ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL) – CHILDREN

A guide for parents, patients and 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 children.

If your child or a child you know has been diagnosed with ALL, you may be feeling anxious or overwhelmed. This is normal. Perhaps your child has already started treatment or you are discussing treatment options with your doctor. It may raise other questions, which you should discuss with your child's health care team.

This booklet is written from the perspective that you are a parent of a child who has ALL. However, the intention of this booklet is to help provide useful information to anyone who knows a child with ALL. Whatever relationship you have to the child, we hope that the information contained in this booklet is useful in answering some of your questions. There is a separate booklet called Acute Lymphoblastic Leukaemia (ALL) in Adults, for specific information for adults with ALL.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your child's circumstances at all times with their 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 child's 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.

Auckland Foundation

This publication was made possible by a grant from the Clinton and Joy Whitley Fund with Auckland Foundation.

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 factsheets, 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 56 there is a glossary (word list). In this booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases. A Dictionary of Terms booklet is also available from LBC.

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 baby (immature) 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 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 in children are:

Acute

Acute lymphoblastic leukaemia (ALL)

Acute myeloid leukaemia (AML)

Chronic

Chronic myeloid leukaemia (CML)

Both children and adults can develop leukaemias but certain types are more common in different age groups. Each year in New Zealand around 680 adults and 50 children are diagnosed with leukaemias.

Acute lymphoblastic leukaemia (ALL) is the most common childhood cancer with around 36 diagnosed each year in New Zealand.

Key points

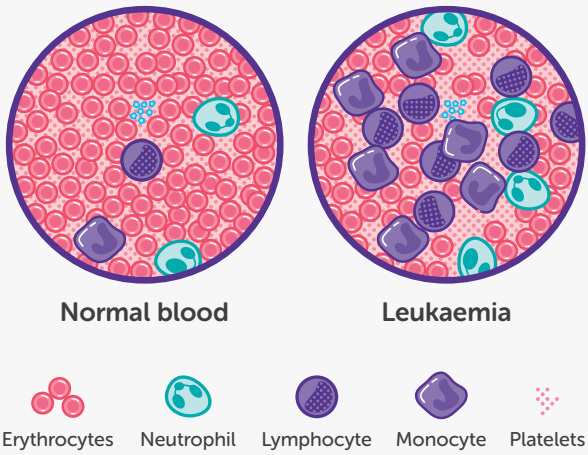
- Leukaemia is a type of blood cancer of the white blood cells.
- Leukaemia can be acute (develops fast) or chronic (develops slowly).

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

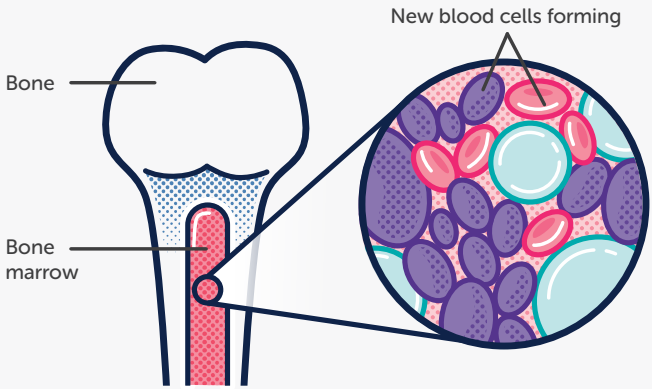


BONE MARROW AND BLOOD STEM CELLS

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.

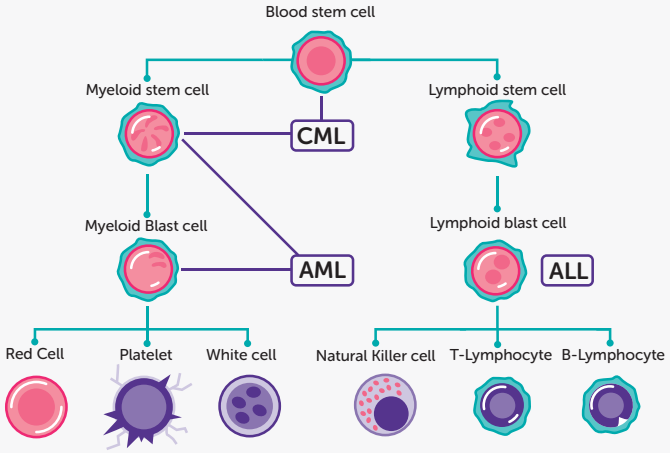
In Figure 03, on the next page, you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create, e.g. the lymphoid stem cell develops into a lymphoid blast cell before further maturing to either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

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

Leukaemias can start 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 8.

Figure 03

The cells created from blood stem cells



Detailed information

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

Key points

- Blood stem cells in the 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 the body, e.g. red blood cells, white blood cells and platelets.
- Leukaemias can either start in the myeloid cell line or the lymphoid cell line.

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 the 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 the body.

Red blood cells

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

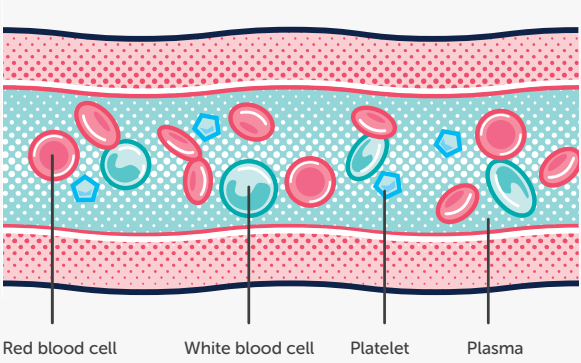
White blood cells

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

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

Figure 04

Blood vessel and cells in your blood



Platelets

Platelets help the blood clot and prevent bleeding. For example, if your child gets a cut, 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).

Detailed information

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

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

- **Neutrophils (nutra-fils)**
  Kill bacteria and fungi.
- **Eosinophils (ee-o-sin-o-phils)**
  Kill parasites.
- **Basophils (bay so-phils)**
  Work with neutrophils to fight infection.
- **T-lymphocytes (T-lim-fo-sites) (T-cells)**
  Kill viruses, parasites and cancer cells.
- **B-lymphocytes (B-cells)**
  Make antibodies which target harmful microorganisms (small 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-fages)**
  Monocytes are known as macrophages when they move to body tissue to help fight infection there.

Key points

- There are three main types of cells in the blood. Each cell type has an important job to do:
  Red blood cells: Carry oxygen to the cells and remove carbon dioxide from the cells.
  White blood cells: Fight infection from bacteria, fungi, viruses etc.
  Platelets: Help the blood to clot.
- 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 various organs including 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 9.

What causes ALL?

The cause of ALL is not known. Like most other types of leukaemias, ALL is thought to develop after DNA is damaged, causing genetic mutations (errors) and the cause of most DNA mutations is replicative error, which can be thought of as bad luck. 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 someone getting ALL. Having a risk factor does not mean a child will definitely get ALL and some children 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
- Having certain genetic conditions, e.g. Down syndrome (trisomy 21)
- Being exposed to X-rays before birth
- Past chemotherapy treatment
- Having certain changes in the chromosomes or genes.

Key points

- ALL is a type of leukaemia that affects the immature white blood cells on the lymphoid cell line.
- 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. ALL cannot be caught from someone else.

WHICH TYPE OF ALL DOES MY CHILD 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 different subtypes of ALL depend on the presence or absence of cell surface markers, which are explained in more detail on pages 15 and 16.

B-cell lymphoblastic leukaemia

This subtype of ALL begins in immature cells that would normally develop into B-lymphocytes (B-cells). This is the most common subtype of ALL. Approximately 80% of children with ALL have B-cell ALL.

T-cell lymphoblastic leukaemia

This subtype of ALL begins in immature cells that would normally develop into T-lymphocytes (T-cells).

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 (cy-toe-gen-et-ic) abnormalities is important, helps doctors plan treatment and predict how well the treatment will work.

The WHO classification is also used to determine if a disease is either a leukaemia or lymphoma. For example, in children, if the bone marrow has 25% or more lymphoblasts, the disease is called B-cell lymphoblastic leukaemia (B-cell ALL). If the lymphoblasts are restricted to a mass in a lymph node or other lymph tissue and less than 25% of the bone marrow cells are lymphoblasts, it is usually called B-cell lymphoblastic lymphoma.

Cytogenetic changes

Translocation

Translocations are 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. Translocations are 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 gene on chromosome 9 breaks off and sticks to a gene called BCR gene on chromosome 22. This makes a new gene called BCR-ABL1 which produces a mutant protein that causes leukaemia.

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 than 44 chromosomes. Normally we have 46.
- **Hyperdiploidy:** When the leukaemia cells have more than 50 chromosomes.

WHAT ARE THE SIGNS AND SYMPTOMS OF ALL?

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

It is common for someone with ALL to feel a loss of well-being 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, which results in low numbers of healthy functioning 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.

The 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 in females
- Red or purple pinhead-sized spots on the skin called petechiae (pe-tee-kee-i).

Infections

Children 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.

Children 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 rigours
- Coughing up yellow or green phlegm
- Fatigue or extreme tiredness.

Common types of infection in children with ALL may include:

- Chest infections (including pneumonia)
- Urinary tract infections (UTI or bladder infections)
- 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 40-42 for more information on how to prevent and manage infections.

Important information

- If your child develops any symptoms of an infection, you will need to contact their health care team at the hospital. It is important to have a low threshold for seeing a doctor, earlier is a lot better than waiting to see if the infection gets worse. Infections can be more severe and can develop more rapidly in children with ALL.
- If your child is currently receiving chemotherapy for ALL, or if they are neutropenic due to their ALL, you must seek urgent medical care if they develop a fever or other symptoms of infection. Their health care team should advise you how to seek help, as this may vary from hospital to hospital.

Other symptoms of ALL

Your child may have other symptoms that are common in ALL, including:

- 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 (only if the ALL has spread to 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 lethargy, shortness of breath and/or fatigue as a result of low red blood cells.
- ALL can cause increased bruising and bleeding as a result of low platelets.
- Children with ALL are at increased risk of infection.
- Other symptoms of ALL may include bone pain, unexplained weight loss and loss of appetite.

WHAT HEALTH PROFESSIONALS WILL WE MEET AFTER MY CHILD'S DIAGNOSIS?

Children with ALL will initially stay in hospital after being diagnosed and will meet a range of health professionals who are part of the health care team.

Your child may need to be transferred to a different city where there is specialised care for children with leukaemia. There is more information about moving to a different city and hospital on page 49.

