (go from immature cells to adult cells) in a controlled way. It is the mature white blood cells which fight infection.

When someone has leukaemia, the immature white blood cells divide too quickly in the bone marrow and do not mature. This means the bone marrow is overcrowded with immature white blood cells that are not able to fight infection.

Types of leukaemia

Leukaemias can be acute or chronic. Acute leukaemias typically develop very quickly and treatment must start right away. Chronic leukaemias usually develop slowly and may not need treatment right away, if at all.

The names of the main types of leukaemias are:

Acute

Acute lymphoblastic leukaemia (ALL)
Acute myeloid leukaemia (AML)

Chronic

Chronic myeloid leukaemia (CML)
Chronic lymphocytic leukaemia (CLL)
Chronic myelomonocytic leukaemia (CMML)

Both children and adults can develop leukaemias but certain types are more common in different age groups. Each year in New Zealand around 760 adults and 50 children are diagnosed with leukaemias.

Around 30 adults are diagnosed with ALL each year in New Zealand.

Key points

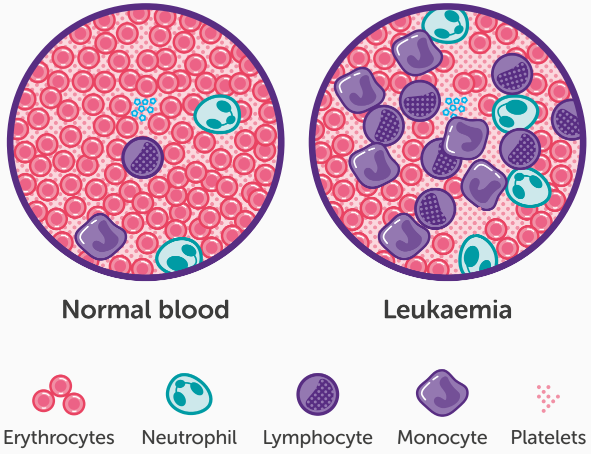
- Leukaemia is a type of blood cancer of the white blood cells.
- Leukaemia can be acute (develops fast) or chronic (develops slowly).

WHAT IS ACUTE LYMPHOBLASTIC LEUKAEMIA?

Acute lymphoblastic leukaemia (ALL) is a type of cancer of the blood and bone marrow. ALL occurs when the bone marrow makes too many immature lymphocytes. Lymphocytes are a type of white blood cell. This type of leukaemia usually gets worse quickly if it is not treated.

To fully understand ALL it is helpful to learn about the function of the blood, bone marrow and blood stem cells.

Figure
01
Normal blood & leukaemia



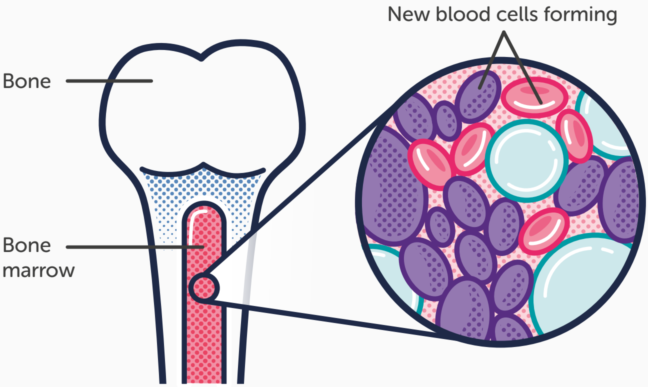
BONE MARROW AND BLOOD STEM CELLS

Bone marrow

Bone marrow is the spongy material inside your bones (see Figure 02). Your bone marrow is like the factory that makes all your blood cells.

Figure 02

Bone marrow



Blood stem cells

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

The two main functions of blood stem cells are to:

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

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

In Figure 03 (on the next page) you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create, e.g. the lymphoid stem cell develops into a lymphoid blast cell before further maturing to either a

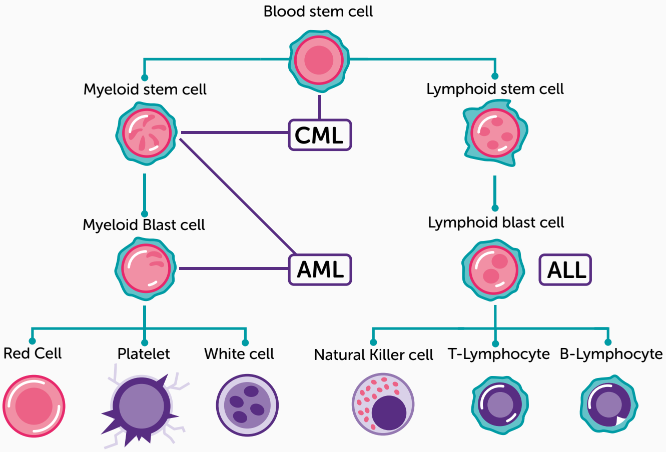
T-lymphocyte (T-cell), B-lymphocyte (B-cell) or natural killer (NK) cell.

Leukaemia can develop in either the myeloid cell line or the lymphoid cell line. This determines what type of leukaemia it is (either ALL or AML). As you can see in Figure 03, ALL affects developing lymphoid blast cells, which will be explained further on page 7.

Figure

03

The cells created from blood stem cells



Detailed information

- Blood stem cells can also be called haematopoietic (he-ma-toe-po-ee-tick) stem cells. When a blood stem cell matures into a blood cell, this is called haematopoiesis (he-ma-toe-po-ee-sis). Haematopoiesis occurs in large bones like the breastbone (sternum), thigh bone (femur) and the hip bone (iliac crest).

Key points

- Blood stem cells in your bone marrow make exact copies of themselves, as well as divide to create myeloid and lymphoid stem cells. These cells create all the blood cells for your body, i.e. red blood cells, white blood cells and platelets.
- Leukaemias can develop from either myeloid cells or lymphoid cells.

YOUR BLOOD

The red blood cells, platelets and white blood cells, created in the bone marrow, are released into the bloodstream so they can function around the body.

Blood is made up of blood cells and plasma. A blood test measures the amount of each type of blood cell in your blood. Figure 04 shows the three main types of blood cells in the plasma. The role of plasma and each type of blood cell is discussed below in this section.

Plasma

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

Red blood cells

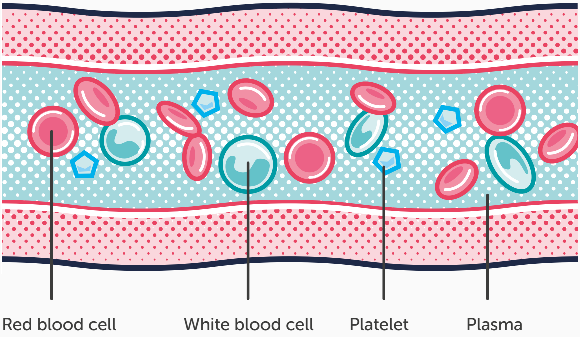
Red blood cells transport oxygen from the lungs to all cells in the body. A protein called haemoglobin (he-ma-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin or red blood cells in your body is called anaemia (a-nee-me-a).

White blood cells

White blood cells, also called leukocytes (loo-co-sites), fight infection. For example, if bacteria enters your bloodstream through a cut, the white blood cells attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

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

Figure
04
Blood vessel and cells in your blood



Platelets

Platelets help the blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding. A low level of platelets in the body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a).

See page 17 for the normal ranges (amount) of blood cells in the blood.

Detailed information

There are many different types of white blood cells, all with specific jobs to do. Following is a list with the names of different types of white blood cells and what they do.

- **Neutrophils (new-tro-fils)** kill bacteria and fungi.
- **Eosinophils (ee-o-sin-o-fils)** kill parasites.
- **Basophils (bay-so-fils)** work with neutrophils to fight infection.
- **T-lymphocytes (T-lim-fo-sites) (T-cells)** kill viruses, parasites and cancer cells.
- **B-lymphocytes (B-lim-fo-sites) (B-cells)** make antibodies that target harmful microorganisms (germs).
- **Monocytes (mono-sites)** work with neutrophils and lymphocytes to fight infection. They also help to produce antibodies that act as scavengers (cleaners) to remove dead tissue.
- **Macrophages (mac-row-far-jes)** are monocytes that have moved into body tissue to help fight infection.

Key points

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

ACUTE LYMPHOBLASTIC LEUKAEMIA

Acute lymphoblastic leukaemia (ALL) is a type of cancer that affects the blood and bone marrow. It is characterised by an overproduction of immature white blood cells, called lymphoblasts or leukaemic blasts.

Under normal conditions these blast cells grow and mature into specialised white blood cells called B-lymphocytes (B-cells) and T-lymphocytes (T-cells).

