

# Acute Myeloid Leukaemia (AML)

A guide for patients, families and whānau



our mission is to care, our vision is to cure



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## INTRODUCTION

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

If you or someone you care for 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 different treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

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

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

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

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

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

### Acknowledgements

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# LEUKAEMIA & BLOOD CANCER NEW ZEALAND

Leukaemia & Blood Cancer New Zealand (LBC) is the only organisation in New Zealand dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma and related blood conditions.

Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants. We do not receive government funding.

LBC manages the New Zealand Bone Marrow Donor Registry, which works towards finding matched volunteer donors from New Zealand or overseas for New Zealand patients who need a bone marrow or stem cell transplant and who do not have a family donor. The registry maintains information on New Zealand donors and has access to a worldwide database of over 14 million donors.

## VISION TO CURE - MISSION TO CARE

Within our vision to cure and mission to care Leukaemia & Blood Cancer New Zealand provides:

### Patient Support

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



### Research

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

### Information

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

## Awareness

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

## Advocacy

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

## Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with leukaemia, lymphoma, myeloma or a related blood condition is not easy, but you don't have to do it alone.

Please call **0800 15 10 15** to speak to a local Support Services Coordinator or to find out more about the services offered by Leukaemia & Blood Cancer New Zealand. Alternatively, contact us via email by sending a message to [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz) or by visiting [www.leukaemia.org.nz](http://www.leukaemia.org.nz).

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

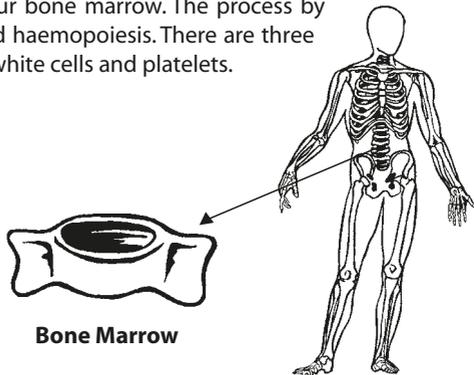


# BONE MARROW, STEM CELLS AND BLOOD CELL FORMATION

## Bone marrow

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

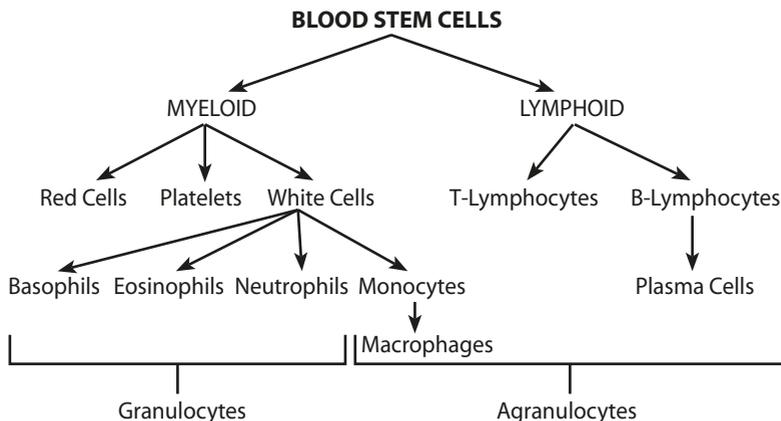
As an infant, haemopoiesis takes place at the centre of all bones. As an adult, fewer new cells are needed - the marrow space in the arms and legs is replaced by fat, and active marrow is limited to the hips, ribs and breastbone (sternum). You may have had a bone marrow biopsy taken from the bone at the back of your hip (the iliac crest) or the breastbone.



