ACUTE MYELOID LEUKAEMIA (AML)

A guide for patients,
families & whānau

leukaemia & blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

INTRODUCTION

This booklet has been written to help you and your family and whānau understand more about acute myeloid leukaemia (AML).

If you or someone you know has been diagnosed with AML, you may be feeling anxious or a little overwhelmed. This is normal. Perhaps you have already started treatment or you are discussing treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your health care team. It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your circumstances at all times with your doctor and treatment team.

Interpreter service

New Zealand's Health and Disability Code states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family/whānau member or friend may assist. The hospital can organise a trained interpreter if needed.

Informed consent

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

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 LBC website can be obtained in a printed version. Ask your 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 Leukaemia & Blood Cancer New Zealand (LBC) Support Services Coordinator. They will be happy to answer your questions or explain something in more detail.

Glossary

On page 45 there is a glossary (word list). In the 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

Leukaemia can be acute or chronic. Acute leukaemia develops very quickly and treatment must start right away. Chronic leukaemia develops slowly and may not need treatment right away.

The names of the main types of leukaemia are:

Acute

Acute Myeloid Leukaemia (AML)

Acute Lymphoblastic Leukaemia (ALL)

Chronic

Chronic Myeloid Leukaemia (CML)

Chronic Lymphocytic Leukaemia (CLL)

Both adults and children can develop leukaemia but certain types are more common in different age groups. Each year in New Zealand around 650 adults and 50 children are diagnosed with leukaemia.

Key points

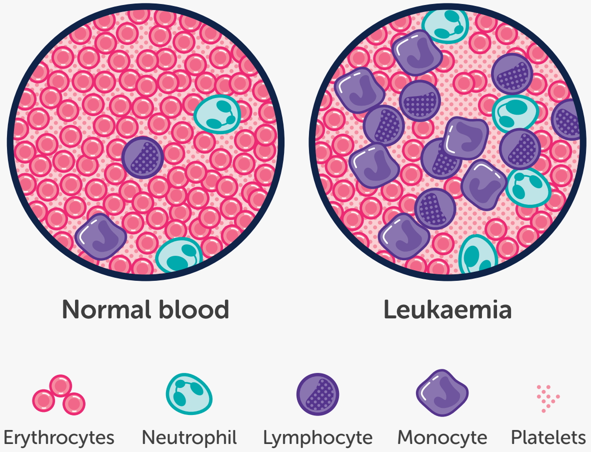
- Leukaemia is a type of blood cancer of the white blood cells. Leukaemia can be acute (develops fast) or chronic (develops slowly).

WHAT IS ACUTE MYELOID LEUKAEMIA (AML)?

Acute myeloid leukaemia (AML) is a type of leukaemia and is a cancer of the myeloid cells. AML develops very quickly.

To fully understand AML it is helpful to learn about the cells in your body and bone marrow.

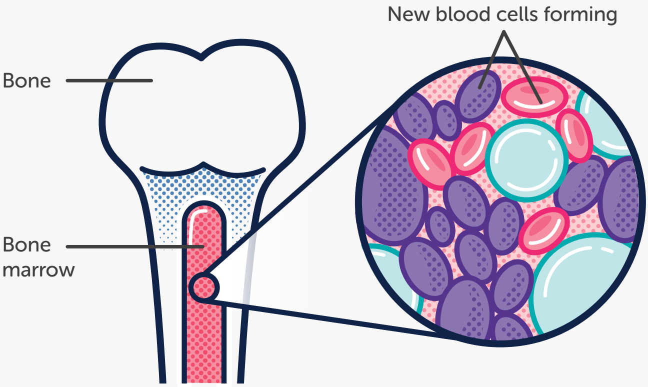
Figure
01
Normal blood & leukaemia



Figure

02

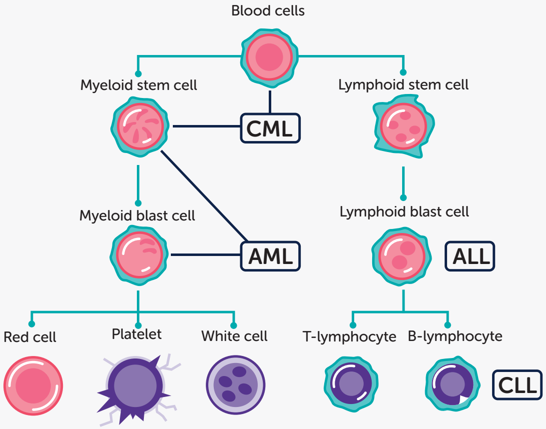
Bone marrow



Figure

03

The cells created from blood stem cells



This indicates the different cells where abnormalities occur causing the different leukaemias

BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 02).

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

The two main functions of blood stem cells are to:

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

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

In Figure 03 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.

Leukaemia 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).

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 adults, haematopoiesis occurs in the bone marrow of large bones such as the breast bone (sternum), thigh bone (femur) and the hip bone (iliac crest).

Key points

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

YOUR BLOOD

The red blood cells, platelets and white blood cells, created in your bone marrow, are released into your blood stream.

Blood is made up of blood cells and plasma. Plasma is a light yellow coloured liquid in which blood cells travel around your body.

A blood test measures the amount of each type of blood cell in your blood. The role of each type of blood cell is discussed in the next section, and blood test results are discussed on page 15. Figure 04 shows the three main types of blood cells in the plasma.

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 your body is called anaemia ('a-nee-me-a').

White blood cells

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

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

Platelets

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

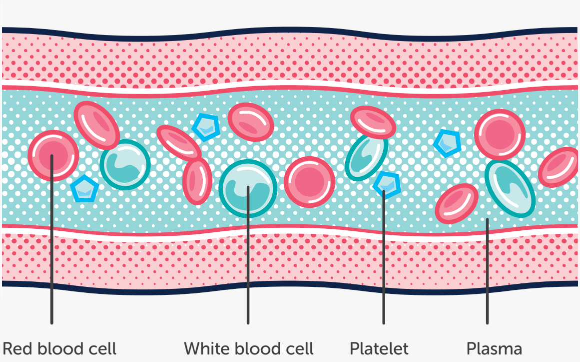
Key points

- 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, remove carbon dioxide from the cells.
  White blood cells: fight infection from bacteria, fungi, viruses etc.
  Platelets: help the blood to clot.