In ALL, they undergo a malignant (cancerous) change. This means that they multiply in an uncontrolled way, quickly crowding the bone marrow, and interfering with normal blood cell production. The leukaemic blast cells spill out of the bone marrow and circulate around the body in the bloodstream. They can also accumulate in organs such as the lymph nodes, spleen, liver, central nervous system (brain and spinal cord) and testes.

If the bloodstream is filled with abnormal lymphocytes, then there is not enough room for the healthy functioning cells (red blood cells, white blood cells and platelets). This causes various symptoms, which are explained in more detail on page 10.

What causes ALL?

The cause of ALL is not known. Like most other types of leukaemia, ALL is thought to develop after DNA is damaged, causing genetic mutations (errors). Most DNA mutations are due to copying errors, which don’t have a specific cause. We do know that you cannot catch ALL from someone else and most people with ALL do not have a family/whānau history of ALL.

There are some risk factors that may increase the chances of developing ALL. Having a risk factor does not mean you will get ALL, and some people will still get ALL even though they don’t have any risk factors.

These risk factors are:

- Being exposed to very large doses of radiation
- Being exposed to X-rays before birth
- Past chemotherapy or radiotherapy treatment
- Having certain genetic or chromosome changes, e.g. Down syndrome (trisomy 21).

Generally, ALL develops more frequently in children under 5 years, and adults over the age of 70. It is slightly more common in men than in women.

Key points

- ALL is a type of leukaemia that affects immature lymphoid white blood cells.
- Immature lymphocytes, also called lymphoblasts, crowd the bone marrow and stop it from making normal red blood cells, white blood cells and platelets.
- The cause of ALL is not known but some risk factors have been identified. You cannot catch ALL from someone else.

WHICH TYPE OF ALL DO I HAVE?

ALL is not a single disease, it is the name given to a group of leukaemias that develop in the lymphoid cell line in the bone marrow.

Depending on the type of abnormal lymphocyte present, ALL can be broadly classified into two main groups:

- ALL that arises in developing B-lymphocytes (B-cells)
- ALL that arises in developing T-lymphocytes (T-cells).

The World Health Organization's (WHO) classification system for ALL uses additional information, obtained from more specialised tests. The various subtypes of ALL are determined by the presence or absence of cell surface markers, which are explained in more detail in the immunophenotyping section on pages 15-16.

The WHO classification is also used to determine if a disease is either a leukaemia or lymphoma. For example, if the abnormal lymphocytes are primarily in the bone marrow, the disease is called B-cell acute lymphoblastic leukaemia (B-cell ALL). If the lymphoblasts are restricted to a mass in a lymph node or other lymph tissue and less present in the bone marrow, it is usually called B-cell lymphoblastic lymphoma.

Pre-B-cell ALL

This is the most common subtype, making up 75–80% of adult cases. Pre-B-cell ALL occurs in (immature) B-cells in the early stages of development in the bone marrow.

B-cell ALL

This subtype of ALL begins in more mature developing lymphocytes and makes up around 3–5% of adult cases. Sometimes pre-B-cell ALL and B-cell ALL are grouped together and all described as B-cell ALL.

T-cell ALL

This subtype of ALL begins in immature cells that would normally develop into T-lymphocytes (T-cells). T-cell acute lymphoblastic leukaemia (T-cell ALL) accounts for 20–25% of ALL cases.

In addition to classifying ALL as either B-cell ALL or T-cell ALL, the WHO further classifies ALL based on changes to certain chromosomes and genes (also referred to as cytogenetic abnormalities). Identifying these cytogenetic (sy-toe-gen-et-ick) abnormalities is important and helps doctors plan treatment and predict how well the treatment will work.

Cytogenetic changes

Translocation

A translocation is when the DNA from one chromosome breaks off and attaches to a different chromosome. The fusing together of two different genes results in an abnormal gene. Translocation is the most common type of genetic change associated with ALL.

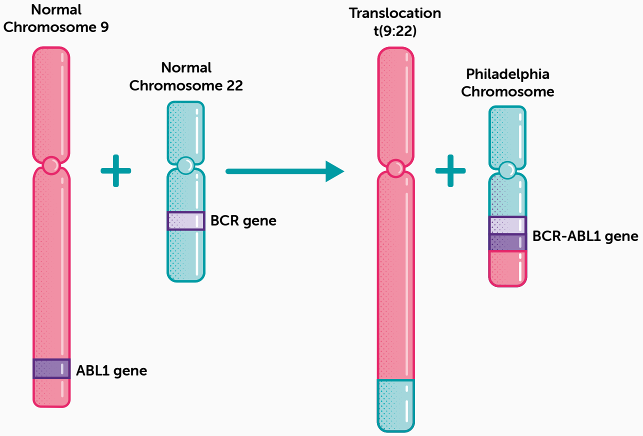
Philadelphia chromosome-positive ALL (Ph+ ALL)

Ph+ ALL is an example of a translocation where a gene called ABL1 on chromosome 9 breaks off and sticks to a gene called BCR on chromosome 22. This makes a new gene called BCR-ABL1, which produces a mutant protein that causes leukaemia.

Figure

05

Philadelphia chromosome translocation



Other cytogenetic changes in ALL include:

- **Amplification**: When there are too many copies of part of a chromosome.
- **Hypodiploidy**: When the leukaemia cells have fewer chromosomes than normal (45 or less).
- **Hyperdiploidy**: When the leukaemia cells have more chromosomes than normal (47 or more).

WHAT ARE THE SIGNS AND SYMPTOMS OF ALL?

The signs and symptoms of ALL will vary from person to person. Symptoms may develop very quickly.

It is common for someone with ALL to feel less well than usual because of the lack of normal, healthy blood cells. This happens when the leukaemia cells in the bone marrow crowd out the normal blood cells.

Anaemia

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

The symptoms of anaemia include:

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

Bleeding and bruising

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

Symptoms of thrombocytopenia include:

- Bruising easily
- Minor cuts or injuries that take a long time to stop bleeding
- Frequent or severe nosebleeds or bleeding gums
- Heavier or more frequent menstrual periods
- Red or purple pinhead-sized spots on the skin called petechiae (pe-tee-kee-i).

Infections

People with ALL are at increased risk of infection, even before receiving any treatment. This is because the leukaemia cells can interfere with normal immune responses and antibody production.

People with ALL tend to get frequent infections or find it harder to recover from an infection.

Common signs and symptoms of infection include:

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

Common types of infection in people with ALL may include:

- Chest infections (including pneumonia)
- Urinary tract infections (UTI or bladder infection)
- Cellulitis (a skin infection causing redness, swelling and tenderness that can spread)
- Viral colds and influenza (head cold or flu)
- Shingles (a rash with tiny blisters, usually localised to one side or area of the body).

See pages 35-37 for more information on how to prevent and manage infections.

Important information

- If you develop any symptoms of an infection, you will need to contact your health care team at the hospital. It is important to see your doctor quickly, rather than waiting to see if the infection gets worse. Infections can be more severe and can develop more quickly in people with ALL.
- If you are currently receiving chemotherapy or are neutropenic (low white blood cell count), you must seek urgent medical care if you develop a fever or other symptoms of infection. Your health care team will advise you how to seek help, as this may vary from hospital to hospital.

Other symptoms of ALL

You may also experience other symptoms that are common in ALL.

These symptoms include:

- Recurrent drenching sweats at night
- Unexplained weight loss
- Loss of appetite
- Swelling and pain in the abdomen (caused by a build-up of leukaemia cells in the liver and spleen, making them larger)
- Enlarged lymph nodes in the neck, groin or underarm areas
- Bone or joint pain
- Wheezing, coughing or painful breathing.

Key points

- Symptoms of ALL may develop very quickly.
- ALL can cause lack of energy, shortness of breath and/or fatigue due to a low number of red blood cells.
- ALL can cause increased bruising and bleeding due to a low platelet count.
- Having ALL can increase your risk of infection.
- Other symptoms of ALL may include bone pain, unexplained weight loss and loss of appetite.

WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

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

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

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

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

advise you on how to take your medicine, possible side effects and interactions with other medications.

- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility.
- **Psychologist** – Specialises in helping you manage any emotional challenges such as stress, anxiety and depression.
- **Registrar** – A doctor who is training to be a specialist. You may see a registrar in clinics, day units and wards. Registrars works closely with senior specialists (haematologists or oncologists).
- **Social worker** – Helps you manage the practical and emotional impact of the condition and its treatment, such as advice about managing at home, employment or school.
- **Ward clerk** – Manages the administration on the ward, including scheduling admissions, and is the first point of contact for visitors.
- **Ward nurse** – A nurse who looks after you during a stay in hospital.

Other people you might meet:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of ALL, helping improve quality of life, and supporting people with a life-limiting illness, including at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.
- **Non-governmental organisation (NGO)** – Gives emotional and practical support for those affected by cancer. Leukaemia & Blood Cancer New Zealand is an NGO.
- **LBC Support Services Coordinator** – A professional who provides education as well as practical and emotional support. They can be contacted by calling 0800 15 10 15.