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

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

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



## Growth factors and cytokines

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

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

## Blood

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

## Blood cells

### RED CELLS AND HAEMOGLOBIN

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

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

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

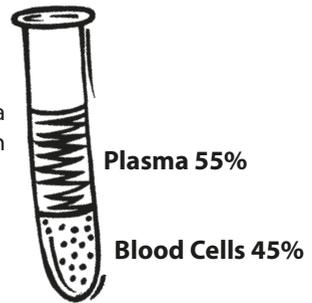
Red cells are by far the most numerous blood cells and the proportion of the blood that is occupied by red cells is called the haematocrit. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

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

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

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

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



## WHITE CELLS

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

### **Granulocytes:**

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

### **Agranulocytes:**

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

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

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

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

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

## PLATELETS

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

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

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

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

## Children

In children, normal blood cell counts vary with age. If your child is being treated for AML you can ask your doctor or nurse for a copy of their blood results, which should include the normal values for each blood type for a male or female child of the same age.

## WHAT IS LEUKAEMIA?

Leukaemia is the general name given to a group of cancers that develop in the bone marrow. Leukaemia originates in developing blood cells, which have undergone a malignant change. This means that they multiply in an uncontrolled way and may not mature as they are supposed to. If they have not matured properly, these cells are unable to function properly. Most cases of leukaemia originate in developing white cells. In a small number of cases leukaemia develops in other blood-forming cells, for example in developing red cells or developing platelets.

### Types of leukaemia

There are several different types, and subtypes of leukaemia.

Leukaemia can be either acute or chronic. The terms 'acute' and 'chronic' refer to how quickly the disease develops and progresses and whether the leukaemia cells are mature or immature.

#### WHAT IS ACUTE LEUKAEMIA?

Under normal conditions the bone marrow contains a small number of immature blood cells, sometimes called blast cells. These immature blood cells develop into mature white cells, red cells and platelets, which are eventually released into the blood stream. In people who have been diagnosed with acute leukaemia, the diseased bone marrow produces an excessive number of abnormal blast cells, called leukaemic blasts. These cells accumulate in the bone marrow interfering with the production of normal blood cells. Without enough red cells, healthy white cells and platelets you can become fatigued, more susceptible to infections, and you may bleed and bruise more easily.

The leukaemic blast cells often spill out of the bone marrow into the blood stream, where they can be detected on a simple blood test. Sometimes leukaemia spreads from the blood to other organs including the lymph nodes (glands), spleen, liver, central nervous system (brain and spinal cord) and testes.

Acute leukaemia develops and progresses quickly and therefore needs to be treated as soon as it is diagnosed. Acute leukaemia affects very immature blood cells, preventing them from maturing properly.

## WHAT IS CHRONIC LEUKAEMIA?

In chronic leukaemia there is an accumulation of more mature but abnormal white blood cells.

Chronic leukaemia progresses more slowly than acute leukaemia and may not require treatment for a long time after it is diagnosed.

There are separate booklets about the different types of chronic leukaemia available from Leukaemia & Blood Cancer New Zealand.

Leukaemia can also be either myeloid or lymphocytic ('lim-fo-cit-ic'). The terms myeloid and lymphocytic refer to the types of cells in which the leukaemia first started.

When leukaemia starts somewhere in the myeloid cell line it is called myeloid leukaemia. This is sometimes called myelocytic, myelogenous or granulocytic leukaemia.

When leukaemia starts somewhere in the lymphoid cell line it is called lymphocytic leukaemia, also known as lymphoblastic or lymphatic leukaemia.

There are four main types of leukaemia:

1. **Acute myeloid leukaemia** (AML)
2. **Acute lymphoblastic leukaemia** (ALL)
3. **Chronic myeloid leukaemia** (CML)
4. **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 700 adults and 40 children are diagnosed with leukaemia.

AML is a relatively rare type of cancer but it is the most common type of acute leukaemia diagnosed in New Zealand adults. AML can also affect children but it more commonly occurs in adults.

Overall, chronic leukaemias are more common in adults than acute leukaemias. Chronic leukaemias rarely occur in children. Chronic lymphocytic leukaemia (CLL) is more than twice as common as chronic myeloid leukaemia (CML).

The most common form of leukaemia in children is acute lymphoblastic leukaemia (ALL), while the most common form of leukaemia in adults is chronic lymphocytic leukaemia (CLL).