Figure

04

Blood vessel and cells in your blood



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.

ACUTE MYELOID LEUKAEMIA (AML)

AML is not a very common type of cancer but it is the most common type of acute leukaemia diagnosed in New Zealand adults. AML can affect children, but it is more common in adults.

AML is a type of leukaemia that affects the immature myeloid blood cells. The myeloid cell line is shown in Figure 03.

When you have AML, your bone marrow makes too many immature white blood cells which then crowd the bone marrow. The large number of immature cells stop the bone marrow from making normal red blood cells, white blood cells and platelets.

What causes AML?

The cause of AML is not known. We do know that you cannot catch AML from someone else and most people with AML do not have a family/whānau history of AML.

AML is a not a very common type of blood cancer particularly in children. It is more common in adults and is the most prevalent type of ‘acute’ leukaemia diagnosed in New Zealander’s over 18.

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 high levels of the chemical benzene over a long period of time.
- Having another type of blood disorder.
- Smoking.

Key points

- AML is a type of leukaemia that affects the immature white blood cells on the myeloid cell line.
- Immature white blood cells crowd the bone marrow and stop it from making normal red blood cells, white blood cells and platelets.
- The cause of AML is not known but risk factors have been identified such as high doses of radiation, exposure to the chemical benzene and smoking.

WHICH TYPE OF AML DO I HAVE?

As well as different types of leukaemia (acute and chronic), there are sub-types of leukaemia.

Sub-types can only be identified when leukaemic cells are looked at under a microscope. Doctors look at cell changes and other factors. AML has eight different sub-types.

Detailed information

There are two main systems for classifying the types of AML:

- The World Health Organisation classification.
- The French-American-British (FAB) classification.

The FAB classifications are listed below:

M0	Undifferentiated acute myeloblastic leukaemia
M1	Acute myeloblastic leukaemia with minimal maturation
M2	Acute myeloblastic leukaemia with maturation
M3	Acute promyelocytic leukaemia (APL)
M4^{eos}	Acute myelomonocytic leukaemia
M5	Acute monocytic leukaemia
M6	Acute erythroid leukaemia
M7	Acute megakaryoblastic leukaemia

Each subtype of AML provides information on the type of blood cell involved and the point at which it stopped maturing properly in the bone marrow.

WHAT ARE THE SIGNS AND SYMPTOMS OF AML?

AML develops quickly. A person may be diagnosed days or weeks from when they first started to feel unwell.

Immature white blood cells crowd the bone marrow and stop it from making normal red blood cells, white blood cells and platelets. The signs and symptoms of AML are a result of low amounts of normal blood cells in the body.

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.
- Feeling very tired all the time.
- Weakness.
- Dizziness.
- Feeling unusually short of breath when doing exercise.
- Pale skin.

Bleeding and bruising

Having a low number of platelets in your blood can cause thrombocytopenia.

The symptoms of thrombocytopenia include:

- Bruising easily.
- Minor cuts or injuries that take a long time to stop bleeding.
- Frequent or severe nose bleeds or bleeding gums.
- Unusually heavy periods in women.
- Red or purple pinhead-sized spots on your skin called petechiae (‘pe-tea-kee-eye’).

Infections

Having a low number of white blood cells in your blood can put you at risk of getting lots of infections.

For example:

- Minor skin infections (redness/swelling/pus) that heal slowly.
- Urinary tract (bladder) infections.
- Fevers (high temperature).
- A throat or mouth infection.

Neutrophils are the most common type of white blood cell, and having a low number of neutrophils in your blood is called neutropenia. If you have neutropenia, you are at risk of getting lots of infections.

Other

Less common symptoms of AML may include:

- Bone pain.
- Swollen lymph nodes (glands).
- Swollen gums.
- Chest pain.
- Sore stomach area.

Sometimes people have no symptoms and AML is discovered when they have a blood test.

Key points

- The main signs and symptoms of AML are the result of low amounts of normal blood cells in the body. Not everyone experiences the same signs and symptoms.
- As a result of low red blood cells, a sign and symptom of AML is anaemia.
- As a result of low platelets, a sign and symptom of AML is increased bruising and bleeding.
- As a result of low white blood cells, there is a risk of getting lots of infections.

WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

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

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

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

- **Charge nurse** – A senior nurse in charge in the outpatient department or on the hospital ward.
- **Clinical nurse specialist (CNS)** – A nurse with advanced skills in a specific area of cancer care. This person works closely with you and members of your health care team to help you manage the symptoms and side effects of AML and treatment.
- **Dietitian** – A dietitian will advise on what to eat and drink to minimise symptoms or side effects from AML or your treatment. A dietitian may prescribe supplements to make sure you are getting the calories and nutrients you need.
- **General practitioner (GP)** – A family and community doctor might already be involved with your diagnosis of AML. They will be informed throughout your diagnosis of AML and will work together with other health professionals to support you at home, in the community and after treatment.
- **Haematologist** – A doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist will be in charge of overseeing your treatment and follow-up.
- **Occupational therapist** – Helps you manage everyday activities and achieve activities you want or need to do.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in clinic.
- **Pharmacist** – Prepares and checks your medications. A pharmacist can advise you on how to take your medicine and the possible side effects.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility. A physiotherapist (or physio) can help you regain independence and fitness following diagnosis and/or treatment of AML.
- **Psychologist** – Specialises in helping you manage the emotional challenges of AML such as stress, anxiety and depression.
- **Registrar** – A doctor who is training to become a haematologist. You will often see your registrar on the ward and in the clinic. Your registrar works very closely with your haematologist.

- **Social worker** – Helps you manage the practical and emotional impact of AML such as advice about managing at home, employment or school.
- **Ward nurse** – A nurse who looks after you during your stay in hospital.

Other people you might hear about or meet are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose role includes managing symptoms of AML, helping improve quality of life and supporting people at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.
- **Non-Governmental Organisation (NGO)** – Gives emotional and practical support for those affected by cancer, e.g. Leukaemia & Blood Cancer New Zealand.
- **Leukaemia & Blood Cancer New Zealand Support Services Coordinator**
  - A professional who provides education as well as practical and emotional support.
  - Phone 0800 15 10 15.