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

TESTS AND INVESTIGATIONS

ALL is diagnosed by examining samples of blood and bone marrow.

Blood test

The main blood test used to first detect ALL is called a full blood count (FBC) or complete blood count (CBC). Blood is taken from a vein in the arm and sent to a laboratory (lab) where it is looked at under a microscope.

An FBC measures the number and appearance of red blood cells, white blood cells and platelets. Normal ranges for blood test results are shown on page 17.

Most people with ALL have low red blood cell and platelet counts. People with ALL often have a high white blood cell count, but most of these are leukaemic blast cells that do not protect against infection. The leukaemic blast cells are immature lymphocytes and live in the bone marrow. However, in ALL these blast cells can spill out of the bone marrow into the bloodstream. Leukaemic blast cells can be seen on a blood test.

An FBC is helpful for diagnosing ALL, but a bone marrow biopsy is needed to confirm a diagnosis. Other specialised blood tests may also be required.

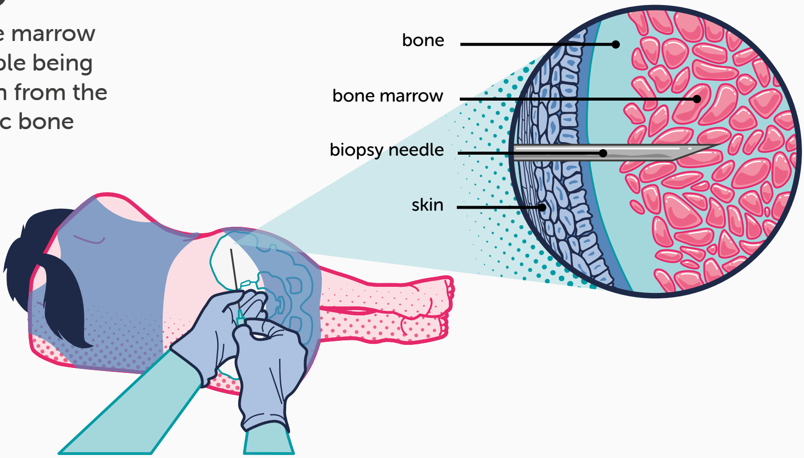
Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a laboratory to be looked

Figure

06

Bone marrow sample being taken from the pelvic bone



at under a microscope and analysed by special equipment. A bone marrow biopsy is required to diagnose most leukaemias accurately. A bone marrow biopsy is usually done at the start of treatment and may also be done during and after treatment to see how well the leukaemia is responding.

A sample of bone marrow is usually taken from the back of the hip bone (also called the pelvic bone, or iliac crest) (see Figure 06).

Once a diagnosis of ALL is made, blood and bone marrow cells are examined further using special laboratory tests. These include immunophenotyping (im-u-no-fee-no-tie-ping), cytogenetic (sy-toe-gen-et-ick) and molecular tests. These tests provide more information about the exact type of disease, how the disease is likely to progress, and the best way to treat it.

Immunophenotyping

Immunophenotyping is a test that looks at special markers called antigens, which are found on the surface of cells. These can determine the exact subtype of leukaemia and therefore the best way to treat it.

The most common method of immunophenotyping is called flow cytometry, which uses lasers to detect the abnormal leukaemic cells in blood or bone marrow samples. Depending on the type of leukaemia, the leukaemic cells can have different antigens on their surfaces.

Detailed information

A bone marrow biopsy is done in hospital, either as an inpatient (staying on the ward overnight) or outpatient (visiting the hospital for the day).

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

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

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

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

The bone marrow aspirate and trephine samples are sent to a laboratory and examined under a microscope.

You will then have an appointment with your haematologist/oncologist to talk about the findings of your bone marrow biopsy.

The presence of these markers can confirm a diagnosis of ALL. Flow cytometry is helpful to rule out related conditions that might be treated differently. It is also used to determine the type of lymphocytes (B-cells or T-cells) in which the disease originated. Flow cytometry can also be used to measure minimal residual disease (MRD), to see how the leukaemia is responding to treatment (see the detailed information section on MRD below).

Cytogenetic and molecular tests

Cytogenetic and molecular tests typically use blood or bone marrow samples to see if the leukaemia cells have changes in their genes compared to normal cells.

Normal human cells contain 23 pairs of chromosomes (a total of 46 chromosomes). Each pair of chromosomes is a certain size, shape and structure. The chromosomes of leukaemia cells have abnormal changes that can be seen under a microscope. These changes include translocations and/or extra chromosomes, which are explained further in the section **Which type of ALL do I have?** on page 8.

One common cytogenetic test used for ALL is fluorescent in situ hybridisation (FISH). FISH uses fluorescent dyes that attach to certain parts of chromosomes. Analysing chromosomes in this way can detect large genetic changes that can affect how ALL responds to treatment.

Molecular tests look at the DNA sequence itself and can detect smaller changes (mutations) that are too small to be seen with a microscope. Very sensitive laboratory techniques such as polymerase chain reaction (PCR) or next-generation sequencing (NGS) may be used and can detect very small numbers of leukaemia cells.

Together, immunophenotyping, cytogenetic and molecular tests provide more information about the exact type of disease you have, its likely response to treatment, and the best way to treat it.

Detailed information

Minimal (or measurable) residual disease (MRD) is the smallest quantity of leukaemia cells that current technology can detect.

Measuring MRD has become a standard way of testing a person's response to initial treatment, their risk of relapse in the future, and what the most appropriate treatment protocol for them is. MRD testing may also be repeated to assess how well you are progressing and responding to your treatment.

Being 'MRD negative' indicates that the number of leukaemia cells left in the body is so low that the technology cannot detect them. Negative MRD does not mean there is no leukaemia in the body and that treatment can end. It simply means the amount of leukaemia is below the levels that can be detected with current technology. The term MRD positive indicates that there are still some leukaemia cells detected and suggests a greater potential for relapse compared with someone who is MRD negative. Being MRD positive does not necessarily mean that the treatment is not working. Usually, it indicates that more treatment is needed to make the leukaemia undetectable.

Other tests

Other tests provide information on your general health and how well your kidneys, liver and other vital organs are functioning. These can include a combination of blood tests and imaging tests (e.g. X-ray, CT scan, ECG). Blood tests may include kidney function tests, liver function tests and coagulation tests, to see if your blood is clotting properly.

You may also have a procedure called a lumbar puncture, where a small sample of the cerebrospinal fluid (CSF) that surrounds the brain and spinal cord is taken via a needle in the lower back. This fluid is tested in the laboratory to check for the presence of leukaemia cells within the central nervous system.

You will be asked to lie on your side in the foetal position to help guide the spine into the optimal position. A local anaesthetic is used just like in a bone marrow biopsy.

You may be asked to lie flat for a short time after the procedure to help minimise the potential side effect of a headache.

These tests are important because they provide baseline results for your general health and organ function. The results may be important in selecting the best treatment option for you. They can also be compared with later results to assess how well you are progressing.

Normal blood test results

The table below gives you information about normal blood test results for adults. You may find this useful when you are having regular blood tests and want to compare your results with the normal range.

Please note that there may be small variations compared with the data used at your hospital or clinic.

Normal blood test range for adults

	Adult men	Adult women
Haemoglobin (Hb) (g/L)	130-175	115-155
Neutrophils (x10^9/L)	2.0-7.5	2.0-7.5
Platelets (x10^9/L)	150-400	150-400

Key points

The two main tests for diagnosing ALL are:

- Blood test (full blood count or FBC)
- Bone marrow biopsy.

Specialised laboratory tests (immunophenotyping, cytogenetic and molecular tests) provide more information about the exact type of disease, the likely course of the disease, and the best way to treat it.

INFORMED CONSENT FOR TREATMENT AND PROCEDURES

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

Consent means that you agree. Informed consent means that you understand the information and accept the possible risks and benefits of the treatment or procedure. Informed consent also means that you have had other treatment or procedure options explained to you. You can still ask questions after you have given informed consent.

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

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

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

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 20.

Key points

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

MAKING TREATMENT DECISIONS

The main aim of treatment for ALL is to destroy the leukaemia cells in the body and allow the bone marrow to function normally again.

The treatment that your doctor recommends will depend on things like:

- The type of leukaemia you have, including the genetics of the leukaemia
- Your general health
- Your age
- How well your ALL is likely to respond to treatment.

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

Many people feel overwhelmed when they are diagnosed with ALL. Waiting for test results and making decisions about treatment can be very stressful. Some people do not feel that they have enough information to make decisions, while other people feel that they have too much information. Some people feel that they are being rushed into making a decision. Not everyone has time to think about their options as they may need to start treatment immediately.