Your child will have a primary (main) paediatric oncologist or haematologist. A paediatrician is a doctor who specialises in the treatment of children. An oncologist is a doctor who has special training in cancer and a haematologist is a doctor who specialises in the treatment of blood cancers and blood conditions. Both paediatric oncologists and paediatric haematologists manage the care and treatment of children with ALL. These doctors work together as a team and take turns being on-call overnight and during the weekends. You may meet several paediatric oncologists/haematologists but will generally have one doctor who manages your child's treatment and recovery.

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will aim to give you, your child and your family/whānau the best available treatment and support.

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

- **Charge nurse** – A senior nurse in charge of an outpatient department, day unit or hospital ward.
- **Clinical nurse specialist (CNS)** – A nurse with advanced skills in a specific area of clinical care. This person works closely with you, your child and members of their health care team to coordinate treatment, and help you manage your child's symptoms of ALL and the side effects of treatment.
- **Dietitian** – A dietitian advises you on how to maintain adequate nutrition for your child, and may include advice on what to eat and drink to minimise symptoms or side effects from treatment. They may also prescribe supplements to make sure your child is getting the calories and nutrients they need. A dietitian can support you and your child if a nasogastric (NG) tube is needed to maintain adequate nutrition (see page 45 for more information about NG tubes).
- **General practitioner (GP)** – A family and community doctor. Once your child is diagnosed with leukaemia, your GP does not generally play a role in your child's treatment. If your child becomes unwell during treatment they should see their oncologist/haematologist, or in shared care they should see their allocated general paediatrician. This is because cancer care is very specialised and only specialised doctors are likely to understand the full spectrum of possible presentations and the right treatments.

GPs will become involved again once treatment has finished, including re-immunisation.

- **Haematologist** – A senior doctor who specialises in the treatment of blood cancers or blood conditions.
- **Oncologist** – A senior doctor who specialises in the treatment of cancer.
- **Outpatient clinic nurse** – A nurse who gives your child treatment as an outpatient or who works alongside a doctor in clinic.
- **Paediatrician** – A doctor who has special training in medical care for children. Your child's oncologist or haematologist will also have trained as a paediatrician.
- **Pathologist** – A doctor who specialises in the laboratory diagnosis of diseases and how diseases can affect the organs of the body.
- **Pharmacist** – Prepares and checks your child's drugs/medications. Pharmacists can advise you on how your child should take their medicine, possible side effects and interactions with other medications.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility.
- **Play specialist** – Hospital play specialists support children during their stay in hospital or in an outpatient clinic. They have many educational activities for children as well as supporting your child through procedures using imagery and distraction.
- **Psychologist** – Specialises in helping you and your child manage emotional challenges such as stress, anxiety and depression.
- **Registrar** – A doctor who is in training. You may see a registrar in clinics, day units and wards. Registrars works closely with senior doctors.
- **Social worker** – Helps you manage the practical and emotional impact of your child's diagnosis and treatment, such as advice about managing at home, school and your employment.
- **Ward nurse** – A nurse who looks after your child during a stay in hospital. Ward nurses generally work 8–12-hour shifts so your child may have several nurses each day.

Other people you might hear about or meet are:

- **Child consult liaison psychiatry team** – Team of specialised health professionals that provides psychological and emotional assessment and support to children and adolescents. There is also a Child Cancer Counselling Network (CCCN) which aims to increase the ability of family/whānau impacted by childhood cancer to access specialised counselling support in or close to their hometown throughout much of New Zealand.
- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of ALL, helping improve quality of life and supporting children at the end of life. A referral to the palliative care service is common for children who are expected to have good outcomes with treatment and survive their cancer, when those children need specialised help in managing complex symptoms.

- **Spiritual care and cultural support** – People who can support individual cultural, spiritual or religious needs.
- **Non-governmental organisation (NGO)** – Gives emotional and practical support for those affected by cancer and their family/whānau, e.g. Leukaemia & Blood Cancer New Zealand (LBC).
- **LBC Support Services Coordinator** – A professional who provides education as well as practical and emotional support. They can be contacted by calling 0800 15 10 15.

Meeting so many people can sometimes be confusing and overwhelming. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit in to your child's 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 or finger prick, and sent to a lab (laboratory) where it is looked at under a microscope.

An FBC measures the number and appearance of red blood cells, white blood cells and platelets. Most children with ALL have low red blood cell and platelet counts, along with the presence of blast cells. Children with ALL often have a high white blood cell count, but most of these are leukaemic blast cells that do not protect against infection.

On page 4 you can see that ALL affects developing lymphoid blast cells. These 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 picked up with a blood test.

Other specialised blood tests may be required to confirm a diagnosis of ALL.

An FBC is helpful for diagnosing ALL but a bone marrow biopsy is needed to make sure.

Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your child's bone marrow and sends them to a lab to be looked at under a microscope and analysed by special equipment. A bone marrow biopsy is required to diagnose most leukaemias accurately.

A sample of bone marrow is usually taken from the back of the hip bone (the iliac crest) (see Figure 05 on next page).

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

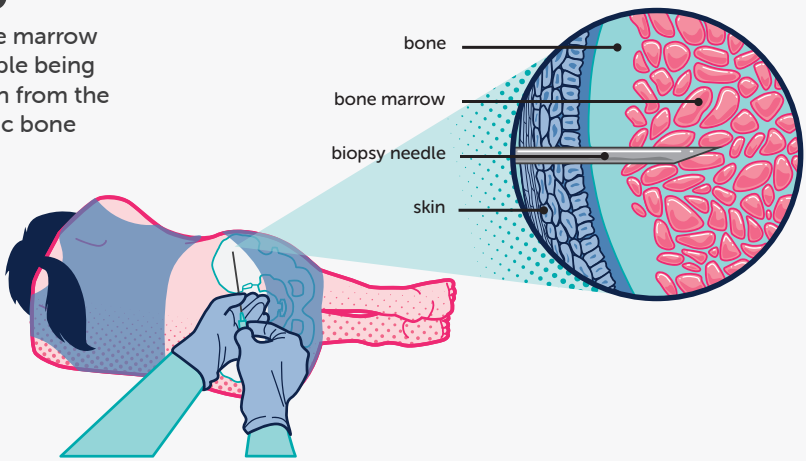
Most children receive a short general anaesthetic for this procedure. Occasionally, older children and adolescents may have a local anaesthetic as well as other pain relief and sedation. The doctors and nurses at the hospital will discuss with you the most appropriate choice for your child. See the detailed information section on page 16 about what to expect when your child has a general anaesthetic.

Samples of bone marrow are collected using a long thin needle inserted through the skin, into the bone and then into the bone marrow. A sample of the bone marrow liquid is taken out. This is called a bone marrow aspirate. A sample of the solid part of the bone marrow is also taken out, which is called a bone marrow trephine (tre-fine).

After the biopsy, a small dressing or plaster is placed over the needle site. This can usually be removed the next day. Your child may have some mild bruising or discomfort, which is usually managed effectively with

Figure 05

Bone marrow sample being taken from the pelvic bone



paracetamol. More serious complications such as bleeding or infection are very rare.

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

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

During treatment, your child will need repeat bone marrow examinations to assess how well the disease is responding.

Once a diagnosis of ALL is made, blood and bone marrow cells are examined further using special laboratory tests. These include immunophenotyping (imm-you-no-feen-o-tie-ping), cytogenetic (cy-toe-gen-et-ik) and molecular tests. These tests provide more information about the exact type of disease, the likely course of the disease 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.

It involves using a machine called a flow cytometer. Flow cytometry uses lasers to detect the abnormal cells typical of ALL in blood or bone marrow samples. Depending on the type of leukaemia, the leukaemia cells can have different antigens on their surfaces.

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 is also the main test the doctors will use to see how the leukaemia is responding to treatment. This test is called MRD, which stands for minimal residual disease or measurable residual disease.

Cytogenetic and molecular tests

Cytogenetic and molecular tests typically use blood or bone marrow samples to see if the leukaemia cells have acquired 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 and are explained further in the section **Which type of ALL does my child have?** on page 8.

Detailed information

Operating theatre and general anaesthetic

Your child will most likely have a general anaesthetic (GA) in an operating theatre (often referred to as theatre) for any procedures that would otherwise be distressing or painful to be awake for. The most common reasons for going to theatre in children with ALL are for a bone marrow biopsy, central line (e.g. portacath) insertion or removal, lumbar puncture and/or intrathecal chemotherapy.

Before going to theatre and having a GA, your child will not be able to have any food or drink prior to the procedure. You will have to give informed consent and sign some documents to ensure that you are aware of what procedure is being done and that you understand any risks involved.

There are a number of health professionals involved and present throughout your child's surgery including nurses and specialised doctors. There will be a paediatric anaesthetist who manages the sedation and pain relief throughout the procedure and recovery. There are also doctors who are experts in whatever procedure your child is having (e.g. lumbar puncture or central line insertion).

You will be able to stay with your child until they go to sleep and greet them in recovery after the procedure is finished. It is important to prepare your child for what is going to happen, how they might feel and to reassure them. If you or your child have any questions, ask the nurses or doctors who are involved in your child's care.

Some terms that are useful to know are:

- **Perioperative (pre-op) area:** Waiting area in the hospital before going to theatre.
- **Post-anaesthetic care unit (PACU):** The area in the hospital where children go to recover from their GA and surgery before going back to the ward or outpatient clinic (often called recovery).
- **Operating room:** Also called operating theatre or theatre.

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. A very sensitive laboratory technique called 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 your child has, its likely response to treatment, and the best way to treat it.

Detailed information

Minimal 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 child's response to initial treatment, their risk of relapse in the future, and what is the most appropriate treatment protocol for them. MRD testing may also be repeated to assess how well your child is progressing and responding to their treatment.

The term 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. Having positive MRD 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 child's general health and how well their 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 and ECG). Blood tests may include kidney function tests, liver function tests and coagulation tests, to see if your child's blood is clotting properly.

Your child 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. Lumbar punctures are explained in more detail on page 27.

These tests are important because they provide a baseline set of results regarding organs that might be affected by disease, and your child's general health. The results may be important in selecting the best treatment option for them. The results can also be compared with later results to assess how well your child is progressing.

Key points

The two main tests for diagnosing ALL are:

- blood test (full blood count)
- 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.

WHAT DOES MY CHILD'S DIAGNOSIS OF ALL MEAN FOR MY FAMILY/WHĀNAU?

You are likely going to experience a wide range of feelings and emotions from the time your child is diagnosed with ALL, during treatment and after their treatment has finished.