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

TESTS AND INVESTIGATIONS

To find out if you have AML, your doctor will ask you to have some tests which will help your doctor make a diagnosis.

There are two main tests for diagnosing AML: a blood test and a bone marrow biopsy.

Blood test

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

If you have AML, the FBC is likely to show the following:

- A lower amount of red blood cells than normal.
- A lower amount of platelets than normal.
- White blood cells that are leukaemic, i.e. have the appearance of leukaemia.

Someone with leukaemia produces a lot of immature white blood cells which go into the blood from the bone marrow. The large number of immature white blood cells stop the bone marrow making normal red blood cells and platelets. This explains why people with AML usually have lower than normal amounts of red blood cells and platelets.

Normal blood test results for adults and children are shown on page 15.

An FBC is helpful for diagnosing AML 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 bone marrow and sends them to a lab to be looked at under a microscope.

A sample of bone marrow is usually taken from the back of your hip bone (the iliac crest).

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

The doctor might give you a drug that makes you feel relaxed and sleepy (a sedative) before the biopsy starts. You might also be given pain relief.

The doctor will give you a local anaesthetic. This is a small injection that is put into your skin where the biopsy is going to be done, to make the area numb.

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

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

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

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 haematologist to talk about the findings of your bone marrow biopsy.

You will also have a bone marrow biopsy or biopsies after you have started treatment for AML to see how well you are responding to your treatment.

MRD testing

MRD stands for minimal residual disease, which represents the smallest quantity of leukaemia cells that current technology can detect. It aims to be able to detect one leukaemia cell if present in 10,000 normal cells whereas the standard microscope method of examination of your bone marrow can only reliably detect leukaemia cells down to a level of 1 in 20.

MRD testing is a method of testing your blood and/or bone marrow to analyse any leukaemia cells. This will require a bone marrow biopsy procedure. There are 3 techniques used to detect MRD:

DNA methods to detect genetic changes in cells.

1. Polymerase chain reaction (PCR): a method to analyse a short sequence of DNA.
2. Next generation sequencing (NGS): a method to determine multiple DNA sequencing.
3. Immunophenotyping to look for certain proteins made by leukaemia cells.

MRD testing can be useful in determining what risk level the leukaemia is and what treatment a person has. It can also be used at the end of treatment to determine how well the treatment worked and how likely it is for the AML to come back.

For example if the MRD testing shows that you have a high-risk AML then your treatment might be more intensive than someone who is low-risk.

MRD negative refers to the fact that the amount of leukaemia left in the body is so low that current technology is unable to detect it. MRD positive refers to the fact that although someone might be in remission there are still some leukaemia cells detected in the bone marrow. Being MRD positive could indicate that there is greater potential for relapse compared with someone who is MRD negative.

There is still research being done into how useful MRD testing is and how often it will be used in practice. If you have any questions about MRD testing you can ask your haematology medical team.

Other tests

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

Preparing for tests

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

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

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

Detailed information

Further tests are done on your bone marrow biopsy samples. The results of these tests will show what sub-type of AML is present.

These tests are called:

- Immunophenotyping (‘imm-you-no-feen-o-tie-ping’).
- Cytogenetic (‘cy-toe-gen-etic’) tests.

Immunophenotyping checks if special markers, called antigens, are found on or in white blood cells. The appearance of the antigens provides information about the subtype of leukaemia that is present.

Cytogenetic tests provide information on the genetic make-up of the leukaemic cells. Changes to the chromosomes provide information about the sub-type of AML and the best way to treat it.

Key points

The two main tests for diagnosing AML are:

- a blood test (a full blood count-FBC)
- a bone marrow biopsy

We recommend that you bring a support person when you have a bone marrow biopsy test.

An interpreter can be arranged for your appointments, if needed.

Normal blood test results

Table 1 gives you information about normal blood test results for adults. You may find this useful when you are having regular blood tests and want to compare your results with the normal range. Table 2 gives you information about normal blood test results for children.

Please note that there may be small variations compared with the data used at your hospital or clinic. If the test is for your child, ask for a copy of their blood results which will include the normal values for each blood cell type.

Table 1

Normal range for adults:		
	Adult men	**Adult women**
Hb (g/L)	130-175	115-155
Neutrophils (x10^{9}/L)	2.0-7.5	2.0-7.5
Platelets (x10^{9}/L)	150-400	150-400

Table 2

Normal range for children:						
	1 month	**1 year**	**3 years**	**5 years**	**9 years**	**16 years**
Hb (g/L)	93-158	105-140	107-136	113-145	115-145	115-150 (F) 125-160 (M)
White cells (x10^{9}/L)	5.8-13	5.0-14.5	4.9-12.8	4.5-12	4.3-12	4.2-10
Neutrophils (x10^{9}/L)	0.5-3.9	1..0-7.0	1..0-7.0	1.5-8.0	1.5-7.0	1.8-7.0
Platelets (x10^{9}/L)	150-650	150-500	150-500	150-475	150-425	150-400

INFORMED CONSENT FOR TREATMENT AND PROCEDURES

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

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

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

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

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

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 18.

MAKING TREATMENT DECISIONS

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

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

- The type of leukaemia you have.
- Your age.
- Your general health.
- How well your AML is likely to respond to treatment.

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

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

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

Second opinion

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

Questions to ask the health care team

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

Key points

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

In Appendix A on page 50 there are some examples of questions you could ask your haematologist. 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 doctor.

Bring a support person

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

Prognosis

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

When doctors and the 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 leukaemic cells can no longer be seen under a microscope.
- **Partial remission** – The number of leukaemic cells is less, but there are still some leukaemic cells present.
- **Stable disease** – The leukaemia is not getting worse or any better.
- **Relapse** – The leukaemia has come back again. Some people may never relapse while others may have a higher chance of relapse.
- **Resistant disease** – Also called 'refractory disease'. The leukaemia is not responding to treatment.

Being in a clinical trial

Your doctor might ask you to take part in a clinical trial. Most of the treatments for AML are part of an international clinical trial. Clinical trials are also called research studies. Clinical trials help find out if a new treatment or different ways of giving treatment are better than treatments that are already available.

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

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

More information available online

TREATMENT FOR AML

The main treatment options for AML are:

- Intensive chemotherapy.
- Low doses of chemotherapy.
- Stem cell transplant.
- Supportive care.
- Palliative care.