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

Second opinion

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

Questions to ask the health care team

It can be useful to write a list of questions before any appointment with your haematologist/oncologist or another member of your health care team.

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

Bring a support person

It can be useful to have a support person (partner, parent, close friend) with you at any important appointments you have with your haematologist/oncologist. Your support person can write down the answers to your questions, remind you of questions you want to ask and help you remember information.

Key points

- Your doctor will recommend a course of treatment to you. They will give you the opportunity to discuss your treatment and ask questions.
- You will be given information so that you can understand the risks and benefits of treatments and procedures.
- You will be asked to give your written or verbal informed consent for treatments and procedures.
- We recommend you bring a support person to your appointments if possible.

Being in a clinical trial

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

Taking part in a clinical trial is voluntary, which means that you do not have to give consent to take part in the trial if you do not want to. If you do not want to be part of the trial, your decision will be respected.

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

More information available online

See the Clinical Trials section of the LBC website.

Prognosis

Prognosis means the likely course of a disease, i.e. how likely it is to be cured or controlled. Your prognosis will depend on many things (see the detailed information section on prognostic factors on the next page). Your haematologist/oncologist is the best person to give you a prognosis and tell you how well your leukaemia is likely to respond to treatment.

When members of your health care team talk about prognosis, they might use the folllowing terms:

- **Complete remission** – The treatment has been successful and the leukaemia cells can no longer be seen under a microscope.
- **Partial remission** – The number of leukaemia cells is less, but there are still some leukaemia cells present.
- **Stable disease** – The leukaemia is not getting worse or better.
- **Relapse** – The leukaemia has come back again.
- **Resistant disease** – Also called refractory disease. The leukaemia is not responding to treatment.

Relapsed disease

Finding out that your ALL has relapsed can be devastating. If your ALL comes back, your haematologist/oncologist will discuss possible options of getting it back under control. The treatment of relapsed disease depends on several factors including the duration of the remission and the site at which the disease has reappeared. Other factors are also considered, including your age and the genetic make-up of the relapsed leukaemia cells. You may need to have similar drugs to what you have already received, different drugs, or a stem cell transplant. LBC has other resources that explain in detail what a stem cell transplant is and what's involved in the procedure.

More information available online

See the autologous and allogeneic stem cell transplant fact sheets on the LBC website.

Late relapse (relapse that occurs years later) is usually more responsive to further treatment than relapse that occurs soon after a remission has been achieved. Clinical trials are continuing to determine the best way to treat relapsed ALL to achieve the best outcomes.

Palliative care

If a decision is made not to continue with curative anti-cancer treatment (chemotherapy and radiotherapy) for your ALL, there are still many things that can be done to help you to stay as well and as comfortable as possible.

Palliative care is aimed at relieving any symptoms or pain a person might be experiencing because of their disease or its treatment. Palliative care can take place alongside active/curative treatment or once treatment has stopped. This is because the palliative care team are experts in symptom management and can improve quality of life and support decision-making. See the section on supportive care on page 28 for more detailed information.

Detailed information

Prognostic factors are certain factors that can affect your prognosis. Doctors use prognostic factors to help predict how your disease is likely to respond to treatment. These factors help doctors plan a more appropriate treatment.

Prognostic factors for adults with ALL include:

- **Age** – Younger patients tend to have a better prognosis than older patients. This may be due to different chromosome changes or because older patients are more likely to have other medical conditions that can make treatment options more difficult.
- **White blood cell count at diagnosis** – People with a lower white blood cell count tend to have a better prognosis.
- **Genetic or chromosome changes** – Different changes or mutations in genes or chromosomes can affect prognosis.
- **Response to treatment** – Patients who go into complete remission earlier tend to have a better prognosis than those who take longer, or those that do not go into remission at all.

TREATMENT FOR ALL

ALL usually progresses quickly so treatment needs to begin as soon as it is diagnosed.

The main treatment options for ALL are:

- Intensive chemotherapy
- Low-dose chemotherapy
- Stem cell transplant
- Supportive/palliative care.

Each of these treatments will be discussed in the following pages.

Chemotherapy

Chemotherapy (chemo) is the name given to anti-cancer drugs (also called cytotoxic drugs), which work by stopping cancer cells dividing. Chemotherapy drugs are the main type of treatment for ALL.

There are many different types of chemotherapy, and each drug affects the cancer cells in different ways. This is why a combination of two or more different chemotherapy drugs is usually given.

Most chemotherapy drugs travel around the body in the bloodstream, which means they can reach the cancer cells anywhere in the body. Sometimes the chemotherapy drugs also kill healthy cells, which leads to side effects. Side effects are discussed later in this section.

Chemotherapy is usually given in several treatment cycles (or courses) with a rest period of a few weeks in between each cycle. This is to allow the body time to recover from the side effects of chemotherapy.

How is chemotherapy given?

Chemotherapy can be given in different ways:

- Into a vein (intravenously or IV/drip)
- In a tablet (orally)
- Injection into a muscle (intramuscular)
- Injection under the skin (subcutaneous or sub-cut or SC injection)
- Into the spinal fluid via a hollow needle (intrathecally or IT).

IV access for chemotherapy

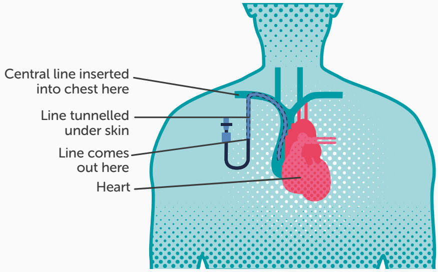
If you are having several cycles of chemotherapy, your doctor may talk to you about having a central line (also called a central venous catheter [CVC] or central venous access device [CVAD]), port or peripherally inserted central catheter (PICC) line inserted. These are special lines inserted through the skin into a large vein in your arm, neck or chest. Once your line is in place, chemotherapy and any other IV drugs can be given and blood tests can be taken from the line, without the need for frequent needles in your arms.

Intrathecal chemotherapy

Intrathecal chemotherapy is when chemotherapy drugs are injected directly into the spinal fluid, through a procedure called a lumbar puncture. This happens when cancer cells are found in the central nervous system (CNS) (brain and spinal cord). The blood supply to the CNS is separate from the blood supply to the rest of the body, so it can be difficult for standard treatments to reach cancer cells in these areas. In some cases, intrathecal chemotherapy may also be given to prevent cancer spreading to the CNS (called preventative or prophylactic treatment).

Figure 07

Central line placement



Intensive chemotherapy

Intensive chemotherapy involves being given a full dose of chemotherapy in hospital, with the aim of curing ALL. If you have intensive chemotherapy, you will spend long periods of time in hospital – often several weeks. To receive this treatment, you may need to move to a hospital in a main centre. More information about this can be found on page 43. Intensive chemotherapy is likely to cause unpleasant side effects, but these can usually be controlled with medicines.

Intensive treatment for ALL is given in two main phases: induction and consolidation.

- Induction chemotherapy aims to put the ALL into remission. If the ALL is not in remission after your planned induction chemotherapy, you may have more cycles of treatment.
- Consolidation chemotherapy aims to get rid of any leukaemia cells that may remain after induction chemotherapy and to reduce the risk of the ALL coming back.

Detailed information

Commonly used drugs for intensive chemotherapy treatment of ALL are:

- Asparaginase
- Cyclophosphamide
- Cytarabine (Ara-C)
- Doxorubicin (Adriamycin)
- Daunorubicin
- Idarubicin
- Methotrexate
- Mercaptopurine
- Nelarabine (Atriance)
- Vincristine.

Several chemotherapy drugs can used in combination with each other, and alongside other drugs such as corticosteroids and immunotherapy or targeted therapy drugs (more information on these medications in the following pages).

Lower doses of chemotherapy

Lower-dose chemotherapy is also sometimes known as 'non-intensive treatment' or 'palliative chemotherapy'. Lower-dose chemotherapy is an alternative treatment to intensive chemotherapy that aims to control ALL rather than get rid of it. A person receiving lower doses of chemotherapy typically spends less time in hospital than someone receiving intensive chemotherapy.

Side effects of chemotherapy

Healthy cells that multiply quickly (such as cells in your mouth, stomach, bowel, bone marrow and hair follicles) can also be killed or damaged during chemotherapy. The damage to these cells can cause side effects.

The side effects for each chemotherapy drug or drug combination are different and may vary from person to person. Most side effects of chemotherapy begin to go away when treatment is finished.

Side effects of treatment may be short or long term. Short-term side effects should go away a few weeks after treatment finishes, when the damaged cells recover. Long-term side effects may continue for months after treatment. Sometimes, new side effects or health issues can appear some time after treatment has finished. These are called late effects.