These feelings may include shock, anger, sadness, denial, worry and guilt. You may feel that life for your child and family/whānau will never be the same. It is normal to have a range of emotions.

Over time, you, your child and family/whānau will find ways to adapt and gradually adjust to a new sense of normal.

It is important to tell a member of your child's health care team if you have prolonged feelings of low mood, anxiety, depression or difficulty coping. They can make sure you get the support you need. There are various support options for you and your family/whānau including psychologists, social workers and spiritual and cultural care providers. It is important to work through your feelings so you can help your child cope and you can continue to manage other aspects of family and work.

Talking to your child about their diagnosis

Regardless of age, children are usually aware when their health is concerning their parents. It is not easy to tell a child about a diagnosis of leukaemia. The amount of information given often varies with their age and emotional and intellectual development. No one knows your child better than you, and no one can tell you when or how to tell them about their illness.

Sometimes parents wish to protect their child from information about ALL and treatment, however children will often use their imagination to fill in the gaps if you don't inform them. Sharing details with your child about their illness and treatment helps them build trust in you and their health care team. It also encourages them to feel okay about asking questions and talking about their fears and concerns.

Utilise the different members of your child's health care team including play therapists, social workers or psychologists for information and support. Your local LBC Support Services Coordinator can also provide you with useful information and resources. There is a children's picture book called Joe has Leukaemia which can be given to your family/whānau or downloaded from our website.

Here is some guidance, organised by age, you may like to consider:

0–3 years: Baby/toddler

- Will not have an understanding of illness or cancer.
- They are aware of changes to routines and the feelings of people around them.
- May be afraid of members of their health care team.
- May be concerned about possible separation from a parent so offer reassurance and comfort, especially around unfamiliar surroundings.

4–6 years: Preschool

- May have some understanding of an illness but may not understand the implications of a serious illness like ALL.
- Their primary focus will be on the symptoms they are experiencing in any specific moment.
- They may be afraid of pain, so explain tests or treatments to them in advance.
- Assure your child that they did nothing wrong to cause the cancer.

7–12 years: Primary/intermediate school

- Children in this age group may have a better understanding of a serious illness like ALL.
- They may have heard things about cancer from school, online, TV, friends or family/whānau. Ask your child what they know and correct any misunderstandings or differences. It may be useful for them to know that there are many different types of cancer and everyone's experience and treatment plan are different.
- Explain tests, treatments and other procedures in advance. Your child may be afraid of pain and resist having certain procedures. Be honest with them and if a procedure may be painful, work with their health care team and decide how to best support them through it.
- Talk to your child in advance about any possible changes to their physical appearance.
- You may need to discuss fertility preservation with your child. There is some information about this on page 38.
- You may see signs of regression in your child's behaviour, e.g. thumb sucking, bed wetting or tantrums.
- It may be useful to use play as a way to explain things to your child, e.g. patient scenarios with dolls or teddy bears.
- Explain any changes to your child's daily routine, particularly around school. See more information on page 51 on involving your child's school/teacher and how they can support you and your family/whānau.

13–18 years: High school/teenager

- Teenagers understand more about cancer and may want to know more. You may still need to correct any misinformation your teenager has heard from school, friends, TV or social media.
- Teenagers may want to be actively involved in decisions about their treatment. Include them in discussions with their health care team, as appropriate.
- You may need to discuss fertility preservation with teenagers. Some ALL treatments can affect fertility and your child's health care team can have these discussions with you. See page 38 for more information on fertility.
- Often teenagers find it difficult to find their independence during their diagnosis and treatment, especially if they are in hospital for long periods of time. They may feel angry or frustrated at this, test boundaries or engage in risky behaviour. Contact your child's health care team if you are concerned about their safety or the safety of others.
- Concerns about changes to their physical appearance, such as hair loss and losing or gaining weight, are normal. They may also be worried about how their peers will react to these changes.

INFORMED CONSENT FOR TREATMENT AND PROCEDURES

You will be asked to give your informed consent for all treatments or procedures suggested by a health professional in your child's 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. Once you have given informed consent you can still ask questions.

If you have any doubts or questions or need more information about a procedure or treatment, it is important you speak to your child's 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).

As the parent or guardian of your child, you will need to give informed consent on their behalf if they are aged 16 years or younger.

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

Even if your child is under 16, they still have a right to autonomy (independence to make their own decisions) and to make decisions about their health and lifestyle. Your child's health care team will need to consider how able your child is to understand the situation and to make decisions.

Informed consent is also required if you agree for your child to take part in a clinical trial. Clinical trials are explained on page 23.

Key points

- Informed consent means that you understand the information around treatment or a procedure.
- Speak to your child's 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 child's doctor will recommend depends on things like:

- The type of leukaemia they have, including the genetics of the leukaemia
- Their general health
- Their age (infants, children and teenagers may be treated differently)
- The response of the leukaemia to the first month of treatment.

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

Feeling overwhelmed, anxious, shocked and/or upset are normal responses to finding out your child has a diagnosis of 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 child's options as they may need to start treatment immediately.

Your child's doctor will spend time with you discussing what they feel is the best option for you and your child. 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 on behalf of your child.

Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist/oncologist about your child's diagnosis and/or treatment. You can ask any member of your health care team, including your current doctor, about getting a second opinion. Even if you are only speaking to one senior doctor, all cases are discussed in larger groups of senior doctors to provide peer review to help ensure that all children are receiving the best treatment.

Questions to ask the health care team

It can be useful to write a list of questions before any appointment with your child's haematologist/oncologist.

In the Appendix on page 61 there are some examples of questions you could ask your child's 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 11 of the Haematology Patient Diary there is also a list of questions that you might like to ask your child's doctor.

Bring a support person

It can be useful to have a support person (spouse, parent, close friend) with you at any important appointments you have with your child's 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.

Being in a clinical trial

Your child's doctor will let you know if your child is 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 for your child to take part in the trial if you do not want them to. If you do not want them 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 informed consent for a clinical trial. Take time to talk through the trial with your child's oncologist/haematologist and other members of the health care team before signing the consent form.

More information available online

Prognosis

Prognosis means the likely course of a disease, i.e. how likely it is to be cured or controlled. Your child's prognosis will depend on many things. Your child's haematologist/oncologist is the best person to give you a prognosis and tell you how well their leukaemia is likely to respond to treatment.

When doctors and other members of the health care team talk about prognosis, they might use the terms: cure, complete remission, relapse or resistant. Here is what these terms mean:

- **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 any 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 child's ALL has relapsed can be devastating, but there are usually ways of getting it back under control. The treatment of relapsed disease depends on a number of factors including the duration of the remission and the site at which the disease has reappeared. Other factors are also considered, including your child's age and the genetic make-up of the relapsed leukaemia cells. Your child may need to have similar drugs to what they've already received, or different drugs, and some children may need a stem cell transplant. See page 31 for more information on stem cell transplants. LBC has other booklets that explain in detail what a stem cell transplant is and what's involved in the procedure.

More information available online

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 outcome for all children.

Palliative care

If a decision is made not to continue with anti-cancer treatment (chemotherapy and radiotherapy) for your child's ALL, there are still many things that can be done to help them to stay as healthy and comfortable as possible. Palliative care is aimed at relieving any symptoms or pain a child might be experiencing as a result of their disease or its treatment, rather than trying to cure or control it. See the section on supportive care on page 32 for more detailed information. Sometimes the palliative care team are involved even when children are expected to survive. This is because they are experts in symptom management and can improve quality of life and support decision-making.

Detailed information

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

Prognostic factors for children with B-cell ALL include:

- **Age:** The leukaemia cells in infants younger than one year old and children older than 10 years tend to be more resistant to treatment. Stronger treatments may be needed to kill the leukaemia cells.
- **White blood cell count:** Children with very high white blood cell counts at time of diagnosis often need stronger treatment.
- **Genetic factors:** Certain changes in the chromosome or genes can make the leukaemia cells either easier or harder to treat. Some of these genetic factors were explained further on page 8.
- **Central nervous system involvement:** Children with ALL who have leukaemia cells in the central nervous system at diagnosis are at a higher risk of disease relapse.
- **Treatment response:** Children who have a better response to the initial induction therapy have a lower risk of disease relapse.

Prognostic factors for children with T-cell ALL are mainly based on their early treatment response. Children who have a better response to the initial induction therapy have a lower risk of disease relapse.

TREATMENT FOR ALL

ALL usually progresses quickly so treatment needs to begin as soon as it is diagnosed. The main treatment for ALL is chemotherapy.

Children in New Zealand who are diagnosed with ALL usually follow established protocols or plans of treatment. Treatment options usually include standard treatment or a clinical trial.

The type of protocol your child is allocated to will depend on which risk group they are in. Your child's doctor will discuss with you which protocol they recommend your child starts. Your child's progress and response to treatment is closely monitored throughout all phases of their treatment. Sometimes adjustments need to be made to your child's protocol depending on how well they are responding to treatment.

Typically, treatment for children with ALL consists of a multi-drug regimen. Usually the first five to seven months of treatment are more intensive and use stronger medicines, with children spending more time in hospital. These phases are called induction, consolidation, interim maintenance and delayed intensification. After that intensive phase there is a longer phase where treatment is less intensive that is designed to help stop the leukaemia coming back.

Most treatment regimens take two to three years to complete. These five phases are explained further on page 34. High-risk patients may have additional phases of treatment.

Each regime or protocol for treating ALL consists of a variety of drugs that work in different ways to kill the leukaemia cells.

The main treatment options for ALL are:

- Chemotherapy
- Corticosteroid drugs
- Immunotherapy
- Targeted therapy
- Supportive care.

Most children have a combination of some of these treatment options. Each of these treatments will be discussed in the following pages.

Some children may require a stem cell transplant however they aren't commonly used to treat ALL. Stem cell transplants are explained further on page 31.

Chemotherapy

Chemotherapy drugs are the main type of treatment for ALL. Chemotherapy is often called chemo.

Chemotherapy is the name given to anti-cancer drugs (also called cytotoxic drugs) which work by stopping cancer cells dividing.

There are many different types of chemotherapy drugs 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 often given in treatment cycles. Each cycle is made up of a certain number of days of treatment, followed by a certain number of days' rest. The rest days can allow the body time to recover before the next cycle. Cycles can vary in length depending on what drugs are used.

The different ways that chemotherapy is given are:

- Into a vein (intravenously or IV)
- In a tablet (orally)
- Into a muscle (by intramuscular injection)
- Under the skin (subcutaneously or sub-cut or SC)
- Into the spinal fluid via a hollow needle (intrathecally or IT).