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

Chemotherapy

Chemotherapy is the main type of treatment for AML. 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.

Each drug affects the cancer cells in different ways. This is why sometimes a combination of two or more different chemotherapy drugs are given.

Most chemotherapy drugs travel around the body in the bloodstream, which means they can reach 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.

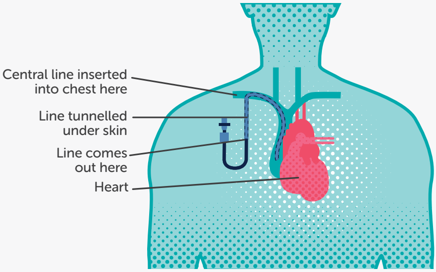
The different ways that chemotherapy is given are:

- 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)

Sometimes a special line or tube called a central line is used for intravenous chemotherapy. A central line is inserted into a large vein in your chest, neck or arm and is left in there until your chemotherapy treatment is finished. Another name for a central line is a Hickman or groshong line. A central line inserted into the arm is called a peripherally inserted venous catheter (PICC).

Figure
05
Central line placement



You can see the placement of the central line into a vein by the heart. Some of the tube is inside the body and the rest is outside the body where it is then connected to more IV tubing.

Chemotherapy drugs are put into the central line, and blood is taken out of the line for blood tests. The advantages of a central line are:

- You do not need to have as many needle pricks for blood tests.
- You do not need to have a needle put in each time you have chemotherapy.

Intensive chemotherapy

Intensive chemotherapy is a treatment that involves being given a full dose of chemotherapy in hospital, with the aim of curing AML. If you have intensive chemotherapy, you will spend long periods of time in hospital, often several weeks. To receive this treatment you may need to move to a hospital in a main centre. On page 39 there is more information about spending time in hospital and moving to a hospital in a main centre.

Intensive chemotherapy is likely to cause unpleasant side effects, but these can usually be controlled with medicines.

A course of intensive chemotherapy is given in several cycles. Each cycle is usually 28 days long. Chemotherapy is given on certain days and then there are days to recover before starting the next cycle. If you are well enough, you might go home or to accommodation near the hospital, for a short period of time.

The aim of intensive chemotherapy is to cure the AML. Unfortunately some people may not respond to this treatment.

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

Induction chemotherapy aims to put the AML into remission. You will usually have two cycles of induction chemotherapy. However, you may have more if the AML is not in remission after two.

Consolidation chemotherapy aims to get rid of any leukaemia cells that may remain after induction chemotherapy and to reduce the risk of the AML coming back.

Detailed information

Below is a list of commonly used drugs used for intensive chemotherapy:

- Amsacrine.
- Cytarabine (also called Ara-C).
- Daunorubicin.
- Etoposide.
- Fludarabine.
- Idarubicin.
- Mitroxantrone.
- Mylotarg*.

Common combinations of chemotherapy are:

- ADE (Ara-C, Daunorubicin, Etoposide).
- DA (Daunorubicin, Ara-C).
- FLAG-Ida (Fludarabine, Ara-C, G-CSF**, Idarubicin).

*Mylotarg is a drug made up of a chemotherapy drug called ozagamicin and a monoclonal antibody called gemtuzumab. Monoclonal antibodies which are sometimes called targeted therapies work by targeting specific proteins on the surface of cancer cells. The gemtuzumab locks onto the leukaemia cell and the ozagamicin kills it.

** G-CSF is not a chemotherapy drug. G-CSF is an injection that helps increase your white blood cell count.

During consolidation chemotherapy you have additional or different chemotherapy from what you had during induction. You will have three or four cycles of consolidation chemotherapy.

Lower doses of chemotherapy

Lower dose chemotherapy is also sometimes known as 'non-intensive treatment' or 'palliative chemotherapy'.

Intensive chemotherapy may not be the right treatment for everyone. Lower dose chemotherapy is an alternative treatment that aims to control AML rather than get rid of it.

A person receiving lower doses of chemotherapy does not have to spend as much time in hospital.

Treatment for people with the AML sub-type APL

People with the subtype acute promyelocytic leukaemia (APL or APML) may also be given all-trans retinoic acid (ATRA) or arsenic trioxide.

ATRA is not a chemotherapy drug. ATRA is a tablet that is given with chemotherapy. It makes the leukaemic cells mature (go from immature cells to adult cells), which can reduce symptoms quickly. Side effects can include headaches, dry skin and mouth, feeling sick, bone pain and dry eyes.

Arsenic trioxide can be used to treat people with APL who have relapsed or who have not gone into remission with treatment.

It is given through an IV infusion (drip) and the side effects can include:

- Heart changes.
- Diarrhoea.
- Tiredness.
- Muscle and bone pain.
- High temperature.
- Raised blood sugar.

Side effects of chemotherapy

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

The side effects for each drug or drug combination are different. Most people will have some side effects, but some people do not. Most side effects of chemotherapy begin to go away when your treatment is finished.

When you receive chemotherapy there are breaks during the treatment so that your body, the bone marrow in particular, has time to recover from the side effects of the chemotherapy.

Side effects of treatment may be short 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 that you may experience side effects for months after treatment.

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

- Anaemia.
- Bruising and bleeding.
- Constipation.
- Diarrhoea.
- Difficulty concentrating or remembering ('chemo brain').
- Early menopause.
- Fatigue (extreme tiredness).
- Fertility issues.
- Hair loss.
- Increased risk of infection.
- Low mood, anxiety, depression or difficulty coping.
- Nausea and vomiting.
- Organ damage.
- Pain.
- Poor appetite and taste changes.
- Skin changes.
- Sore mouth (mucositis).

These side effects, and what you can do if you have these side effects, are discussed in the section called 'Living with AML, its treatment and beyond' on page 27.

Chemotherapy is the main treatment for AML, however you may have other treatments which are outlined below.

Stem cell transplant

High doses of chemotherapy and radiotherapy destroy stem cells and your body cannot recover on its own. If you have a stem cell transplant, you are given high dose chemotherapy followed by stem cells through a drip to replace the ones that were destroyed. The stem cells you are given may come from someone else (a donor) or may be your own stem cells that were frozen before the high dose treatment.