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

- Anaemia
- Bruising and bleeding
- Changes in mood
- Constipation
- Diarrhoea
- Difficulty concentrating

Key points

- Chemotherapy is the main form of treatment for ALL. There are many different types of chemotherapy that can be given alone or with other drugs.
- Chemotherapy can be given into a vein (IV), as a tablet (orally), as an injection into a muscle (intramuscular injection) or under the skin (subcutaneous injection), or into the spinal fluid (intrathecally).
- Chemotherapy can be given in hospital, as an outpatient or at home, depending on the type of chemotherapy you are having and how well you are.

Detailed information

Tumour lysis syndrome

People with ALL may be at risk of a condition called tumour lysis syndrome (TLS). This condition occurs when many cancer cells die within a short period of time, releasing their contents into the blood. Uric acid is one of the chemicals released by dying cancer cells and can increase potassium and phosphate in the blood.

TLS is an uncommon but potentially life-threatening emergency, so if you are at a high risk of developing TLS, you will have regular blood tests to monitor the potassium and phosphate levels in your blood. TLS is most common at the beginning of treatment.

- Fatigue (extreme tiredness)
- Fertility issues
- Hair loss
- Increased risk of infection
- Nausea and vomiting
- Organ damage
- Pain
- Poor appetite and taste changes
- Skin changes
- Sore mouth (mucositis).

These side effects, and what you can do if you experience them, are discussed in the section **Living with ALL** on page 31.

Corticosteroids

Corticosteroids (often just called steroids) are drugs that mimic different hormones in the body. Steroids are often used in the treatment of ALL to kill leukaemia cells directly and enhance the activity and effectiveness of other treatments, like chemotherapy.

Two corticosteroid drugs commonly used in ALL are:

- Dexamethasone
- Prednisone.

Side effects of corticosteroid drugs

Steroids can cause side effects, some of which can be hard to manage. These include:

- Mood changes (irritability, tearfulness, anger, anxiety).
- Difficulty sleeping.
- Stomach pain or reflux caused by irritation of the stomach lining. Medications to prevent this are often prescribed at the same time as the steroids.
- Increased blood sugar or steroid-induced diabetes (see detailed information below)
- Increased appetite and weight gain. See page 33 for more information about changes to appetite.
- High blood pressure.
- Difficulty walking.
- Increased risk of infection. See pages 35-37 for more information about infection.

More information available online

See the Steroids and Cancer Treatment fact sheet on the LBC website.

Detailed information

Steroid-induced diabetes

High doses of corticosteroids can cause diabetes in some people. Taking high-dose steroids can cause problems with the production and effectiveness of insulin, causing blood sugars (glucose) to rise and spill over into the urine. Some people will need insulin injections to maintain blood glucose levels in the healthy range. Steroid-induced diabetes usually resolves once you stop taking the steroids.

While on steroids you will likely have your blood glucose levels monitored regularly, and you may also need to monitor your food and drink intake. Your health care team will give you more information about how to manage your steroid-induced diabetes.

Stem cell transplant

High doses of chemotherapy and radiotherapy destroy stem cells in the bone marrow, so the bone marrow cannot continue to produce blood cells. A stem cell transplant (SCT) involves receiving high dose chemotherapy followed by stem cells through an IV/drip to replace the ones that were destroyed, allowing your bone marrow to produce blood cells again. As a result, stem cell transplants allow you to have much higher doses of treatment, which may prolong remission (keep ALL away for a longer time).

A stem cell transplant may also be called a bone marrow transplant, a haematopoietic (he-ma-toe-po-ee-tick) stem cell transplant or a peripheral blood stem cell transplant.

A stem cell transplant is not suitable for everyone, and not everyone with ALL needs a transplant. If your specialist thinks a stem cell transplant is an option for you, they will discuss it with you in detail.

There are two types of stem cell transplants:

- Autologous (or-tol-o-gus) SCT – Your own stem cells are removed before the chemotherapy, frozen, and then given back to you after the chemotherapy.
- Allogeneic (al-o-jen-ay-ick) SCT – You receive stem cells from someone else (a donor) after chemotherapy.

Allogeneic SCT

An allogeneic stem cell transplant (also called an allograft or allo) is when you are given stem cells from a donor. The donor may be your brother, sister or an unknown volunteer who has been genetically matched to you (a matched unrelated donor, or MUD).

These donated stem cells replace your immune system with the immune system of the donor. One of the main jobs of the immune system is to attack anything it doesn't recognise, such as infections and cancer. The donated immune system is helpful because it can kill any remaining leukaemia cells. This is called 'graft versus leukaemia' and reduces the chance of the leukaemia coming back (relapsing).

An allogeneic stem cell transplant is a high-risk treatment option, and a lot of factors are taken into consideration before it is offered by your haematologist/oncologist.

Autologous SCT

An autologous stem cell transplant (also called an autograft) is not often used for people with ALL. For an autologous stem cell transplant, some of your stem cells will be collected and stored. You will have high doses of chemotherapy and then your stem cells are returned through an IV infusion.

Key points

- A stem cell transplant is when stem cells are given following high-dose chemotherapy, to allow the bone marrow to recover.
- Stem cell transplants allow you to have much higher doses of treatment to improve chances of recovery.

More information available online

See the Allogeneic Stem Cell Transplant and Autologous Stem Cell Transplant fact sheets on the LBC website.

Immunotherapy

Immunotherapy is any medical treatment that uses the immune system to improve health or fight disease. Some types of immunotherapy are now being studied and used to treat ALL.

These include:

- Monoclonal antibodies
- Chimeric antigen receptor (CAR) T-cell therapy.

Monoclonal antibodies

Antibodies are proteins made by the body's immune system to help fight infections. Monoclonal antibodies are man-made versions of these proteins, which are designed to attack a specific target such as a protein on the surface of leukaemia cells.

Chimeric antigen receptor (CAR) T-cell therapy

CAR T-cell therapy works by changing a patient's own T-cells so they can recognise and attack cancer cells. The T-cells are multiplied in the laboratory and then given back to the patient via IV/drip a few days after receiving some chemotherapy.

This treatment is not currently available for ALL in New Zealand but there are hospitals in Australia and abroad where it may be a treatment option for some people who have relapsed or refractory ALL.

More information available online

See the Immunotherapy and Cancer fact sheet on the LBC website.

Detailed information

Rituximab is a monoclonal antibody that binds to a cell marker called CD20 on cancerous B-cells. Once attached, Rituximab triggers immune cells and a series of proteins called the 'complement system' to destroy the cancer cell.

Blinatumomab is a kind of monoclonal antibody called a bi-specific T-cell engager (BiTE) as it can attach to two different proteins at the same time. One part of blinatumomab attaches to the CD19 protein, which is found on B-cells. Another part attaches to CD3, a protein found on T-cells. By binding to both of these proteins, this drug brings the cancer cells and immune cells together, which helps the immune system attack the cancers cells.

Inotuzumab is a type of monoclonal antibody that carries a chemotherapy drug. The antibody binds only to cells carrying the CD22 marker on the outside, which is common on leukaemia cells. When the antibody binds to these cells, it then releases the chemotherapy into the leukaemia cells. The specific delivery of chemotherapy to the leukaemia cells reduces the chemotherapy exposure of normal cells.

Targeted therapy

Targeted therapy uses drugs to identify and attack specific types of cancer cells. Targeted therapy can be used in combination with other treatments, such as chemotherapy.

People who have the Philadelphia (Ph) chromosome in their leukaemia cells often have a targeted therapy called tyrosine kinase inhibitors (TKIs), as well as chemotherapy.

TKIs work to block overactive enzymes that occur in Philadelphia chromosome-positive ALL (Ph+ ALL). Examples of TKIs used in ALL include Imatinib and Dasatinib, which are both given orally (tablets by mouth).

Common side effects of TKIs include:

- Low blood cell counts
- Abnormal bleeding
- Nausea and vomiting
- Diarrhoea
- Fatigue
- Headaches
- Rashes
- Pain in muscles, bones and joints.

Supportive care

Supportive care focusses on improving comfort and quality of life. It includes measures to help you cope with your diagnosis, symptoms of ALL and the impact of treatment. Supportive care can be given alongside anti-cancer treatments (e.g. chemotherapy) or on its own.

Examples of supportive care are:

- Blood products given via a drip (transfusion) to help with symptoms of a low number of red blood cells or platelets
- Prescribed drugs to help manage side effects or symptoms, e.g. pain relief or anti-nausea drugs
- Antibiotic drugs to help prevent or manage infections
- Support from a dietitian, psychologist or chaplain
- Practical support at home
- Support for family/whānau.

Blood transfusions

You may be given blood transfusions at the time of your diagnosis or during your treatment. The two main types of blood products given are red blood cells and platelets. Blood transfusions can quickly increase the levels of healthy, functioning blood cells that are low because of treatment or the ALL itself.