Chemotherapy into a vein (IV)

Usually a special line or tube called a central line is inserted and used for intravenous chemotherapy. A central line is inserted into a large vein in your child's chest, neck or arm and is left in there until their chemotherapy treatment is finished. Different central lines include portacath, hickman line or PICC (peripherally inserted central catheter) line.

The most common central line used for children with ALL is called a portacath (port). Your child will have this inserted in theatre under general anaesthetic. See page 16 for more information about surgery and theatre.

A portacath has two parts, the port and the catheter (see Figure 06). The port is implanted under the skin in the upper-chest area. The plastic membrane is made up of a self-sealing plastic rubber so it can be punctured many times.

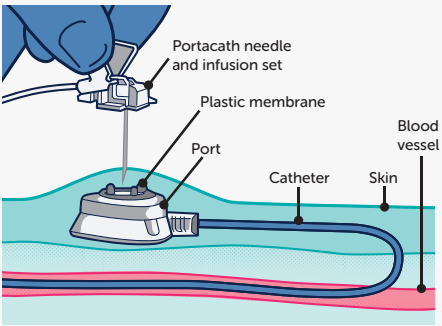
The catheter is connected to the port under the skin which enters the large vein in the neck with its end lying in the right side of the heart.

As you can see in Figure 06, the nurse is accessing the portacath with a special needle that goes through the skin and into the port membrane. Once the needle is in correctly, blood can be directly taken out of the blood vessel and IV drugs, like chemotherapy, can be administered into the bloodstream. The needle is connected to a tube called an infusion set.

During an IV infusion, the drugs are injected slowly over the course of a few minutes, hours or several days.

When your child has finished chemotherapy or is being discharged home from hospital, the portacath can be de-accessed. Usually a drug (e.g. heparin) is inserted into the portacath before the needle is removed,

Figure 06
Portacath



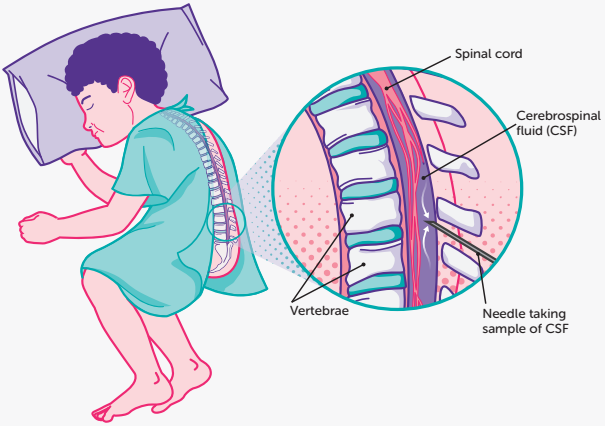
which prevents it from getting blocked, and a small dressing is applied over the skin. There may be a small amount of bleeding or clear liquid at the needle site but this should stop soon after the portacath is de-accessed. If bleeding continues or you notice any pus, redness or swelling at the portacath site, contact your child's health care team.

Intrathecal chemotherapy

Most treatment protocols for childhood ALL include treatment to prevent the spread of leukaemia cells to the central nervous system (CNS) and to kill any leukaemia cells that may already be present in the brain and spinal cord.

This treatment is often called CNS prophylaxis and involves intrathecal chemotherapy being administered under general anaesthetic into the lumbar area of the back. The procedure is called a lumbar puncture (LP) where a small needle is inserted between the vertebrae into the fluid-filled space between the thin layers of tissue that cover the brain and spinal cord (see Figure 07). On page 16 there is more information about surgery and theatre.

Figure 07
Lumbar puncture



Detailed information

Chemotherapy drugs can be excreted in body fluids so it is important that you take care when handling your child's nappies, taking them to the toilet, or if they're being sick (vomiting). Some chemotherapy drugs can also be excreted in sweat so it's important to frequently change your child's bed linen.

It is also important to be careful with your child's IV lines when chemotherapy is being administered. IV lines have multiple connections on them so if these disconnect or get pulled open, you need to immediately let your nurse know as it is a safety emergency.

Oral chemotherapy

Your child may be prescribed oral chemotherapy drugs (chemotherapy taken by mouth) as part of their treatment protocol. These drugs will often be taken at home, so it is important that a parent or caregiver knows how and when these are to be taken.

All oral chemotherapy drugs can pose risk to parents/caregivers and patients. It is extremely important to take care when handling these drugs and try to prevent the drug from touching your skin. You can do this by wearing gloves while handling any oral chemotherapy drugs and washing your hands thoroughly if your skin does come in contact with the drug. Have a clean area, away from food and children, when preparing any oral chemotherapy drugs. Clean up any spills that may occur.

Most oral chemotherapy drugs are tablets that need to be swallowed. Sometimes a half tablet may be prescribed, and it is recommended to use a designated tablet cutter.

If your child cannot swallow the tablets, discuss other options with their health care team. These options may include:

- Dissolving the drug in a small amount of water and giving it to your child in an oral syringe, on a spoon or in a small glass.
- Placing the tablet in a spoon of food, e.g. yogurt.

Side effects of chemotherapy

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

The side effects for each chemotherapy drug or drug combination are different. Most children will have some side effects, but may vary from child to child. Most side effects of chemotherapy begin to go away when treatment is finished.

Side effects of treatment may be short or long-term (sometimes called late effects). Short-term side effects should go away a few weeks after treatment finishes, after the damaged cells recover. Long-term means

Detailed information

Tumour lysis syndrome

Children with ALL may be at risk for developing a condition called tumour lysis syndrome (TLS). This condition occurs when a large number of 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 your child is at a high risk of developing TLS, they will have regular blood tests to monitor the potassium and phosphate levels in the bloodstream. The most common time for a child to develop TLS is when they've just commenced treatment.

that your child may experience side effects for months after treatment.

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

- Anaemia
- Bruising and bleeding
- Constipation
- Diarrhoea
- Difficulty concentrating
- Fatigue (extreme tiredness)
- Fertility issues
- Hair loss
- Increased risk of infection
- Changes in mood
- 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 your child is experiencing them, are discussed in the section **Living with ALL and side effects of treatment** on page 36.

Corticosteroid drugs

Corticosteroids (often just called steroids) are drugs which mimic different hormones in the body. There are several types of steroids and are often used in the treatment of ALL as they are known to be effective in killing leukaemia cells. Steroids can also enhance the activity and effectiveness of other treatments, like chemotherapy, so are often used in combination with other drugs.

The two corticosteroid drugs used in ALL are:

- Dexamethasone
- Prednisone.

These are usually given orally as a tablet or liquid. See pages 32-33 for some tips around your child taking oral medications.

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 or falling asleep.
- Stomach pain: Steroids can irritate or damage the lining of the stomach, which can result in pain or reflux. There are

Detailed information

Steroid-induced diabetes

High doses of corticosteroids can cause diabetes in some children. Usually the diabetes resolves shortly after your child stops taking those medications. Corticosteroids and some other drugs can cause problems with the production and effectiveness of insulin, causing the level of glucose to rise and spill over into the urine. Some children will need insulin injections to maintain blood glucose levels in the healthy range.

Your child will need their blood glucose levels monitored regularly, and you will also need to monitor their food and drink intake. Your child's health care team will give you more information about how to support your child with steroid-induced diabetes.

medications to prevent this and these are often prescribed at the same time as the steroids.

- Increased blood sugar: Steroids may increase the levels of sugar in the blood. Some children may get steroid-induced diabetes, which is explained below under detailed information.
- Increased appetite: Increased hunger is common while taking steroids. Weight gain may occur as a result. See page 44 for more information about changes to appetite.
- High blood pressure.
- Difficulty walking.
- Increased risk of infection: Like chemotherapy, steroids can suppress the immune system, making it easier to get infections. See page 9 for more information about signs of infection.

Immunotherapy

Immunotherapy is the use of drugs to help a patient's own immune system recognise and destroy cancer cells. There are several types of immunotherapy drugs that are being studied and used in some children with ALL.

These include:

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

Monoclonal antibodies

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

Detailed information

Blinatumomab is a type of monoclonal antibody which can be used to treat some children with ALL. It is a special kind of monoclonal antibody 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.

Blinatumomab is given as an IV infusion over 28 days. There is a risk of serious side effects so usually the child needs to stay in hospital for a period of that time to be monitored.

The most common side effects are fever, headache, swelling of the hands and feet, nausea, tremor, rash, constipation and low potassium levels in the blood. It can also cause low white blood cell counts, which increase the risk of infection.

Inotuzumab is a type of monoclonal antibody which carries a payload of chemotherapy. 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 payload of chemotherapy into the leukaemia cells and reduces the exposure of healthy cells to the chemotherapy.

CAR T-cell therapy

CAR T-cell therapy involves removing T-cells from the child's blood and genetically altering them in the lab to have specific receptors on their surface. These receptors can attach to proteins on leukaemia cells and attack them. The T-cells in the lab are then multiplied and given back to the child through an IV line.

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

This treatment can have serious or even life-threatening side effects, which is why the procedure is done in specially trained hospitals.

Targeted therapy

Targeted therapy is a type of cancer treatment that uses drugs to identify and attack certain types of cancer cells. Targeted therapy can be used in combination with other treatments, such as chemotherapy.

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

TKIs work to block overactive enzymes that occur in patients with Philadelphia chromosome-positive ALL (Ph+ALL). These drugs are taken orally (pills taken by mouth).

The following TKIs have been approved to treat Ph+ALL in children:

- Imatinib
- Dasatinib.

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.

Stem cell transplant

A stem cell transplant may also be called a bone marrow transplant, a haematopoietic stem cell transplant or a peripheral (per-if-er-ral) blood stem cell transplant. A stem cell transplant is not commonly used to treat ALL in children. If your child's doctor thinks a stem cell transplant is necessary or an option for your child, they will discuss it with you in detail.

With a stem cell transplant, your child is given high-dose chemotherapy followed by stem cells through a drip to replace the ones that were destroyed. The stem cells they are given may come from someone else (a donor) or may be your child's own stem cells that were frozen before the high-dose treatment. Radiation therapy (also known as radiotherapy) is sometimes used before a stem cell transplant.

Stem cell transplants allow for much higher doses of treatment. This may help to improve your child's recovery from ALL or keep it away for as long as possible (prolong remission). Stem cell transplants are usually only given if other treatments for ALL do not work, and because of severe side effects, are not suitable for everyone. The oncologist/

haematologist will discuss with you if they think your child will benefit from having a stem cell transplant.