A stem cell transplant may also be called a bone marrow transplant, a haematopoietic ('he-ma-to-po-ee-tick') stem cell transplant or a peripheral ('per-if-er-ral') blood stem cell transplant.

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

Stem cell transplants allow you to have

Key points

- Chemotherapy is the main form of treatment of AML. There are many different types of chemotherapy and it is given in a variety of different ways, e.g. via a drip (IV) or a tablet.
- Chemotherapy can be given in hospital, as an outpatient or at home depending on the type of chemotherapy you are having and how well you are.

much higher doses of treatment. This may help to improve the recovery from AML or keep it away for as long as possible (prolong remission).

Radiation therapy also known as radiotherapy is sometimes used before a stem cell transplant.

There are two main types of stem cell transplants:

- Allogeneic ('al-o-jen-ayic').
- Autologous ('or-tol-o-gus').

Allogeneic stem cell transplant

An allogeneic stem cell transplant is also called an allograft or an 'allo'.

An allogeneic stem cell transplant is when the stem cells you are given are from a donor. The donor may be your brother, sister or an unknown volunteer who has been genetically matched to you.

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

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

More information available online

Detailed information

- **Secondary cancers**
  Some chemotherapy drugs can increase the risk of developing some types of cancer later in life, but this is rare. Your doctors will weigh up the small increase in the risk of this happening against the benefit of the treatment for your AML.

Key points

- A stem cell transplant is a treatment option that your haematologist might discuss with you if it is suitable.
- A stem cell transplant is when you are given high dose chemotherapy followed by stem cells through a drip (IV).
- Stem cell transplants allow you to have much higher doses of treatment to improve chances of recovery.

Autologous stem cell transplant

An autologous stem cell transplant is also called an autograft or high-dose treatment with stem cell support.

An autologous stem cell transplant is not often used for people with AML. However it may be a treatment option for a person who has a relapse of acute promyelocytic leukaemia (APML).

For an autologous stem cell transplant, some of your stem cells will be collected and stored. You will have high doses of chemotherapy and then your stem cells are returned through an IV infusion.

More information available online

Supportive care

Supportive care is important to help people cope with their diagnosis of AML, symptoms of AML and the impact of treatment. Supportive care ensures that you have the best quality of life.

Examples of supportive care are:

- Being given blood products via a drip (a transfusion) to help with symptoms of low red blood count or platelets.
- Being prescribed drugs to help manage side effects or symptoms, e.g. pain relief or anti-emetics (drugs to stop you feeling sick).
- Being given antibiotics to help prevent or manage infections.
- Support from a dietitian, psychologist or chaplain.
- Practical support at home.
- Support for families/whānau that have to relocate for treatment.

Supportive care is used in two situations:

1. Supportive care is the choice a person makes for managing symptoms of their AML, when they do not have chemotherapy.
2. Supportive care can help a person receiving treatments (such as intensive or lower dose chemotherapy) to manage difficult side effects or overwhelming symptoms, e.g. nausea or pain.

Key points

There are two main types of stem cell transplants:

- allogeneic
- autologous

Allogeneic stem cell transplant is when the stem cells you are given are from a donor. This is the most common type of transplant for AML.

Palliative care

The palliative care team is made up of doctors, nurses and other health care professionals who specialise in managing symptoms of AML. They aim to improve quality of life through support and services as you face a life limiting illness. The palliative care team may be involved in providing you with supportive care.

Many people associate the word 'palliative' with end of life care. The palliative care team supports all people with AML.

This table compares palliative supportive care, and supportive care alongside treatments such as chemotherapy or a stem cell transplant. Supportive care is important regardless of whether you are receiving chemotherapy or not. It can help a person manage the symptoms of AML or the side effects of treatment.

Palliative supportive care	Supportive care alongside other treatments
• You either have no chemotherapy or low-dose chemotherapy for AML symptoms. • Health care team and palliative care team support the person to control AML symptoms e.g. pain, nausea, anaemia or infection. • Emotional and practical support is given to ensure the best quality of life. • End of life wishes are supported. • End of life care is provided. • Support given in hospital, hospice, at home or as an outpatient.	• A treatment is given such as chemotherapy or stem cell transplant. • Health care team involves the palliative care team to support the person to control severe side effects of treatment or AML symptoms e.g. pain, nausea or infection. • Emotional and practical support is given to ensure the best quality of life. • Support given in hospital, at home or as an outpatient.

Supportive care may start at diagnosis, during treatment, after treatment and at end of life. Family/whānau and friends can also receive supportive care.

Key points

- Supportive care helps people cope with their diagnosis of AML, the impact of symptoms and the side effects of treatment.
- Supportive care ensures you have the best quality of life.
- Palliative and end of life care provides people with support and services as they face a life limiting illness.
- The palliative care team supports all people with AML regardless of whether or not they are receiving treatment.

Complementary therapies

Many people find complementary therapies, or a combination of them, help them to feel better physically and emotionally.

Examples of complementary therapies are:

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

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

Treatment for children

Children will commonly have intensive treatment. Depending on the type of AML a child has, they will either have an allogeneic stem cell transplant or consolidation treatment (intensive chemotherapy) after having some initial (induction) chemotherapy.

Having a stem cell transplant or intensive chemotherapy decreases the chances of relapsing after responding well to the initial (induction) treatment. Approximately 60% of children will have an allogeneic transplant.

Supportive care for children will include support for them to continue their schooling and family/whānau support.

Treatment for relapsed disease in adults and children

If the AML returns after treatment, your haematologist will talk to you about your options for treatment. It could include any of the options discussed in this section and will depend on many factors, including:

- How long after the treatment finished the relapse happened, e.g. months or years.
- How well the AML responded to the first treatment.
- How you coped physically with the treatment.
- Your age and general level of health.
- If there is a donor available for an allogeneic stem cell transplant.
- How you feel about further treatment.

LIVING WITH AML, ITS TREATMENT AND BEYOND

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

Each person's experience will be different. Some people feel very unwell, while others have milder symptoms. If you are having intensive chemotherapy, your side effects may be more severe.

This section helps you manage the more common symptoms of AML and the side effects of treatment. Remember to report any side effects to your doctor or nurse. Your LBC Support Services Coordinator can give you support or more information.

Anaemia

A low red cell count is called anaemia. Anaemia was described on page 9.