## ACUTE MYELOID LEUKAEMIA (AML)

Acute myeloid leukaemia (AML) is a type of cancer that affects immature blood cells on the myeloid cell line. AML causes an overproduction of abnormal blast cells (immature white cells), which crowd the bone marrow and prevent it from making normal blood cells. Because the bone marrow cannot function properly, it cannot produce adequate numbers of red cells, normal white cells and platelets. This makes people with AML more susceptible to anaemia, recurrent infections, bruising and bleeding easily. The abnormal blast cells (leukaemic blasts) eventually spill out into the blood stream and can accumulate in various organs including the spleen and liver.

### WHAT CAUSES AML?

Many people who are diagnosed with AML ask the question “why me?”. Naturally, they want to know what has happened or what they might have done to cause the disease. The truth is that no one knows exactly what causes AML. We do know that it is not contagious. You cannot ‘catch’ AML by being in contact with someone who has it. In most cases people who are diagnosed with AML have no family history of the disease.

There are certain factors that may put some people at a higher risk of developing this disease. These are called risk factors and they are described below.

Like many cancers, damage to special proteins which normally control the growth and division of cells may play a role in the development of AML.

#### **Radiation**

People exposed to large doses of radiation are more likely to develop leukaemias, including AML. These include the survivors of the nuclear bomb blasts in Japan and those exposed to radiation following the Chernobyl nuclear power plant disaster in the Ukraine. People who have previously received large doses of radiation therapy for the treatment of another cancer also have an increased risk of developing AML.

There is some concern that living near high-voltage power lines may increase the risk of developing leukaemia. Currently, there is no clear evidence to support this.

#### **Genetic factors**

Although AML is not inherited, genetic factors may play a role in its development. Some congenital disorders are associated with the development of AML. These include Down syndrome, Bloom syndrome and Fanconi anaemia. In these cases AML tends to develop in childhood or early adolescence. In very rare cases, AML develops because an abnormal gene is passed down from one generation to the next.

## Chemicals

Exposure to high levels of benzene over a long period of time may increase the risk of some blood disorders including leukaemia. People who have been previously treated for cancer using certain types of chemotherapy drugs are more likely to develop AML.

## Smoking

Exposure to cancer-causing substances in tobacco smoke increases the risk of developing AML. About 20 percent of all adult cases of AML are linked to smoking.

## Pre-existing blood disorders

People with pre-existing blood disorders including myelodysplastic disorders, myelofibrosis, aplastic anaemia and paroxysmal nocturnal haemoglobinuria have an increased risk of developing AML. Some people with another type of leukaemia called chronic myeloid leukaemia (CML) may also develop acute leukaemia.

## WHAT ARE THE SYMPTOMS OF AML?

The most common symptoms of AML are caused by a shortage of normal blood cells because the bone marrow is no longer able to function properly. It is overrun with abnormal leukaemic blast cells and unable to produce adequate numbers of normal red cells, white cells and platelets.

Because AML develops quickly, people usually report feeling unwell for only a short period of time before they are diagnosed (days or weeks). The most common symptoms of AML include:

### Anaemia

A low haemoglobin level can cause symptoms of anaemia. These include lack of energy, persistent tiredness and fatigue, weakness, dizziness or feeling unusually short of breath when physically active. In addition, people with anaemia often have a pale complexion.

### Increased bleeding or bruising

A very low platelet count can cause bruising for no apparent reason, or excessive or prolonged bleeding following minor cuts or injury. Some people notice frequent or severe nose bleeds or bleeding gums and some women may have unusually heavy menstrual periods. Red or purple pinhead-sized spots may appear on the skin, especially on the legs. These are called petechiae ('pe-tee-key-eye') and they are caused by tiny bleeds under the skin.

## Frequent or repeated infections

People with AML don't have enough normal white blood cells so they are more likely to develop frequent or repeated infections. These may present as minor skin infections, slow healing of minor cuts and grazes, a sore throat, sore mouth, persistent coughing, urinary tract infections (frequent passing of urine with a sensation of burning) and often fevers.