There are two main types of stem cell transplants:

- Allogeneic (al-o-jen-ay-ick)
- Autologous (or-tol-o-gus).

See the LBC website for specific booklets about stem cell transplants.

Supportive care

Supportive care is important to help your child cope with their diagnosis of ALL, the symptoms of ALL and the impact of treatment. Supportive care ensures that they have the best quality of life.

Examples of supportive care are:

- Blood products given via a drip (a 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 antiemetics (drugs to stop nausea and/or vomiting)
- Antibiotic drugs to help prevent or manage infections
- Support from a dietitian, psychologist or chaplain
- Practical support at home
- Support for family/whānau who have to relocate for treatment.

Blood transfusions

Blood transfusions may be given to your child at the time of their diagnosis or during their treatment. The two main types of transfusions are either red blood cells or platelets. The purpose of blood transfusions is to 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 through an intravenous (IV) line. Most blood transfusions will be given over 30 minutes to three hours. Your child will be closely monitored as there is a risk of having an allergic reaction while the transfusion is running. Monitoring will include your child having their temperature, heart rate, respiratory rate, blood pressure and oxygen saturations measured. It is also important that you report any changes in your child like becoming breathless, itchy skin, rash or shaking (chills).

Supportive drugs

There are many supportive drugs that have different roles in making your child feel more comfortable and preventing further sickness. Supportive drugs may include antibiotics, pain relief, antiemetics (anti-sickness) and/or laxatives.

Your child's doctor can prescribe these drugs and they are usually given orally (as liquid or tablet). It can be challenging to get your child to take oral drugs. They might not understand the reason why they need to take them, not like the taste and/or find it stressful swallowing tablets. Each child is different. Their health care team can work with you to try different approaches and to make sure it's safe (e.g. which tablets can or cannot be crushed) and age appropriate for your child.

Some helpful strategies may include:

- Mix drug in a spoon of yogurt, peanut butter or other spread that your child likes

- For older children, practice swallowing tablets with small lollies
- Make a sticker chart for them to work towards a small reward
- Role play with a doll or teddy who needs to take their medications
- Explain clearly, using age-appropriate words, what is going to happen or what they need to do.

Antibiotics

Antibiotic drugs can be prescribed for several reasons:

- To prevent certain infections, also called prophylaxis
- To treat infections.

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

Almost all children with leukaemia will be prescribed a low-dose antibiotic called cotrimoxazole, which is used to help prevent an infection called pneumocystis carinii. This is an organism that most children have been exposed to and it can reactivate when the immune system is compromised (such as children on chemotherapy) and cause a life-threatening pneumonia. Cotrimoxazole prophylaxis generally continues until chemotherapy is completed. There is a group of children that are intolerant of cotrimoxazole, who will be prescribed a different antibiotic drug.

Antibiotics used to treat infections are usually given through an IV line or orally (liquid or tablet). There are many different types of antibiotic drugs that are used to treat different infections, e.g. bacterial, viral or fungal infections.

As mentioned in the section **Side effects of chemotherapy** on page 28, your child has 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 your child is neutropenic and develops an infection, they need to urgently be seen by a doctor and start IV antibiotics. Your child's health care team will let you know who to call or what hospital to go to if your child develops an infection. The common signs of infection are explained on page 9.

Detailed information

New drugs

Researchers are working to develop effective and safer treatments for ALL. ALL treatment can be very effective for most children, but it does not cure all children. New treatments are needed for these children with relapsed, refractory or high-risk ALL. You can ask your child's haematologist/oncologist if you have any questions about new drugs or other treatment options for your child.

PHASES OF ALL TREATMENT

ALL treatment for children is typically divided into five phases: induction, consolidation, interim maintenance, delayed intensification and maintenance.

Children with high-risk ALL may have additional phases of treatment. It usually takes two to three years to complete these 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 a remission and hopefully make the leukaemia undetectable.

Induction lasts for four weeks. If everything is going as planned, and the family feels ready, some children with ALL may be discharged after the first week of treatment.

Children with standard-risk ALL often have several drugs over this first month of treatment. This is a combination of chemotherapy drugs and a corticosteroid drug. These drugs and their side effects are discussed in the previous section **Treatment for ALL**.

Consolidation

Consolidation therapy begins after induction therapy with the goal of killing any remaining leukaemia cells in the body.

Usually higher doses of chemotherapy are used during the consolidation phase than those used in the induction.

Consolidation treatment usually lasts for a period of four to eight weeks, usually depending on your child's treatment protocol. Consolidation treatment is often given as an outpatient (in a day stay or outpatient clinic). Sometimes children are required to stay overnight in hospital if there are any complications, such as a fever or infection.

Generally, a combination of several chemotherapy drugs is given that work together to kill the leukaemia cells.

Interim maintenance

After consolidation therapy, there is a recovery period called interim maintenance. The aim of this phase is to maintain the remission, but also allows the bone marrow to recover from the effects of treatment so far.

Interim maintenance is typically given for up to eight weeks, depending on your child's treatment protocol. Sometimes interim maintenance is repeated.

Delayed intensification

The goal of delayed intensification is to eliminate any remaining leukaemia cells that may have been drug-resistant. This phase of therapy is quite intensive, which means side effects, including serious infections, are more common.

Delayed intensification typically lasts eight weeks and includes a combination of chemotherapy drugs similar to those used in the induction and consolidation phases. Most children do not need to stay overnight in hospital for this phase of treatment unless they have any complications, such as fever and infection.

Maintenance

The maintenance phase is the last and longest phase of treatment. The goal of maintenance treatment is to prevent relapse.

Children receive lower doses of chemotherapy and as a result most children have less severe side effects. However, children can still develop serious and life-threatening infections during maintenance therapy, so it is important that parents respond to fevers at all stages of treatment even if they are not currently receiving chemotherapy or are neutropenic.

Maintenance treatment usually lasts two years.

LIVING WITH ALL AND SIDE EFFECTS OF TREATMENT

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

Each child's experience will be different. Some children feel very unwell, while others have milder symptoms. Some children feel better with treatment because the symptoms caused by ALL go away.

This section helps you manage the more common symptoms of ALL and the side effects of treatment. These are listed below in the following pages.

Remember to report any side effects to your child's doctor or nurse. Your LBC Support Services Coordinator can also 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 9.

If your child has a low red blood cell count, they may have a blood transfusion via a drip (IV). Blood transfusions are explained in more detail on page 32.

It is important to let your child's doctor know if they are getting puffed easily or finding it hard to breathe.

If your child is on maintenance treatment and being more active around home or school, they may still experience tiredness, fatigue and getting puffed (heavy breathing) with exercise. It can be useful to let them have restful times each day so they can regain some energy.

Bruising and bleeding

If your child has a low platelet count (thrombocytopenia), they may bruise easily or bleed more than usual from minor cuts.

Things that can help prevent your child from bruising and bleeding include:

- Use a soft toothbrush and don't floss teeth.
- Don't play contact sports such as rugby or hockey.
- Don't eat food with sharp edges, e.g. potato chips.

Important information

Call the hospital straight away if your child has:

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

- Let their doctor or nurse know if they are constipated.
- Older children should not shave with a razor blade.
- Let their friends, other parents and teachers know to be careful (gentle play and no high-risk activities or contact sports).

If your child has a low platelet count, they may be given platelets via a drip (IV) to help stop bleeding or bruising. This is called a blood transfusion and is described in more detail on page 32.

Constipation

Constipation is when someone cannot pass a bowel motion easily, usually because the bowel motions are hard. Tell your child's nurse or doctor if they 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 children are receiving a chemotherapy drug called vincristine and often doctors will prescribe a laxative to help.

Things that can be done to help:

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

Damage to organs

Chemotherapy drugs can sometimes damage body organs such as the heart, lung, liver or kidneys. Your child will have regular tests to check that all their body organs are working properly.

Your child's oncologist/haematologist will also discuss any long-term effects that treatment may have on your child. This is often called late effects and is discussed further on page 54.

Diarrhoea

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

Other symptoms may include:

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

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

Important information

Call the hospital if your child has more than four episodes of diarrhoea in a day.

Things that can be done to help:

- Use soft toilet paper or wipes when wiping your child's bottom.
- Apply a barrier cream around their bottom to protect and soothe the skin.
- Drink plenty of fluids.
- If your child is unable to drink fluids, tell their doctor or nurse as they may need to have a drip (IV).
- Eat less fibre, such as cereals, raw fruits and vegetables.

If your child wears a nappy, it is important to change it frequently to keep the skin, around the nappy area clean. Chemotherapy drugs can be excreted in urine and bowel motions and can irritate the skin which may lead to broken skin sores. It's important to regularly inspect the skin around their nappy area and let your child's health care team know of any redness, rash, bleeding or broken skin. Skin damage can be very painful so let the doctor know if your child is getting very upset or distressed with nappy changes as they can prescribe appropriate pain relief.

Fatigue (extreme tiredness)

Fatigue is very common for children with ALL or following 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 child's life. It can sometimes be several months before energy levels improve.

Things that can be done to help:

- Ensure your child has a regular night sleep routine.
- Have regular rest periods throughout the day.
- Note the times of the day when your child has the most energy and set goals to do the main activities at these times.
- Ensure they do some light exercise each day.
- Try to stick to some routines to structure the week.

In hospital your child's sleep can be very interrupted. Speak with their 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

Fertility issues

Fertility means a person's ability to get pregnant or father a child. Infertility means that a person may not be able to become pregnant or father a child.

Most children who are treated for ALL will grow up and be able to have normal, healthy babies. For some, treatment may cause a reduction in their fertility and their ability to have children in the future. This may depend on the age of a child when they were treated

and the type of treatment they received. The onset of puberty can also be affected and some children may require hormonal supplements to support sexual development.

Treatment and fertility for boys

In boys, sperm production may be impaired for a while following chemotherapy but production of new sperm may become normal again in the future.

There may be some options for preserving your son's fertility if their treatment is likely to affect their ability to father a child in the future.

Adolescent males who are post-pubertal may have the option of sperm cryopreservation through sperm banking. The two options are to collect a sample of semen (through masturbation) or if this isn't possible, a fertility specialist can discuss the options of testicular biopsy/aspiration.

Treatment and fertility for girls

Most girls who are treated for ALL are able to have children and therefore fertility preservation is usually not required or offered for this diagnosis. Intensive chemotherapy can cause some damage to the normal functioning of the ovaries, but this is uncommon.

The two main options for fertility preservation in females are:

- Oocyte cryopreservation (egg freezing)
- Ovarian tissue cryopreservation (ovarian tissue freezing).