If you have a low red blood cell count, you may have a blood transfusion via a drip (IV).

Bruising and bleeding

When you have a low platelet count, you may bruise easily or bleed more than usual from minor cuts.

Things you can do to help:

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

If you have a low platelet count, you might be given platelets via a drip (IV) to help stop bruising and bleeding. This is called a transfusion.

Important information

Call the hospital straight away if you have:

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

Constipation

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

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

Things you can do to help:

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

Damage to organs

Chemotherapy drugs can sometimes damage body organs such as heart, lung, liver or kidney. You will have regular tests to check that all your body organs are working properly.

Diarrhoea

Sometimes chemotherapy damages the lining of your bowel wall. This might cause diarrhoea ('die-a-rea') (loose bowel movements) and other symptoms such as:

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

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

Things you can do to help:

- Take the drugs that your doctor or nurse give you to stop the diarrhoea.
- Wipe your bottom with soft toilet paper or wipes.
- Apply a 'barrier cream' around your bottom to protect and soothe the skin.

Important information

- If you experience any chest or abdominal pain or are worried about any symptoms between your regular tests then you should contact your health care team as soon as possible.

Important information

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

Key points

- The symptoms and treatment side effects for AML can be unpleasant, for example an increased risk of infection, bruising, hair loss, diarrhoea or constipation, nausea and vomiting.
- There are things you and your health care team can do to help you feel more comfortable. Ask your health care team for support and information.
- It is important to know when to ring for medical help, for example, if you are dehydrated or have the signs of an infection. The signs to look out for are under 'Important information'.

- Drink plenty of fluids.
- If you are unable to drink fluids, tell your doctor or nurse you may need to have a drip (IV).
- Eat less fibre, such as cereals, raw fruits and vegetables.

Difficulty concentrating or remembering – 'chemo brain'

'Chemo brain' is another symptom or side effect of AML or chemotherapy.

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

The symptoms of chemo brain are:

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

Chemo brain can be frustrating and it can make everyday life difficult. Things you can do to help:

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

Early menopause

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

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

Symptoms of menopause include:

- Short term: hot flushes, night sweats, trouble sleeping, mood swings, irritability.
- Medium term: reduced libido (sex drive), vaginal infections, aches and pains.
- Long term: cardiovascular disease, stroke, osteoporosis.

If you have symptoms of menopause, it is important to speak with your doctor or nurse. They will be able to help you manage the symptoms and side effects.

Fatigue (extreme tiredness)

Extreme tiredness is very common for people with AML or after AML treatment. Extreme tiredness can be caused by:

- AML itself.
- Chemotherapy and other treatment.
- Emotional stress.
- Poor sleep.
- Low blood counts.
- Muscle loss.
- Loss of appetite or dehydration.

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

Things you can do to help:

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

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

More information available online

Fertility issues

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

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

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

LBC has a 'Fertility' fact sheet available on the LBC website or from an LBC Support Services Coordinator.

Sex and fertility

Even though chemotherapy can cause infertility, it does not make all people infertile. Chemotherapy can affect a developing foetus, so use a condom when you have sex in the months before, during and after chemotherapy to avoid a pregnancy.

More information on sex and relationships can be found on page 42.

More information available online

Hair loss

Hair loss is a common side effect of the intensive chemotherapy for AML. Hair loss usually happens over a number of days or weeks after you start treatment.

You should start to feel and see new hair growing back six to twelve weeks after you finish treatment. It might take longer for some people.

Hair loss can happen on all parts of your body including on your head, eyebrows, eye lashes, beard or moustache, underarms, pubic hair and legs.

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

Things you can do to help:

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

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

Scalp cooling is not recommended

There is a method for reducing hair loss called scalp cooling. Scalp cooling is not recommended for people who have a blood cancer because it can reduce how well the chemotherapy kills blood cancer cells.

Emotional support

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

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

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

Shaving your head and head wear

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

Things you can do to help:

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

As your hair grows back, you 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

AML and chemotherapy cause your blood cell count to drop.

Having lower than normal blood cell counts (red cells, white cells and platelets) causes you to experience symptoms such as anaemia, tiredness and an increased risk of infection.

Having a low white cell count can be very serious and fatal if you do not see a doctor quickly for an assessment and antibiotics.

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

Low white blood cells mean you are at risk of infection. Infections can be life threatening. If you are having intensive chemotherapy, you will probably be admitted to hospital while your white blood cell count is below 1x10^9. This is usually about seven to fourteen days after treatment.

There are a number of things you can do to reduce your chance of getting an infection. These are as follows:

Food

Your doctor, nurse or dietitian will tell you what foods to avoid when you have a low white cell count. They may suggest you have a 'neutropenic' or 'clean' diet. This type of diet protects you from germs found in some foods and drinks. Your doctor or nurse will tell you when you can return to your usual diet. This will be when your white cell count has increased.

Important information

- Call the hospital if you have a temperature over 38°C.
- Don't wait to see if your temperature goes away.
- Make sure you have a thermometer at home and you know how to check your temperature correctly.
- Don't take any drugs such as paracetamol to bring your temperature down before you see a doctor.
- Don't take aspirin or ibuprofen in any form. This can increase your risk of bleeding if your platelets are low. Always check with a doctor or nurse first.
- At the hospital they might give you an injection just under your skin (sub-cut) called G-CSF which helps increase your white blood cell count.
- Ask a member of your health care team for the phone numbers of the hospital and write them here:

  Monday to Friday (during office hours)

  ph...

  Evenings/nights/weekends

  ph...

You need to be very careful when preparing and cooking food. You need to:

- Always wash your hands before preparing or eating food.
- Tell your family/whānau to wash their hands before preparing food.
- Prepare food in a clean place.
- Prepare raw 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 yourself clean

When you have a low white cell count, you are more likely to get an infection from germs on your body. You need to:

- Have a bath or shower every day.
- Use a clean towel every day.
- Wash your hands after using the toilet and ask family/whānau members to do the same.
- Clean your teeth regularly. If your platelets are low, don't floss. See 'How and when to do mouth care' on page 37.
- Keep your central IV line clean and check for signs of infection such as redness, swelling, pus or pain.
- Use sanitary towels rather than tampons during your period.