Blood transfusions are generally administered at the hospital and are given via IV/drip. Most blood transfusions will be given over 30 minutes – 3 hours. You will be closely monitored as there is a risk of having an allergic reaction while the transfusion is running. Monitoring will include having your temperature, heart rate, respiratory (breathing) rate, blood pressure and oxygen saturations measured. It is important that you report any changes in how you feel, such as difficulty breathing, itchy skin, rash or shivering (chills).

Supportive care medications

There are many supportive care medications that play different roles in making you feel more comfortable and preventing further sickness. These include antibiotics, pain relief, antiemetics (anti-sickness) and laxatives. Your doctor can prescribe these drugs, and they are usually given orally (as liquid or tablet) or by IV/drip.

Antibiotics, antivirals and antifungals

Antibiotic, antiviral and antifungal drugs can be prescribed to prevent infections (called prophylaxis, or prophylactic medications) or to treat infections. They are used to treat or prevent bacterial infections (antibiotics), viral infections (antivirals) or fungal infections (antifungals). Antibiotics, antivirals and antifungals can be given via IV /drip or taken orally (liquid or tablet).

Prophylactic medications may be prescribed at the same time you start chemotherapy treatment. This is because chemotherapy drugs can increase both the risk of getting an infection and its severity. Your doctor will let you know if you need to take any regular medications, how to take them and what they are for.

You may be prescribed a low-dose antifungal called cotrimoxazole, which is used to help prevent an infection called pneumocystis jirovecii. This is a common fungal infection that can reactivate when the immune system is compromised (e.g. when on chemotherapy) and cause a life-threatening pneumonia. Cotrimoxazole prophylaxis generally continues until chemotherapy is completed.

People with ALL have an increased risk of developing infections. This is because chemotherapy drugs can kill the functioning white blood cells, which lowers the immune system. Neutrophils (a type of white blood cell) play an important role in fighting infections. Neutropenia means that there are low numbers of neutrophils in the blood. If you are neutropenic and develop an infection, you need to urgently be seen by a doctor and start IV antibiotics. Your health care team will let you know who to call or what hospital to go to if you develop an infection. More information about infections can be found on pages 35-37.

PHASES OF ALL TREATMENT

ALL treatment is typically divided into three phases: induction, consolidation and maintenance.

People with high-risk ALL may have additional phases of treatment. Each phase is explained below in more detail.

Induction

The first phase of chemotherapy is called induction therapy. The goal of induction is to destroy as many cancer cells as possible to achieve remission and allow your bone marrow to function normally again.

The induction phase usually lasts for four weeks. After induction is complete, you will likely have another bone marrow biopsy and tests to see how the leukaemia has responded. Most people (around 80%) will be in remission after induction chemotherapy. Unfortunately, some people will not achieve remission after induction chemotherapy and may require more intensive treatment. This is sometimes described as resistant or refractory disease.

Consolidation

Consolidation therapy begins after induction therapy with the goal of killing any remaining leukaemia cells in the body. It is normal for there to be some leftover leukaemia cells, even in people who achieve remission. Consolidation treatment helps prevent the disease from reappearing or spreading.

Consolidation can also be called ‘intensification’. Usually, higher doses of chemotherapy are used during the consolidation phase than those used in induction. The exact type of consolidation treatment will depend on a number of factors, including your risk of relapse. Some people may also be offered a stem cell transplant following consolidation treatment. More information about stem cell transplants can be found on page 26.

Consolidation treatment usually involves several blocks (cycles) of treatment given over several months. Consolidation treatment is often given as an outpatient (in day stay or outpatient clinic). You may be required to stay in hospital overnight if there are any complications, such as a fever or infection.

Maintenance

Maintenance therapy is the last and longest phase of treatment. The goal of maintenance treatment is to prevent relapse of ALL in the future.

Maintenance therapy protocols may include chemotherapy tablets (taken daily or weekly), chemotherapy injections and steroids.

Maintenance treatment can last for up to two years. It is usually given as an outpatient (in day stay or outpatient clinic), however in some instances you may need to be admitted to hospital.

LIVING WITH ALL

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

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

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

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

Anaemia

A low red blood cell count is called anaemia. Anaemia and its associated symptoms are described on page 10.

If you have a low red blood cell count, you may be given red blood cells via IV/drip, which is called a blood transfusion. More information about blood transfusions can be found on page 28.

Bruising and bleeding

If you have a low platelet count (thrombocytopenia), you may bruise easily or bleed more than usual from minor cuts.

To minimise bruising and bleeding while your platelets are low:

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

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

Important information

Call the hospital straight away if you have:

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

Constipation

Constipation is when you cannot pass a bowel motion (poo) easily, usually because your bowel motions are hard. Tell your nurse or doctor if you are constipated or sore.

Hard bowel motions can damage the lining of the bowel and cause bleeding or infection. Constipation can be painful. Constipation is particularly common when you are receiving chemotherapy drugs called vinca alkaloids (such as vincristine) and often doctors will prescribe a laxative to help.

Things you can do to help:

- Drink plenty of water
- Eat more fibre such as cereals, washed raw fruit and vegetables
- Gentle exercise, e.g. walking
- Tell your doctor or nurse, as they can give you something to soften your bowel motions
- Talk to a dietitian.

Chemo brain

Chemo brain can be a symptom of ALL or a side effect of treatment such as chemotherapy. Chemo brain is also called mild cognitive impairment. It can also affect people with cancer who have not had chemotherapy. The exact cause of chemo brain is not known.

The symptoms of chemo brain are:

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

Chemo brain can be frustrating, and it can make everyday life difficult.

Some things you can do to help are:

- Keep a diary of your symptoms
- Make lists, take notes and use sticky pads or your phone for reminders
- Keep a calendar or diary
- Do mental exercises such as crosswords and puzzles
- Try to keep calm
- Exercise regularly
- Get plenty of rest and sleep
- Read short articles instead of books, watch episodes of TV shows instead of movies.

More information available online

See the Chemo Brain fact sheet on the LBC website.

Diarrhoea

Sometimes chemotherapy damages the lining of the bowel wall, which might cause diarrhoea (die-a-rea) (loose bowel motions).

Important information

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

Other symptoms may include:

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

If you have diarrhoea, your health care team will likely do a test to see if you have an infection. The doctor may prescribe some drugs to help stop the diarrhoea, if appropriate.

Things that can be done to help:

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

Difficulty eating or drinking

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

More information available online

See the Eating Well fact sheet on the LBC website.

Early menopause

Some chemotherapy drugs can lower the amount of hormones that the ovaries make. This can lead to early menopause and menopausal symptoms. Menopause usually starts any time after 40 years of age when, due to hormonal changes, women's periods stop and they can no longer have children.

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

Fatigue (extreme tiredness)

Fatigue is very common for people with ALL or after ALL treatment.

Fatigue can be caused by:

- ALL itself
- Chemotherapy and other treatments
- Poor sleep
- Low blood counts (especially low red blood cells)
- Muscle loss
- Loss of appetite or dehydration
- Low mood such as depression.

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

Things that can be done to help:

- Have a regular night sleep routine
- Have regular rest periods throughout the day
- Don't try to do too many things in a day, just do the important things

- Note the times in the day when you have the most energy and set goals to do your main activities at these times
- Do some light exercise each day
- Keep a diary so you can look back and see changes in your energy levels over time.

In hospital your sleep can be interrupted. Speak with your health care team if you are finding this difficult. It can be useful to know why it's necessary to have various tests and monitoring overnight and can make you feel more prepared knowing what to expect and why.

More information available online

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

Feelings of isolation

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

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

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

Fertility, sex and contraception

Fertility means a person's ability to get pregnant or father a child. Infertility means that you may not be able to become pregnant or father a child. Intensive chemotherapy may cause infertility, or changes to your fertility.

It is important that you ask any questions and discuss concerns you might have about your fertility with your health care team as soon as possible. There may be some things you can do before you start treatment to preserve your fertility.

If you are sexually active or could become sexually active while receiving treatment, it is important that you use appropriate contraception. Chemotherapy can be excreted in all body fluids (including semen and vaginal secretions) so it's important that a condom is used to protect both partners. Chemotherapy can also affect a developing foetus, so it is important to avoid a pregnancy during and immediately after having chemotherapy.

More information about sex and relationships can be found on page 44.

More information available online

See the Fertility fact sheets on the LBC website.

Hair loss (alopecia)

Hair loss is a common side effect of chemotherapy and some forms of radiotherapy. It is typically only temporary and usually occurs 3–6 weeks after you begin treatment. You should start to feel and see new hair growing back 6–12 weeks after you finish treatment, although the colour and/or texture may be different. Each person is different, so the timing and extent of your hair loss may differ.

Hair loss can happen on all parts of your body including your head, eyebrows, eyelashes, beard or moustache, underarms, pubic hair and legs. You may experience hair thinning, or it may fall out completely. Your scalp may feel sensitive, sore or itchy when your hair is falling out.