Ovarian tissue freezing involves surgically removing one ovary and freezing this tissue. Once treatment has finished this tissue must be tested for the presence of cancer cells before being transplanted back into the female. Currently ovarian tissue collection can be funded in New Zealand, but the risk of infertility is usually low following ALL and is not high enough to justify the risks of this procedure, including removal of healthy ovarian tissue.

Egg freezing is a procedure that takes 10–17 days and involves stimulating and collecting eggs in females who have started menstruating (post-pubertal). The eggs that have been collected are frozen and stored. Leukaemia usually needs to be treated quickly and therefore there is not usually time for this procedure to take place, so is not routinely offered.

Talk to your child's health care team if you are concerned about your child's fertility or have any questions. If your child's fertility may be impacted due to their treatment, they can be referred to a fertility specialist who will be able to explain what options may be available.

More information available online

Sex and contraception

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

Hair loss (alopecia)

Hair loss is a common side effect of chemotherapy used to treat ALL. Hair loss usually happens over a number of days or weeks after treatment starts.

Hair loss can happen on all parts of the body including on the head, eyebrows, eye lashes, face, underarms, pubic hair and legs.

For many children, hair loss can be one of the most distressing side effects of their cancer treatment. Children can be sensitive about how they look and how others may perceive them.

Your child's scalp may feel sensitive, sore or itchy when their hair is falling out.

Things that can be done to help:

- Pat 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.

Head wear and shaving your child's head

Unfortunately, there is nothing you can do to prevent your child's hair from falling out.

Some children find it useful to get their hair cut short or shave their head before their hair falls out. This may allow children to feel some control over their hair loss. Other children may want to wait and see what happens.

Some children like to wear wigs, hats and other headwear. Talk to your child's health care team about government-funded headwear for children who have lost their hair due to chemotherapy.

As your child's hair grows back, they may find that it has changed. It may be curlier, thicker, a different colour or grow back unevenly. These changes do not always stay that way forever.

Increased risk of infection

ALL and chemotherapy can cause your child's blood cell count to drop. Having lower than normal blood cell counts (red blood cells, white blood cells and platelets) causes symptoms such as anaemia, tiredness and an increased risk of infection.

Having a low white blood cell count can be very serious, and even fatal, if a child does not see a doctor quickly for an assessment and antibiotics.

Your child's health care team will tell you if they have a low white blood cell count. They may use other names to describe this such as neutropenia, reduced or weakened immune system or immunocompromised.

Important information

In summer, it is important to protect your child against sunburn. Their skin will be more sensitive to the sun after chemotherapy so it's important to ensure they apply sunblock and cover up.

When your child has a low white blood cell count (neutropenic), they are at risk of infection. Infections can be life threatening. If your child is receiving intensive chemotherapy, they may be admitted to hospital while their white blood cell count is below $1x10^9$. The white blood cells are usually at their lowest about 7 to 14 days after treatment.

There are a number of things that can be done to help reduce your child's chance of getting an infection.

Food

Your child's doctor, nurse or dietitian will tell you what foods to avoid when they have a low white blood cell count (neutropenic). Caution around eating some foods is recommended to reduce chances of food poisoning.

You need to be very careful when preparing and cooking food for your child. Be sure to:

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

Keeping your child clean

When your child has a low white blood cell count, they are more likely to get an infection from germs on their body.

You need to ensure your child:

- Has a bath or shower every day.
- Washes their hands after using the toilet and ask family/whānau to do the same.
- Cleans their teeth regularly. If their platelets are low, don't floss. See sections **How to do mouth care** and **When to do mouth care** on page 47.
- Keeps their central IV line clean and check for any signs of infection such as redness, swelling, pus or pain.
- Use sanitary towels rather than tampons during their period.

Other people

When your child has a low white blood cell count, they are at a higher risk of getting an infection from other people.

Your child needs to:

- Stay away from people who have been near others who have had chicken pox, measles and other similar infectious diseases.
- Stay away from crowded places such as buses, busy shops and events where you can't control who is around you.

If you have children who are attending school (siblings or a child with cancer), talk to their school or preschool. They need to let you know of any infectious diseases in the school, e.g. chicken pox, measles, diarrhoea or vomiting. If any of your children have been exposed to chicken pox or measles, let your

child's health care team know immediately as they may need to be treated.

It is important that your child keeps up some social activities and connection with close family/whānau. Touching, hugging and kissing their close family/whānau is important. It is fine if they are well.

Talk to your child's health care team if you would like more information.

Pets

When your child has a low white blood cell count, they may get an infection from pets.

You need to ensure your child:

- Always washes their hands after touching pets.
- Doesn't let a pet lick their face.
- Doesn't touch the litter tray or animal poo.

It is important to keep pets treated for worms and fleas. Keep pets away from areas where food is prepared.

Playing outside

Here are some things to consider if your child has a low white blood cell count:

- Garden soil can have harmful germs in it so it's important for your child to wash their hands thoroughly after playing with soil and dirt.
- Some particles around building sites can have harmful germs that could cause infection in someone who is neutropenic. Wearing a mask could reduce the chances of inhaling any harmful germs.

Low mood, anxiety, depression or difficulty coping

Following a diagnosis of ALL, it can be common for your child and/or their family/whānau, to have a low mood, feel anxious or

Important information

If your child is neutropenic (has a low white blood cell count), call the hospital if they have a temperature of 38°C or above, unless advised otherwise by your health care team.

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

depressed, or find it difficult to cope. There are a lot of things that cause these feelings, and they can happen to you as the parent, or to your child.

Things that you can do to help yourself and/or child:

- Talk about how you're feeling with someone you are comfortable with, e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your child's health care team about a referral to a psychologist or counsellor. They will be able to provide some options for yourself and/or your child.
- Make a list of things that make you and/or your child feel better such as a favourite TV show or hobby.
- Try to spend some time each day relaxing, e.g. listening to music, meditating.
- 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 and/or your child express feelings without needing to talk to anyone.

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

Feelings of isolation

A diagnosis of ALL can make you and/or your child feel isolated or alone, for a number of reasons.

These can include:

- Being unable to do the usual things, e.g. school or work.
- Symptoms and side effects, such as fatigue or risk of infection, can make it hard to be with other people or attend social events.
- A lack of support from family/whānau or friends who may not know what to say or do.
- Financial difficulties can make it hard to maintain social activities or visit family/whānau and friends.

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

Nausea, vomiting and dehydration

Some chemotherapy, especially intensive chemotherapy, can make your child 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 your child may have one or more types of antiemetic drugs to treat their nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch. Tell your child's doctor or nurse if they still feel sick because they might be able to try a different antiemetic drug or give it to them in a different way.

Controlling your child's nausea and vomiting is important so they can keep up their food and drink intake. If they have bad nausea and vomiting and are unable to drink or keep fluid down, it is important you speak with their doctor or nurse to ensure they don't become dehydrated.

Things that can be done that may help your child's nausea and/or vomiting:

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

Pain

Some children may experience pain as a result of ALL or their treatment. It is important to tell your child's health care team if they have pain.

The health care team will ask your child about the pain, for example:

- What is the pain like, e.g. dull, sharp, burning?
- How bad is the pain on a scale of 0–10? (0 being no pain, 10 being the worse pain your child has ever felt)
- What makes the pain worse and what makes it better?

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

Change in appetite and taste changes

Your child may not feel like eating and/or have changes in tasting food. This may be because of the chemotherapy, other drugs, the worry of having ALL, or doing less physical activity. Some drugs, e.g. corticosteroids (dexamethasone and prednisone), can cause hunger and your child may eat a lot of food and gain weight over this time.

Poor appetite

Having a poor appetite can be disappointing for people who usually enjoy eating. It is important that your child keeps eating to help maintain their weight and energy levels. It can be hard to encourage young children to eat as they don't know the importance of maintaining good nutrition. It is also important they drink plenty of fluids, especially if they are not eating very much.

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

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

Things that can be done to help:

- Eat small amounts of food as often as possible.
- Keep snacks handy such as nuts, crackers or dried fruit.
- Add extra energy and protein to your child's diet by using full-fat products.

Taste changes

You may find that your child's sense of taste changes or that the texture of food seems

different to them. This may mean that they no longer enjoy food, all food tastes the same, or food has a metallic taste. Their sense of smell can also be affected.

Things that can be done to help:

- Eat food cold as it often tastes better and smells less.
- Suck boiled sweets or drink fruit juice as they leave a pleasant taste in the mouth.

If you are in hospital with your child and they don't feel like eating the hospital food, ask their doctor or nurse about suitable foods that can be brought in.

Managing weight loss

It is important that your child doesn't lose a significant amount of weight due to nausea, vomiting or lack of appetite. Weight is expected to fluctuate in the first few months of treatment, however there can be serious complications if too much weight is lost because the body doesn't have the fuel it needs to heal or fight infections.

Your child's weight will be monitored at the hospital either on the ward (if they're staying overnight) or in the outpatient clinic. If you're at home and you are concerned about your child's weight loss, contact their health care team.

Your child may need to see a dietitian who can offer support and may need to prescribe nutritional supplements to ensure your child is getting enough calories.

The health care team may decide that your child needs additional nutritional support through a nasogastric (NG) tube. Not all children need a nasogastric tube and the doctor and dietitian will talk to you if they think it's needed. Many families and children find that life is actually easier when an NG is inserted because it can take the stress out of eating and taking medicines.

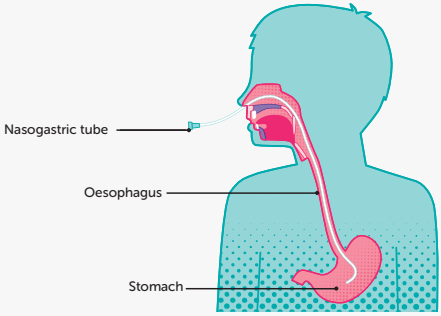
An NG tube is a soft hollow tube that is inserted into a nostril and goes down the back of the throat into the stomach (see Figure 08). The end of the tube is usually taped to the cheek, so it is held in place.

An NG tube is used for many reasons but often for children with ALL it is used for administering oral medications and/or prepared liquid food or fluids that can be given through the tube.

Inserting an NG tube is usually a short procedure, and the tube will go down easily if your child is relaxed. It doesn't usually hurt but it is not very pleasant and can be scary and overwhelming.

Figure 08

NG tube



The following tips may help both you and your child manage the procedure better:

- Prepare your child by telling them what to expect.
- Try to distract them by watching a favourite TV show or cuddling a soft toy.
- Offering them a drink with a straw can help the tube go down more easily.
- Reassure them during the procedure and affirm they are doing well.