Other people

When you have a low white cell count you are at a higher risk of getting an infection from other people. You need to:

- Stay away from people including children who are unwell with colds, flu or other infections.
- Stay away from people who have been near others who have had chicken pox or measles.
- Stay away from crowded places such as buses, trains and busy shops.

If you live with children, talk to their school or pre-school. They need to let you know of any infectious diseases in the school, for example chicken pox, measles, diarrhoea or vomiting.

Your haematologist will tell you if the people you live with need a flu vaccine to help protect you.

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

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

Pets

When you have a low white cell count, you may get an infection from pets. You need to:

- Always wash your hands after touching pets.
- Do not let a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Keep pets away from areas where food is prepared.
- Don't touch the litter tray or dog poo.

Gardening

Garden soil can cause infections in people with a low white cell count. You need to:

- Wear gloves, as soil or potting mix can have harmful germs in it.
- Wash any cuts from gardening very thoroughly.
- Check cuts for signs of infection.
- Wear a mask to avoid breathing in particles.

Low mood, anxiety, depression or difficulty coping

After finding out you have AML or during treatment, it can be common to have a low mood, feel anxious or depressed or find it difficult to cope. There can be a lot of things that cause these feelings.

Things you can do to help:

- Talk about how you feel with someone you feel comfortable with e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger longer term goals.
- Make a list of things that make you feel better such as your favourite TV show, talking to someone on the phone or doing a hobby.
- Try to maintain your social circle by keeping in touch with friends and family/whānau.
- Try to spend time each day relaxing, e.g. meditation, listening to music.
- Exercise regularly.
- Try to keep a regular sleep pattern.
- Keep a diary. This can help you express how you feel without needing to talk to anyone.
- Cry if you need to.
- Try complementary therapies such as massage, aromatherapy or reflexology. Information on complementary therapies can be found on page 26.

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

Feelings of isolation

A diagnosis of AML can also make you feel isolated or alone for a number of reasons, for example:

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

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

Nausea, vomiting and dehydration

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

There are drugs or medicines called 'antiemetics' which can help treat nausea and vomiting.

Different drugs work in different ways and you may have one or more types of antiemetic drugs to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch. Tell your doctor or nurse if you still feel sick because they might be able to try a different anti-emetic or give it to you in a different way.

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

Things you can do to help:

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

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

Pain

Some people may experience pain as a result of treatment, for example with mucositis or heartburn.

It is important to tell your health care team if you have pain. Your health care team will ask you about the pain, for example:

- What is the pain like, e.g. dull, sharp, burning?
- How bad is the pain on a scale of 0-10?
- What makes the pain worse and what makes it better?

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

Poor appetite and taste changes

You may not feel like eating and have taste changes. This may be because of the chemotherapy, medicines, the worry of having AML or doing less physical activity.

Poor appetite

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

It can be common for people to really feel like eating certain foods 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 eat, or are worried about your weight, ask to speak with a dietitian who will be able to advise you.

Things you can do to help:

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

Taste changes

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

Things you can do to help:

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

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

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 skin and nails.

Your skin may become dry or more oily. Your skin can also become red, sore, itchy and more sensitive.

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

Things that you can do 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.
- Don't shave with razor blades.
- Use oil free moisturiser on oily skin.
- Use hand cream regularly.
- Use nail-strengthening cream.
- Wear gloves when doing chores.

Sun protection

After chemotherapy, you might find that the sun burns your skin much quicker than it used to. Things you can do to help:

- Wear sunscreen with high SPF and reapply regularly.

- Don't go outdoors in the hottest part of the day.
- Cover exposed skin with clothing.

You should do this for the rest of your life.

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

Sore mouth

A sore mouth is an uncomfortable side effect of chemotherapy. 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').

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

The symptoms of mucositis can include any of the following:

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

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

When to do mouth care

You need to do mouth care five times a day. When you wake up, after meals and before bed. Doing mouth care can be painful, however it is very important to do it. Mouth care reduces the risk of infection, especially from mouth ulcers.

To do mouth care:

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

Things you can do to help:

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

Managing mouth pain

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

- 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.

Unfortunately painkillers might not get rid of all the pain.

Sometimes mucositis can also affect the oesophagus (food pipe) and bowel (gut). This can cause discomfort, pain, indigestion and heartburn or diarrhoea. Tell your doctor or nurse if you have any of these symptoms.

Continue mouth care when you go home to make sure your mouth is clean, especially after eating.

If you notice any bleeding, ulcers, cold sores or problems with your teeth, let your doctor know. Don't visit a dentist until you have spoken with your doctor.

Mucositis should start to get better when your white cell count starts to increase.

Important information

When to contact your doctor or the hospital for help.

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

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

Contacting the hospital after-hours

Remember to ask your health care team for the hospital after-hours phone number.

If you are feeling unwell, ring the number and ask for advice, no matter what time it is. Your health care team and the hospital would rather that you rang to discuss how you feel than not ring and feel worse. If in doubt, make the call. The emergency department at the closest hospital will always be open and their phone numbers can be found on page 55.

Coping with isolation in hospital during intensive chemo

During intensive chemotherapy for AML you may spend long periods of time in hospital in a side-room or in 'isolation'. Isolation means that you are in a hospital room by yourself and the main visitors you will be allowed are family/whānau and close friends. This is to protect you from serious infections while your white cell count is low. Being seperated from family or whānau, can be a challenging time for everyone especially children.

Things you can do to help:

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

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

Moving to a main centre hospital for treatment

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

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 and your family/whānau.

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

RELATIONSHIPS

Relationships with family/whānau and friends

A diagnosis of AML can have a positive and negative impact on relationships with family/whānau and friends.

Relationships with your partner

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

Other things you can do to help:

- Planning activities together such as meals out together. If you are in hospital and feel well enough, you and your partner could eat together and you could ask your nurse if it would be possible to have some time when no one comes into your room.
- Tell your partner how they can support you.
- Get support from a counsellor or psychologist. Ask your health care team or LBC Support Services Coordinator for more information.

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

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

Financial worries

A diagnosis of AML can cause money worries, perhaps through a drop in income or extra expenses. If you are working, keep in touch with your boss to discuss sick leave and your plans for returning to work. Information about your employment rights while undergoing cancer treatment can be found on the LBC website or by asking your Support Services Coordinator.