Things you can do to help:

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

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

Emotional support

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

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

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

Shaving your head and head wear

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

Things you can do that can help:

- Speak to other people who have experienced hair loss.
- Wear a wig, hat, scarf or turban to protect yourself from the cold.
- Apply sunblock and wear a hat to protect sensitive skin against the sun.

Increased risk of infection

ALL and its treatments can increase the risk of infection.

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

Even if you are not receiving chemotherapy, and do not have a low white blood cell count, you should consider yourself at increased risk of infection due to your leukaemia.

The most common infections in people with ALL are:

- Chest infections (including pneumonia)
- Skin infections (including cellulitis and shingles)
- Urinary tract infections (UTIs, including kidney and bladder infections).

You should contact your health care team quickly if you develop a fever or other symptoms of an infection, as you are more likely to need antibiotic or antiviral treatment than someone who does not have ALL.

You may also be prescribed preventative (prophylactic) antibiotics to prevent infection, especially during and after some types of treatment.

Avoiding food-related infections

Take care when preparing and cooking food:

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

Avoiding viral infections

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

If possible, you should:

- Try to avoid people, including children, who are currently unwell with a cold, flu or another infection.
- Try to avoid people who have, or have been near others who have, active chicken pox, shingles or measles.
- Try to avoid people who have Covid-19, who have recently had Covid-19 and are still symptomatic and/or returning positive tests, or are currently isolating due to Covid-19 exposure.

The annual influenza and Covid-19 vaccines are recommended for most people with ALL but might be less effective if you are currently having or have recently had treatment. Your doctor may also recommend that you get a vaccination for shingles. The shingles vaccine (Shingrix) is now funded for anyone with a blood cancer. Check with your doctor about

Important information

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

what vaccinations you should have, and the best time to have them.

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

Pets

To avoid catching an infection from a pet, it is recommended that you:

- Wash your hands after touching pets.
- Avoid letting a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Keep pets away from areas where food is prepared.
- Wash your hands thoroughly if you touch a litter tray or animal poo.

Gardening

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

It is important that you:

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

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

Important information

If you are neutropenic (have a low white blood cell count), call the hospital if you have a temperature of 38°C or above.

- Don't wait to see if your temperature goes down.
- Make sure you have a thermometer at home and you know how to check your temperature correctly.
- Don't take any drugs such as paracetamol to bring your temperature down before you see a doctor.
- Don't take aspirin or ibuprofen in any form. This can increase your risk of bleeding if your platelets are also low. Always check with a doctor or nurse first.

Ask a member of your health care team for the phone numbers of the hospital and write them here:

Monday to Friday (during office hours)

ph...

Evenings/nights/weekends

ph...

Low mood, anxiety, depression or difficulty coping

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

Things you can do to help:

- Talk about how you're feeling with someone you feel comfortable with, e.g. family/whānau, a friend or your LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger long-term goals.
- Try to keep socialising by staying in touch with friends and family/whānau.
- Make a list of things that make you feel better such as a favourite TV show or hobby.
- Try to spend some time each day relaxing, e.g. listening to music, meditation.
- Exercise regularly, even if it's a brief walk outside.
- Try to keep a regular sleep pattern.
- Keep a diary or journal. This can help you express feelings privately.
- Cry if you need to.
- Try complementary therapies such as massage, aromatherapy or reflexology.

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

Nausea, vomiting and dehydration

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

There are drugs (medicines) called antiemetics which can help treat nausea and vomiting. Different drugs work in different ways, and you may be given more than one type of antiemetic drug to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch. Tell your doctor or nurse if you still feel sick as they might be able to try a different antiemetic drug, change the dose or give it to you in a different way.

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

Things you can do to help:

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

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

Organ damage

Sometimes chemotherapy can cause damage to cells in organs such as your kidneys, liver, heart and lungs. This damage can be temporary (short term) or less likely, permanent. Some types of chemotherapy are more likely to cause organ damage than others.

Examples include:

- Doxorubicin (which can cause heart damage)
- Cyclophosphamide (heart damage)
- Methotrexate (kidney damage)
- Vincristine (damage to nerve ends).

Your treatment team will be able to give you more information about whether organ damage is a likely side effect of the chemotherapy you are having.

Things you can do to help:

- Have all recommended blood tests – these are often used to monitor organ function, so your health care team can see if damage is occurring.
- Ask your health care team if there is any regular follow up you should have after you have finished treatment (such as regular heart checks or lung function tests).

Pain

Some people may experience pain because of ALL or their treatment. It is important to tell your health care team if you have pain.

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

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

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

Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to nerves in the hands, feet, arms and legs. Some people might experience numbness, tingling, pain, hot or cold sensations, or increased sensitivity. This can be caused by the leukaemia itself, but more commonly from some of the drugs used to treat ALL.

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

Things you can do to help:

- Take care of your feet by wearing covered shoes that fit well.
- Keep hands and feet warm.
- Be careful when getting into baths and showers to make sure the water isn't too hot and could burn your skin.

- Eat a well-balanced diet – try to include as many essential vitamins and minerals as possible.
- Keep your home tidy to reduce the risk of tripping and falling.
- Stop smoking as this can affect the blood flow to your hands and feet.
- Use ice packs or hot-water bottles to provide short-term relief of symptoms.

Poor appetite and taste changes

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

Low appetite

Having a low appetite (not feeling like eating) can be disappointing for people who usually enjoy eating. It is important to keep eating to help maintain your weight and energy levels. It is also important to drink plenty of fluids, especially if you are not eating very much.

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

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

Things you can do to help:

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

Taste changes

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

Things you can do to help:

- Choose cold foods as they often taste better and smell less.
- Suck boiled sweets or drink fruit juice as they leave a nicer taste in the mouth.
- Try different seasonings such as herbs and spices on your food.

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

More information available online

See the Eating Well fact sheet on the LBC website.

Skin and nail changes

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

Things you can do to help:

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

Sun protection

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

Things you can do to help:

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

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

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

Sore mouth (mucositis)

A sore mouth can be an uncomfortable side effect of chemotherapy. Chemotherapy can cause damage to the cells in the lining of your mouth and digestive system. The medical name for this side effect is mucositis (mew-co-site-is). You will usually notice symptoms of mucositis a couple of days after you start chemotherapy.

The symptoms of mucositis can include any of the following:

- Mild soreness of the mouth, especially the insides of your cheeks and the sides and underneath of your tongue.
- Sore throat.
- Taste changes.
- White, rough-feeling patches on the inside of your mouth.
- Red and inflamed patches on the inside of your mouth.
- Painful ulcers (sores) on the inside of your mouth.
- Difficulty or pain eating, drinking and taking tablets.
- Thick saliva (spit).
- Sore and cracked lips.

Mouth care

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

It is recommended that you do mouth care five times a day: when you wake up, after each meal and before bed. Doing mouth care can be painful, however it is very important that you do it regularly and carefully.

How to do mouth care:

- Brush your teeth with a soft or baby toothbrush or use a mouth sponge if a toothbrush is too painful.

- Rinse with mouthwash or water, as instructed by your health care team.
- Use a lip balm or petroleum jelly (Vaseline) on your lips.
- Don’t use dental floss as this increases the risk of bleeding gums.

Things you can do to help:

- Suck ice cubes or ice blocks.
- Suck on hard-boiled lollies if your mouth is dry.
- Drink fizzy water.
- Spit saliva into a bowl instead of swallowing. If you are in hospital, ask the nurse how to use the suction.
- Avoid acidic foods if they are causing you pain, e.g. lemon, orange, mandarin, grapefruit, tomato.
- Ask your doctor about prescribing a saliva substitute.

Managing mouth pain

Let your health care team know if your mouth is painful, especially if it stops you from eating. They can advise you how and when to use pain relief.

This may include:

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

If you think your mouth pain is getting worse and the pain relief isn’t helping, contact your health care team as you may need to have support with eating and drinking, or you may require stronger pain relief.

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

Important information

When to contact your doctor or the hospital for help.

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

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

Contacting the hospital after hours

Remember to ask your health care team for the hospital after-hours phone number. If you are feeling unwell, ring the number and ask for advice, no matter what time it is. Your health care team and the hospital would rather that you rang to discuss how you are feeling than not ring and feel worse or your condition deteriorate. If in doubt, make the call.

The emergency department at the closest hospital will always be open and their phone numbers can be found on page 59.

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

Moving to a main centre hospital for treatment

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

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

Moving to another hospital for treatment can be stressful for you and your family/whānau. Contact your LBC Support Services Coordinator for more advice about moving to a main centre hospital.

RELATIONSHIPS

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

Relationship with your partner

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

Other things you can do to help:

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

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

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

Talking to your children

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

You can encourage younger children in your treatment journey to use an LBC sticker journal. Your children can record your treatments and write and share journal entries with you. LBC also has a picture book called Joe Has Leukaemia available in English and Te Reo Māori, which can be helpful to explain your diagnosis to younger children. Ask your LBC Support Services Coordinator for more information about the LBC sticker journal and picture books.