It can take a few days for your child to get used to the feeling of having the NG tube in. If your child is staying in hospital, the nurses will test to make sure the NG tube is sitting in the stomach properly. After using the NG tube for liquid food or medications, it needs to be flushed with clean water to make sure the tube doesn't get blocked. If your child is going home with an NG tube, the nurses will teach you how to use it and make sure you feel comfortable.

Managing increased appetite

You may notice if your child is taking corticosteroids as part of their treatment plan that they are hungry and increase their food intake. This is a common side effect of corticosteroids and can be overwhelming to manage as the parent.

Some children appear to be hungry during the day and can also wake overnight feeling hungry. They may also put on weight over this time due to their increased eating and appetite.

Some ways that you can support your child are to:

- Ensure healthy snacks are available for them during the day and night.
- Keep the same boundaries around eating that you had prior to their diagnosis.
- Reassure your child that their increased appetite is a side effect to some of the drugs they're taking, and this will return to normal once they stop taking them.

LBC has an Eating Well fact sheet available on the LBC website or from an LBC Support Services Coordinator.

More information available online

Skin changes

Chemotherapy can affect your child's skin and nails. Skin may become dry or more oily. It can also become red, sore, itchy and more sensitive.

Detailed information

Chemotherapy can be excreted through body fluids including sweat, urine and bowel motions. It's important to inspect your child's skin regularly to make sure they don't have any rashes or areas of broken skin that may be painful or infected. If your child wears a nappy, regularly change it and use a barrier cream to protect their skin. Let their health care team know if you notice any redness, bleeding, rashes, broken skin or if your child gets upset and distressed with nappy changes.

Nails may become brittle and flaky. Ridges or lines may appear on their nails, and they can also become painful or swollen.

Things that can be done to help:

- Don't use soap and perfumed products or products that contain alcohol.
- Moisturise dry skin once a day, more if needed.
- Use lip balm regularly.
- Don't scratch.

Sun protection

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

Things that can be done to help:

- Wear sunscreen with a high SPF and reapply regularly.
- Don't go outdoors in the hottest part of the day.
- Cover exposed skin with clothing.

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

Sore mouth

A sore mouth can be an uncomfortable side effect of some chemotherapy drugs. Chemotherapy causes 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). Symptoms of mucositis may appear a couple of days after your child starts chemotherapy. Not all children will get mucositis.

The symptoms of mucositis can include any of the following:

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

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

When to do mouth care

It's important that your child does mouth care several times a day, ideally when they wake up, after meals and before bed. Doing mouth care can be painful, however it is very important to do it especially if the treatment your child is having can cause mucositis. Mouth care reduces the risk of infection, especially from mouth ulcers.

How to do mouth care

- Brush teeth with a soft or baby toothbrush or use a mouth sponge if a toothbrush is too painful.
- Rinse with mouthwash or with water, as instructed by your health care team.

- Use a lip balm or petroleum jelly (Vaseline) on the lips.
- Don't use dental floss as this increases the risk of bleeding gums.

Things that can be done to help:

- Suck ice cubes or ice blocks
- Suck on hard-boiled lollies or tinned pineapple if your mouth is dry.
- Drink fizzy water.
- Spit saliva into a bowl instead of swallowing or if in hospital, ask the nurse how to use the suction.
- Don't eat citrus fruit such as lemon, orange or grapefruit.

Managing mouth pain

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

This may include:

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

If you think your child's mouth pain is getting worse and the pain relief isn't helping, contact

Important information

When to contact your child's doctor or the hospital for help

Contact the doctor, or the hospital, straight away (night or day) if your child is feeling unwell or has any of these symptoms:

- A temperature of 38°C or over and/or shivering.
- Bleeding or bruising, e.g. blood in their urine, bowel motion or sputum (spit), bleeding gums or a nosebleed.
- Nausea or vomiting that prevents them from eating or drinking or taking their 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 their body.
- Exposure to chicken pox, measles or similar infectious diseases.

their health care team as they may need to have support with eating and drinking, or may require stronger pain relief.

Contacting the hospital after-hours

Remember to ask your child's health care team for the hospital after-hours phone number. If your child is feeling unwell, ring the number and ask for advice, no matter what time it is.

Your child's health care team and the hospital would rather that you rang to discuss how your child is feeling than not ring and feel worse or their condition deteriorate. If in doubt, make the call.

The emergency department at the closest hospital will always be open.

Moving to a main centre hospital for treatment

Treatment for ALL in children, especially in the early stages of their diagnosis, requires specialist care that is only available at specialised paediatric cancer units. If your local hospital cannot provide the treatment your child needs you may need to move to another hospital in a main centre. There are two hospitals in New Zealand that provide specialist paediatric oncology/haematology care. These are at Starship Children's Hospital in Auckland and Child Haematology and Oncology Centre (CHOC) in Christchurch. Your local hospital will still be involved in your child's care and may do some tests, treatment and follow-up care.

There are other hospitals around New Zealand that are shared-care providers and work together with the specialist centres to support your child closer to home. The list of these hospitals and their contact details can be found on page 65.

A social worker will 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, your child and your family/whānau. Contact your LBC Support Services Coordinator to obtain a relocation booklet with practical information about moving to a main centre hospital.

SOCIAL AND EMOTIONAL EFFECTS

Parents

Parents cope with a diagnosis of ALL in different ways and there is no right, wrong or standard reaction. Hearing that your child has been diagnosed with leukaemia is extremely distressing and can trigger a range of intense emotional responses, ranging from denial to devastation. It is not uncommon to feel angry, helpless and confused, all at the same time. It is important to understand that the diagnosis of leukaemia is not your fault, and there is nothing you could have done to prevent it.

Naturally, many parents feel a great sense of sadness and grief at the possibility of the death of their child. While it is sometimes difficult to avoid focusing on the possibility of death, it is important to remember that survival rates for children with leukaemia have risen dramatically, and will continue to improve in the future. It is important to remember that the doctors, nurses and other health professionals caring for your child are experts in this area. They have a great deal of knowledge and experience in caring for children with leukaemia.

Every effort will be made to ensure that your child feels comfortable during any test or procedure. For example, local anaesthetic creams may be applied to the skin prior to any necessary needle pricks while stronger painkillers, sedation and/or a general anaesthetic can be given for very painful procedures. If your child requires a general anaesthetic you will be allowed to stay by their side until they are asleep, and be there when they wake up afterwards. Parents are encouraged to stay, where possible, and comfort their child during various tests and procedures. Remaining calm and confident and encouraging your child can be of great assistance during these times. If you find it too distressing, you can always stay close by instead, and return to comfort your child as soon as possible afterwards.

It is best for parents to speak directly to their doctor regarding any questions they might have about their child's disease or treatment. It can also be helpful to talk to other health professionals including social workers or nurses who have been specially educated to take care of children with blood cancers.

Social workers are available to help you and offer advice on financial assistance that may be available to you in terms of travel, accommodation, and other benefits you or your child may be entitled to. They are also able to offer you emotional support and help with planning your child's care.

Children

It is not easy to tell a child about a diagnosis of leukaemia. The amount of information that can be given often varies with the child's age and level of intellectual and emotional development. No one knows your child better than you, and no one can tell you when (or how) to tell them about their illness. See pages 19-20 for age-appropriate guidelines and what to expect from children regarding their diagnosis or time in hospital. Generally speaking, we recommend telling

children the truth but in a gentle manner and avoiding unnecessary detail. In most situations this is the best approach to help your child understand what is happening. When children are worried and can see their parents are worried, they can sometimes imagine things are worse than they actually may be. For instance, they may imagine that death is certain, but in fact most children survive ALL and have meaningful quality of life.

There are a number of things that will temporarily change while your child goes through treatment for ALL. Some of these include:

- Socialising with other children
- Schooling.

Socialising with other children

Interacting with other children is an essential part of any child's social and psychological development. Because of the nature of treatment for ALL, most children spend more time out of hospital than in hospital.

Between treatments and when your child is well enough, they can participate in their usual daily activities including attending playgroups, day care or school. These settings provide children with opportunities for learning, for socialising with their peer group and for making friends. It can also provide your child with a sense of returning to normal and hope for the future.

Schooling

Children undergoing ALL treatment will have interrupted school attendance during treatment and at other times when they are unwell. While your child is undergoing treatment it is natural, as a parent, to feel that they may be missing out at school. Be assured that children do catch up.

In the meantime they often gain valuable experiences from their time away from school, which can be a special bonding time with parents. Many treatment centres have hospital-based teachers who can help your child stay as up to date as possible during these times. In addition, your child's teacher may be able to supply lessons from school, which your child can follow when they feel well enough.

Some children miss their school friends and the social life that comes with being a student. This may also be true for young adults attending university or other training institutions, and for other siblings, where the family has had to relocate for specialist treatment.

At times your child may feel bored, left behind or forgotten about by their friends. Where possible, keep in contact with the school, inform them of your child's progress, and encourage classmates to stay in touch with your child through visits, phone calls, letters, cards and online, which can be accessed while your child is at home or in the hospital. This will benefit them while they are out of school and will also make the transition back to school after or in between treatments easier.

It is important to provide teachers and/or carers with an adequate amount of medical information about your child's illness and how the disease or its treatment may affect them at different times. This will help them to anticipate and meet your child's needs. Tiredness and risk of infection are important concerns when your child is undergoing treatment and for some time afterwards.

The doctors and nurses at the treatment centre will provide you with information and strategies to help reduce these risks while allowing your child to lead as normal a life as possible during this time. You can pass this information on to teachers and carers. It is also important to make teachers, carers and other parents aware of your child's situation and the need to be informed about any outbreaks of contagious infections like chicken pox or measles, so that you can take appropriate steps to prevent infection. Preparing teachers and students for the way your child may look (e.g. without their hair), how your child might feel about returning to school (anxious, excited, self-conscious), and how they might make things easier for their classmates (acceptance, inviting them to join in) can be important in supporting your child's self-confidence and self-esteem.

When your child does return to school, encourage the teachers and students to treat them as a 'normal' student, just one of the class, while being aware of any special needs they might have.

Many paediatric treatment centres run outreach programmes where health professionals, like the clinical nurse specialist, may be able to visit the school and explain the illness both to teachers and to your child's classmates. Educational psychologists, counsellors or school liaison officers can help.

Organisations such as Leukaemia & Blood Cancer New Zealand, Child Cancer Foundation and Canteen can be useful sources of information and peer support during this time. Talk to your LBC Support Services Coordinator about the Monkey in My Chair presentation that can be delivered to your child's school or preschool to support them, their teacher(s) and classmates.