More information available online

If you are studying, contact your departmental Dean to discuss your situation.

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

Talking to your children

Helping children to understand AML and how this will affect them will help them to cope with the changes and challenges.

You can encourage younger children in your treatment journey to use a LBC sticker diary. Your children can record your treatments and write and share journal entries with you.

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

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

LBC has a 'Supporting a child through a loved one's cancer diagnosis' factsheet available on the LBC website or from a LBC Support Services Coordinator.

More information available online

Talking to friends and colleagues

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

Most people are very keen to offer support but just don't know how. Here are some suggestions to help you build your own support team:

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

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

Information for people supporting someone with AML

As the partner, parent or carer of someone with AML it is quite common to experience feelings of stress, anger, fear, anxiety or depression. Speak with the health care team or LBC Support Services Coordinator if you are feeling this way. There is a lot of support available for you.

Other things you can do:

- Look after yourself by eating well, getting enough sleep, taking regular exercise and relaxing.
- Keep doing your normal social activities.
- Join a support group, or see a counsellor.
- Write down a list of things that have helped you get through a tricky situation previously. Use these tips to assist you now. Some ideas might include talking to friends or writing a diary.

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

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

Sexual relationships

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

People who receive a diagnosis of AML and have treatment can experience changes in their sex life. The reasons for this include:

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

After your treatment, your sex life should start to return to how it was before your diagnosis.

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

Always use a condom when having sex.

Even if you are beyond child bearing age or no longer need birth control, it is still important to use condoms from your diagnosis of AML until after your treatment has finished for two main reasons:

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

Sex when you have a low platelet count

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

New relationships

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

Contact your LBC Support Services Coordinator if you would like more information about sexual relationships or new relationships.

KEEPING IN GOOD HEALTH AFTER YOUR AML DIAGNOSIS

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

So that you do not have complications from your treatment, or long term side effects, the following health changes should be made immediately:

- Stop smoking.
- Protect your skin from the sun.
- Stop drinking alcohol or cut down.

Your health care team can advise you on how to keep well. The physiotherapist can advise you about the exercise that is right for you. The dietitian can advise you about eating well, especially if your treatment is making you feel sick or you have taste changes.

Ask your doctor or nurse about support to help you stop smoking and reducing or stopping alcohol.

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

THE FUTURE

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

For some people, a diagnosis of AML can mark a turning point in their lives. For other people a diagnosis means they feel their life has been put 'on hold'. The length of time it may take you to recover emotionally and physically from an AML 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 healthcare team and LBC Support Services Coordinator can help you manage:

- Day to day practical problems including work, travel and travel insurance.
- Relationships and communication with family, friends and colleagues.
- Emotional effects of AML 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.

Speaking to someone who has already experienced an AML diagnosis and treatment

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

Travelling overseas

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

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

After treatment

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

GLOSSARY

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

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

Antiemetic – A drug which prevents or reduces feelings of sickness (antisickness).

Antigens – An antigen can stimulate white blood cells to get rid of the antigen or attack it directly. This is called an immune response. Also see 'immune system' later in this glossary.

Anxiety – An on-going 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 seem greater than they should be for a situation.

Aplastic anaemia – A bone marrow disorder characterised by failure of normal blood stem cell growth and development.

Blast cells – Immature blood cells normally found in the bone marrow.

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

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

Bone marrow – The tissue found at the centre of 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.

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

Cardiovascular disease – Heart and blood vessel disease, e.g. heart attack or stroke.

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

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

Cold sores – Red sores filled with fluid which mainly form around the mouth. Caused by a herpes virus which is contagious and can take two weeks or longer to go away.

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

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

CT scan 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.

Echocardiogram (echo) – A special ultrasound scan of the heart.

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

Foetus – An unborn child.

Growth factors – A complex family of proteins produced by the body to control the production and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy or bone marrow or peripheral blood cell transplantation, e.g. G-CSF (granulocyte colony stimulating factor).

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

Haemopoiesis (or 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 left over cancer cells.

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

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

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

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

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

Inversion – Where parts of a chromosome turn upside down or when two parts of a chromosome reverse their positions.

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 blood stream and can accumulate in other organs.

Localised disease – Disease that is confined to a small area or areas.

Lymph nodes or glands – Structures found throughout the body, for example in the neck, groin, armpit, chest and abdomen, which contain both mature and immature lymphocytes. There are hundreds of lymph nodes throughout the body.

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).

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

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

Myelodysplastic syndromes (MDS) – These are a group of blood diseases that affect normal blood cell production in the bone marrow.

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, for example medical, radiation, surgical oncologist.

Osteoporosis – A condition where bones become brittle and fragile and can break more easily.

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

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 five percent. 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.

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

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

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

Psychological – Concerning your mental and emotional wellbeing.

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.

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

Stem cells – Stem cells are primitive blood cells that can give rise to more than one cell type. There are many different types of stem 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 (haemopoeitic 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.

Stroke – Occurs when the blood supply to the brain is blocked or there is not enough blood. The part of the brain where the blood was going cannot work properly so this can affect a person's walking, talking, sight etc.

Sub-types – A smaller group of something that belongs to a more general or bigger group. For example a type of leukaemia is AML, a sub-type of AML (a smaller group within the AML type) is called acute promyelocytic leukemia (APL).

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

T-lymphocyte – A type of white 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).

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

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

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

APPENDIX A

The following are sample questions to ask your doctor when considering treatment options for AML.

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

☐ What is the expected outcome of this treatment for me? For example: complete remission, prolong remission, symptom management.

☐ What exactly does the treatment involve?

☐ How long will the entire treatment take?

☐ What are the alternatives to this treatment?

☐ How ill might I feel before, during and after treatment?

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

☐ Why are you recommending this treatment for me?

☐ If the AML comes back (relapse), what are the options for me?

☐ Which doctor will be looking after me while I am having this treatment?

☐ How can I prepare myself for treatment?

QUESTIONS & NOTES

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Leukaemia & Blood Cancer New Zealand

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. We do not receive government funding.

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

HAEMATOLOGY CENTRES IN NZ

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

Contacting us

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

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

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PO Box 99182, Newmarket 1149
Auckland, New Zealand

leukaemia.org.nz

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leukaemia & blood cancer NEW ZEALAND

Vision to Cure. Mission to Care.