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

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

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

More information available online

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

Talking to friends and colleagues

It can sometimes feel difficult to talk to friends and work colleagues about your ALL diagnosis – and they can also feel the same way. Sometimes people unintentionally make comments that can be hurtful or make suggestions that are unhelpful.

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

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

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

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

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

Some people find that after a year or so of having ALL, others don't ask how they are doing or understand that they might still be having ongoing treatment and appointments for their ALL. Try and find a support network to help you feel validated and cared for. This might be a variety of people like close friends, family/whānau, a colleague, counsellor or psychologist, or your LBC Support Services Coordinator.

Sexual relationships

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

The reasons for this can include:

- Fatigue
- The side effects of treatment, e.g. nausea
- Changes in mood, e.g. anxiety
- Changes to body image, e.g. due to hair loss, weight change
- Changes to libido
- Vaginal dryness or difficulty getting an erection.

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

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

Contraception

It is recommended that you do not try to get pregnant or father a child while on treatment for ALL. This is because some drugs may harm a developing baby or affect sperm quality, potentially leading to birth defects. It is important to use contraception (such as condoms, the pill etc) during treatment and for several months afterwards.

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

1. To protect yourself from getting an infection. A low white blood cell count puts you at a higher risk of infection.
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, bowel motions and sperm and vaginal secretions. The small amounts of chemotherapy that come out this way can cause irritation (a rash or itching) to your partner's skin.

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

Sex when you have a low platelet count

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

New relationships

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

Information for people supporting someone with ALL

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

Other things you can do:

- Look after yourself by eating well, getting enough sleep, doing regular exercise and relaxing.
- Keep doing your normal social activities.
- Join a support group and/or see a counsellor.

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

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

Financial worries

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

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

More information available online

See the Blood Cancer and Your Job section of the LBC website.

KEEPING IN GOOD HEALTH AFTER YOUR ALL DIAGNOSIS

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

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

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

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

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

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

THE FUTURE

A diagnosis of ALL can affect many areas of your family's life such as work, school, finances, relationships and emotions.

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

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

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

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

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

Travelling overseas

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

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

After treatment

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

GLOSSARY

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 is found in red blood cells and carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

Antibiotic – A group of drugs used to prevent or treat infections caused by bacteria (bacterial infections).

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 (nausea) and vomiting (also called anti-sickness drugs).

Antifungal – A drug or substance that prevents or treats infections caused by fungi (fungal infections).

Antigens – An antigen can stimulate white blood cells to get rid of the antigen or attack it directly. This is called an immune response. Also see Immune system (below).

Antiviral – A drug or substance that fights against viruses and inhibits their growth. Antiviral drugs can be used to treat a viral infection or prevent a viral infection from developing.

Anxiety – An ongoing worry or concern about something that doesn't go away. Feelings of worry that seem uncontrollable or greater than they should be.

B-lymphocyte (B-cell) – A type of white blood cell normally involved in the production of antibodies to combat infection.

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

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

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

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

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

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

Central line – Also known as a central venous catheter (CVC) or central venous access device (CVAD). 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 and giving intravenous fluids, blood, chemotherapy and other drugs without the need for repeated needles.

Cerebrospinal fluid (CSF) – The fluid that surrounds and protects the brain and spinal cord. Samples of this fluid can be collected for examination using a procedure known as a lumbar puncture. Chemotherapy is sometimes given into the cerebrospinal fluid to prevent or treat cancer in the brain or spinal cord (also known as the central nervous system or CNS).

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). Most of the side effects of chemotherapy are usually temporary and reversible.

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

Complementary therapies – Therapies used alongside medical treatment that help a person feel better or help them cope with their diagnosis and treatment, e.g. meditation, massage, yoga.

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

Corticosteroids (or steroids) – A group of man-made hormones, including dexamethasone and prednisolone, that are used in the treatment of certain blood and bone marrow cancers. As well as having anti-cancer effects, corticosteroids also have anti-inflammatory and immunosuppressive effects.

CT scan (or CAT scan) – A specialised scan 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 – These are commonly carried out on samples of blood and bone marrow to detect chromosomal abnormalities (things that are wrong with the chromosomes) associated with disease. This information helps in the diagnosis and selection of the best treatment.

Digestive system – The system in your body that deals with food. It starts at your mouth and ends at your bottom, turning food and fluids into fuel for your body.

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

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

Foetus – An unborn baby.

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

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

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

Hickman line – A type of central venous catheter sometimes used for patients undergoing intensive treatment. It may have a single, double or triple tube (lumen).

High-dose therapy – The use of high doses of chemotherapy to kill off resistant and leftover cancer cells.

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

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

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

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

Late effects – Side effects of chemotherapy and/or radiotherapy that may only become apparent with long-term monitoring over a period of time.

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

Leukaemic blasts – Abnormal blast cells that multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the blood stream and can accumulate in other organs.

Lumbar puncture – A procedure for taking a sample of the fluid that surrounds the brain and spinal cord to look for leukaemia or lymphoma cells, using a long, thin needle inserted into the lower back/spine. A local anaesthetic is given to numb the area.

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.

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.

Malignancy – See Cancer (above).

Markers (also cell surface marker) – A protein or carbohydrate that is attached to the outside of a cell that can be used for cell recognition, immune regulation and cell communication.

Menopause – The time in a woman's life when her periods stop permanently and she is no longer able to have children. Also see Ovaries (next page).

Mucositis – Inflammation of the lining of the mouth, throat or gut.

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

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.

Oncologist – A specialist doctor who treats cancer, e.g. medical, radiation, surgical oncologist.

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

Partial remission – When the proportion of blast cells in the marrow has been reduced following treatment, but there are still some leukaemia cells present.

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

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

Philadelphia chromosome – The abnormal chromosome present in some cases of ALL. It is formed when part of chromosome 9 (ABL1 gene) breaks off and attaches itself to part of chromosome 22 (BCR gene) in a process called translocation. See also Translocation (next page).

PICC line – Peripherally inserted central venous catheter, inserted in the middle of the forearm. PICC lines are sometimes used for people having chemotherapy.

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

Platelets – A type of blood cell produced in the bone marrow that circulates in the blood. They are involved in clotting and the control of bleeding.

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

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

Psychological – To do with mental and emotional well-being.

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

Red blood cells – Cells that transport oxygen from the lungs to all cells in the body.

Relapse – The return of the original disease.

Resistant or refractory disease – The disease is not responding to treatment or has returned shortly after treatment.

Rigors – Intense shivering or shaking, usually associated with a high fever (temperature) or chills (feeling cold).

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

Stable disease – When the disease is stable, it is not getting any worse or any better.

Standard treatment – The most effective and safest therapy currently being used.

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

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

Steroids – See Corticosteroids (above).

Supplements – Tablets or liquids you take in addition to the food you eat. Supplements can include vitamins, minerals, herbs and other plants.

T-lymphocyte (T-cell) – A type of white blood cell involved in controlling immune reactions.

Translocation – When a chromosome or part of a chromosome migrates onto another chromosome. See also Philadelphia chromosome (above).

Tyrosine kinase – Enzymes that help send growth signals in cells. Blocking them stops the cell growing and dividing.

Tyrosine kinase inhibitors (TKIs) – A group of drugs that inhibits tyrosine kinases to stop cancer cells from growing and dividing.

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

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

Vaccine – A preparation used to help the immune system develop immunity against a particular infectious disease. It is usually produced from an inactivated or weakened form of the disease-causing agent. The process of giving a vaccine is called vaccination.

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

More information available online

A Dictionary of Terms booklet is also available from the LBC website or ask your LBC Support Services Coordinator for a printed version.

APPENDIX

The following are sample questions to ask your doctor following a diagnosis of ALL.

Place a tick alongside the questions you'd like to ask, and use the space below (and on the next pages) to add your own questions and record answers. There's also room in the LBC Haematology Patient Diary to note down any questions and responses and other important information from clinic appointments.

☐ Which doctor will be managing my leukaemia?

☐ What does the treatment involve?

☐ How long will the entire treatment take?

☐ What are the alternatives to this treatment?

☐ What are the expected outcomes of this treatment (e.g. complete remission or symptom control)?

☐ What are the potential side effects, how long might they last and how serious are they?

☐ What should I do if I develop an infection during the night or at the weekend?

☐ How can I prepare myself and my family/whānau for starting treatment?

☐ Who can I contact if I have any questions or concerns about my treatment or recovery?

QUESTIONS AND NOTES

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ACKNOWLEDGEMENTS

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Leukaemia & Blood Cancer New Zealand

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

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

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

HAEMATOLOGY CENTRES IN NZ

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

Contacting us

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

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

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

leukaemia.org.nz

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