Less common symptoms of AML may include bone pain, swollen lymph nodes, swollen gums, chest pain and abdominal discomfort due to a swollen spleen or liver.

Occasionally people have no symptoms at all and AML is discovered during a routine blood test.

Some of the symptoms described above may also be seen in other illnesses, including viral infections. Therefore most people with these symptoms will not have leukaemia. However, it is important to see your doctor if you have any unusual symptoms, or symptoms that don't go away so that you can be examined and treated appropriately.

## WHICH DOCTOR?

If your GP suspects that you might have leukaemia you will be referred to another specialist doctor called a haematologist for further tests and treatment. A haematologist is a doctor who specialises in the care of people with diseases of the blood, bone marrow and immune system.



## HOW IS AML DIAGNOSED?

AML is diagnosed by examining samples of your blood and bone marrow.

### Full blood count

The first step in diagnosing AML requires a simple blood test called a full blood count (FBC), also known as a complete blood count (CBC). This involves taking a sample of blood from a vein in your arm, and sending it to the laboratory for examination under the microscope. The number of red blood cells, white blood cells and platelets, and their size and shape, is noted as these can all be abnormal in AML.

Most people with AML have a low red cell count, low haemoglobin level, and a low platelet count. Many of the white blood cells may be abnormal leukaemic blast cells. The presence of leukaemic blast cells in your blood suggests that you have AML. A diagnosis of AML needs to be confirmed by examining the cells in your bone marrow.

Your full blood count will be checked regularly both during and after treatment to see how well the disease is responding.

## Bone marrow examination

A bone marrow examination involves taking a sample of bone marrow, usually from the back of the iliac crest (hip bone) or from the sternum (breast bone) and sending it to the laboratory for examination under the microscope. A diagnosis of AML is confirmed by the presence of an excessive number of blast cells in the bone marrow. In healthy adults the bone marrow contains less than five percent of blast cells but this can increase to between 20 percent and 95 percent in people who have been diagnosed with AML.

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

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

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

Once a diagnosis of AML is made, blood and bone marrow cells are examined further using special laboratory tests. These include immunophenotyping, cytogenetic and molecular tests.

These tests provide more information about the exact type of disease, the likely course of the disease and the best way to treat it.

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

This test detects special markers, called antigens, found on the surface of blast cells to determine the exact subtype of AML you have.

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

Cytogenetic tests provide information about the genetic make-up of the leukaemic cells, in other words, the structure and number of chromosomes present. Chromosomes are the structures that carry genes. Genes are collections of DNA, our body's blueprint for life. Certain cytogenetic changes, such as missing, extra or abnormal chromosomes help to confirm the specific subtype of AML you have, its likely course and the best way to treat it. These chromosomal changes are only found in the leukaemic cells. They are not passed down from parent to child (inherited). Instead, they are acquired over time.

**Molecular tests**

Molecular tests are more specific and sensitive than cytogenetic tests. They allow detection of certain gene mutations seen in some subtypes of AML and can help predict response to treatment. The number of gene mutations found to be associated with AML is increasing all the time.

Following treatment, you will need another bone marrow examination to assess how well the disease is responding to treatment.

**Other tests**

Other tests provide information on your general health and how well your kidneys, liver and other vital organs are functioning. These include a combination of blood tests and imaging tests. These tests are important because they provide a baseline set of results regarding your disease and general health. These results may be important in selecting the best treatment for you. They can also be compared with later results to assess how well you are progressing.

OTHER BLOOD TESTS

- kidney function tests
- liver function tests
- coagulation tests (to see if your blood is clotting properly)

IMAGING TESTS

- chest x-ray (to detect a chest infection or any other abnormalities)
- electrocardiogram (ECG) and echocardiogram  
(to see how well your heart is working)

Occasionally a CT (computer assisted tomography) scan or ultrasound scan may be used to see if the leukaemia cells have spread to areas outside the blood and bone marrow.