Occasionally children experience some learning difficulties as a result of their treatment. Most schools have early intervention and support programmes that can assist your child if necessary.

Your family/whānau

The diagnosis and treatment of leukaemia can cause an extreme amount of stress within any family. The demands of treatment bring many disruptions to normal day-to-day lives. Family routines are often disrupted with frequent trips to the hospital for tests or treatment. Members of the family may suddenly have to perform roles with which they are not familiar, e.g. cooking, cleaning and taking care of children. In other cases they may have to take on extra roles and responsibilities within the family, sometimes on top of their paid work. This can be physically, mentally and emotionally exhausting.

Some parents find that, where possible, allowing themselves to maintain as much of their familiar role as possible within the family helps to maintain some normality in the situation and give them and everyone else in the family a better sense of control and hope for the future.

Many parents are understandably concerned about the social and financial impact of the diagnosis and treatment of ALL on their family. In many cases, one or both parents may have to spend time out of the workforce and away from home while they care for a sick child.

Financial support may be available through government allowances to help with the costs of travel, accommodation and other financial pressures. Your child's social worker will be able to help you and your family access services, including from other organisations.

It is okay to tell people that everything is not okay and that you need help. Nobody expects you to cope with everything alone. Sometimes if you need help for precise things, it can help to explain that to other people, so they know what help you actually want.

Caring for siblings

When a child is diagnosed with cancer, their siblings (brothers and sisters) may experience many confusing emotions. The way in which they respond to these emotions will depend on their age and development level. Siblings can feel angry, anxious, lonely, sad, guilty or even resentful at the attention their sibling receives. Reassuring siblings that they are loved and giving them opportunities to talk about how they are feeling is important. This helps them to feel better about themselves and acknowledge that what they are feeling is normal and a result of the situation.

During this time all children within the family need a great deal of support, guidance and love. Sticking as much as possible to normal routines like bedtimes, applying the expected boundaries on behaviours, and having a reasonable and consistent approach to discipline can help to make children feel more secure, when so many other things appear to be changing within their family.

Giving siblings appropriate information (and repeating this information when required) about what is happening to their unwell sibling, and including them in some hospital visits, can be helpful. This may help to reduce their anxiety and assist them to understand the reasons for the hospital visits and treatment.

Asking other family/whānau members or friends to spend time with the sibling or take them on a special outing can also help.

Talk to your LBC Support Services Coordinator about support for your other children. There are a number of services and programmes for siblings of children with cancer.

You and your partner

Serious illness within a family can be very challenging for partner relationships. As well as dealing with a sick child, treatments make many demands on partners' time and emotional resources.

Effective communication between partners is essential. Acknowledging and talking about the stress in the situation can help. Many treatment centres have a counsellor, psychologist, social worker and pastoral care workers who can assist you and your family/whānau in coping better with the practical and emotional difficulties you may be experiencing. They can also identify strategies that will help you and your family cope during and after treatment.

Your LBC Support Services Coordinator is available to provide you with support and resources.

THE FUTURE

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

The length of time it may take you and your child to recover emotionally and physically from an ALL diagnosis or treatment is different for everyone. Getting back to your previous routine of work, school or childcare, for example, may be a goal or may not be what you want any more. You may need to make a few adjustments to your life.

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

- Day-to-day practical problems including work, school and travel
- Relationships and communication with family/whānau and friends
- 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 your family cope.

After treatment

After your child's treatment has finished, they will continue to have regular check-ups with their haematologist/oncologist and health care team.

You will also be encouraged to go back to see your child's general practitioner (GP). Your child's health care team will send regular letters to their GP to tell them about their progress and what needs to be followed up. If your child's GP has any questions, they are able to contact your child's haematologist/oncologist for advice.

Late effects

Most children go on to enjoy long and healthy lives after being successfully treated for ALL. Sometimes, however, the treatment can affect a child's health months or even years or decades after treatment has finished. These are called long-term or late effects.

Your child's doctor will discuss any potential long-term effects of their treatment and the steps that can be taken to help reduce or prevent them. The long-term effects of treatment depend on several factors, including the types and combinations of drugs used, and the dose(s) given.

In general, more intensive treatments like a stem cell transplant and treatments that involve radiation can cause more significant long-term effects. In children, areas of the brain that control normal growth and development are immature and therefore more sensitive to the effects of some treatments. For example, radiation to the central nervous system (CNS) can cause a number of long-term problems including obesity, reproductive difficulties and delayed growth.

Delayed growth can be treated using growth hormone replacement therapy. CNS radiation, and other CNS treatments (intrathecal chemotherapy and some types of intravenous chemotherapy), have also been associated with learning difficulties in some children.

Your child's school progress is monitored as part of their routine follow-up after treatment.

Fear of relapse

Even though your child has been treated successfully for ALL, it is normal for parents to continue to experience feelings of vulnerability for their child, uncertainty about the future and fear that the illness could return.

The fear of a relapse of leukaemia may cause some parents to become overprotective of their child. Naturally, they are more aware of any physical signs and symptoms than previously. For example, a bruise, which the child has sustained in normal play, may cause the parent to become very anxious that this may be a sign their child has relapsed.

Follow-up appointments, after treatment has finished, are often times of great anxiety as people wait for the all clear from their doctor. As time passes, often anxiety reduces. As life gets busy again with school and activities, parents shift their attention away from their child's illness.

Many people find it useful to talk with other parents and family/whānau members who understand the complexity of feelings and the kinds of issues that come up for parents and families/whānau living with an illness of this nature.

If you find yourself still having low mood, anxiety or depression, please contact your GP, LBC Support Services Coordinator or your child's health care team, who can offer you support.

Finding a 'new normal' as a family

After your child's treatment has finished there is the opportunity to find a new normal as a family. Often people want to get back to normal, which can be hard after all the experiences you've had and things you've learnt throughout your child's diagnosis and treatment.

The phase after treatment has finished can be exciting, scary or overwhelming. Don't feel guilty if you find this phase difficult. There are supports available for you, your child and family/whānau.

It can be useful for your child to talk and reflect about their time in hospital or having treatment. Encourage these discussions and if you feel like they need ongoing emotional support, contact their health care team.

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 normally 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.

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 (anti-sickness).

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

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

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

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

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

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

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

Central line – Also known as a central venous catheter (CVC), central venous access device (CVAD) or central venous line (CVL). A line or tube passed through the large veins of the arm, neck, chest or groin and into the central blood circulation. It can be used for taking samples of blood, 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 central nervous system (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). Nausea and vomiting are also common, but nowadays largely preventable with modern antiemetic medication. Most of the side effects of chemotherapy are usually temporary and reversible.

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

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

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

Corticosteroids – A group of man-made hormones, including dexamethasone and prednisone, 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 X-ray or imaging technique that produces a series of detailed three-dimensional (3D) images of cross sections of the body.

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

Cytogenetic tests – Cytogenetic tests 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. Starts at your mouth and ends at your bottom. Turns food and fluids into fuel for your body.

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

Electrocardiogram (ECG) – Recording of the electrical activity of the heart.

Foetus – An unborn child.

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

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

Haematopoiesis – The processes involved in blood cell formation.

Hickman line – A type of central venous catheter (see above) sometimes used for patients undergoing intensive treatment including bone marrow or peripheral blood cell transplant. It may have a single, double or triple tube (or lumen).

High-dose therapy – The use of higher-than-normal 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 which multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the bloodstream and can accumulate in other organs.

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

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

Myeloid – A term used to describe a pathway of maturation of blood cells in the bone marrow. Red blood cells, 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 – General term used for a specialist doctor who treats cancer by different means, e.g. medical, radiation, surgical oncologist.

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

Paediatrician – A doctor who has special training in medical care for children.

Partial remission – The tumour shrinks to less than half its original size after treatment. In people with leukaemia, this means that the proportion of blast cells in the marrow has been reduced following treatment, but not necessarily below 5%. There are still some leukaemic 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 (ABL gene) breaks off and attaches itself to part of chromosome 22 (BCR gene) in a process called translocation.

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

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

Psychological – Concerning mental and emotional well-being.

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

Relapse – The return of the original disease.

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

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

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

Splenomegaly – Enlargement of the spleen.

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

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

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

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

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.

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

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

Tyrosine kinase inhibitors (TKIs) – A group of drugs that inhibits tyrosine kinases.

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

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

APPENDIX

The following are samples of questions to ask your child's doctor following a diagnosis of ALL.

Place a tick alongside the questions you would like to ask. You could add your own questions and answers in the space provided. LBC also has a Haematology Patient Diary that has space for any answers and/or documenting relevant information from clinic appointments.

- ☐ What exactly does the treatment involve?
- ☐ How long will the entire treatment take?
- ☐ What are the alternatives to this treatment?
- ☐ What are the expected outcome 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?
- ☐ Which doctor will be looking after my child while they have their treatment?
- ☐ How can I prepare myself, my child and my family/whānau for the different phases of treatment?
- ☐ Who can I contact if I have any questions or concerns about my child's treatment or recovery?

QUESTIONS AND NOTES

QUESTIONS AND NOTES

ACKNOWLEDGEMENTS

Leukaemia & Blood Cancer New Zealand (LBC) would like to thank everybody who has helped in the development of this booklet: those whose children have experienced ALL, their personal supporters, health care team members and LBC staff.

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.

SPECIALIST TREATMENT CENTRES FOR CHILD CANCER IN NEW ZEALAND

Centre	Address	Phone
Starship Blood and Cancer Centre	Level 7, Starship Children's Hospital, Park Road, Grafton, Auckland	09 367 0000
Child Haematology and Oncology Centre (CHOC)	Riccarton Avenue, Christchurch	03 364 0640

Regional paediatric hospitals in New Zealand (shared care)

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
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
Gisborne Hospital	Ormond Road, Gisborne	06 869 0500
Taranaki Base Hospital	David Street, Westown, New Plymouth	06 753 6139
Whanganui Hospital	Heads Road, Whanganui	06 348 1234
Wellington Hospital	Riddiford Street, Newtown	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
Dunedin Hospital	Great King Street, Dunedin	03 474 0999
Invercargill Hospital	Kew Road, Invercargill	03 218 1949
Greymouth Hospital	71 Water Walk Road, Greymouth	03 769 7400
Timaru Hospital	Queen Street, Parkside, Timaru	03 687 2100

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

OD - 9148 - 2018
Charities Commission no. CC24498

leukaemia & blood cancer NEW ZEALAND

Vision to Cure. Mission to Care.