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



## WHICH TYPE OF AML DO I HAVE?

AML is not a single disease. It is the name given to a group of leukaemias that develop in the myeloid cell line in the bone marrow. Some years ago doctors from France, America and Great Britain decided to classify AML into eight different subtypes based on the appearance of the leukaemic cells under the microscope. Each subtype provides information on the type of blood cell involved and the point at which it stopped maturing properly in the bone marrow. This is known as the French-American-British (FAB) classification system.

The current World Health Organization's classification system for AML uses additional information, obtained from more specialised laboratory techniques (such as genetic studies) to classify AML more precisely. This also provides more reliable information regarding the likely course (prognosis), of a particular subtype of AML, and the best way to treat it.

The most important factor in predicting prognosis in AML is the genetic make-up of the leukaemic cells. Certain cytogenetic and/or molecular changes are associated with a more favourable prognosis than others. This means that they are more likely to respond well to treatment, and may even be cured. Favourable cytogenetic changes include: a translocation between chromosome 8 and 21 (t(8;21)), inversion of chromosome 16 (inv(16)); and a translocation between chromosome 15 and 17; (t(15;17)). This final change is found in a subtype of AML called acute promyelocytic leukaemia (also known as APML or AML M3). APML is treated differently to other types of AML, and usually has the best overall prognosis.

Other cytogenetic and/or molecular changes are associated with an average or intermediate prognosis, while others still are associated with a poor, or unfavourable prognosis. It is important to note that in most cases of AML (approximately 40%), neither 'good-risk' or 'bad-risk' cytogenetic changes are found. People with 'normal' cytogenetics have been typically regarded as having an average prognosis, however, newer molecular markers such as FLT-3 and NPM-1 are helping to group individuals further into those with a more favourable or more unfavourable outlook with treatment.

Some subtypes of AML are associated with specific symptoms. For example, in some subtypes of AML, leukaemic cells can spread from the blood stream into other parts of the body like the gums, causing swelling and discomfort in this area. Acute promyelocytic leukaemia (APML or AML M3) is associated with bleeding and abnormalities in blood clotting.

## PROGNOSIS

A prognosis is an estimate of the likely course of a disease. It provides some guide regarding the chances of curing the disease or controlling it for a given time.

Certain factors (known as prognostic factors) give some people a better chance of being cured of the disease with treatment than others. As mentioned above, the genetic make-up of the leukaemic cells is the most important factor in predicting prognosis in AML. Other factors include age, white cell count at diagnosis, the history of a pre-existing blood disorder or the use of chemotherapy to treat another type of cancer in the past.

In general, older people and people with a high white blood cell count at diagnosis have a poorer prognosis. Having a pre-existing blood disorder, or AML that developed following treatment for another type of cancer, is also associated with a poorer prognosis.

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

### Commonly used terms

The following terms may be used to describe how well AML has responded to treatment.

**Cure** - This means that there is no evidence of leukaemia and no sign of it reappearing, even after many years. With treatment, more and more people who have AML are being cured of their disease.

**Complete remission** - This means that the treatment has been successful and that so much of the leukaemia has been destroyed that it can no longer be detected under a microscope. The proportion of blast cells in the marrow has been reduced to less than 5 percent. There are no blast cells present in the circulating blood and the blood count has returned to normal. Some people may never relapse while others may have a higher chance of relapse. The length of time that a remission lasts varies from person to person.

**Relapse** - The leukaemia has reappeared or recurred.

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

## TREATING AML

The treatment chosen to treat AML will depend on several factors including the exact type of leukaemia you have, your age, other prognostic factors and your general health.

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

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

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

Because AML progresses so quickly, treatment needs to begin as soon as it is diagnosed. Treatment for AML can be divided into two phases:

- induction therapy
- consolidation (post-remission) therapy

### Chemotherapy

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxics (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells. Chemotherapy for AML often involves a combination of drugs (combination chemotherapy). These drugs act together and in different ways to destroy the leukaemic cells. The names of combinations are commonly derived from the first letters of each drug used. Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks between each cycle. This is to allow the body to recover from the side effects of chemotherapy.

Initially, chemotherapy is given to bring about, or induce, a remission. This means reducing the proportion of blast cells in the bone marrow to less than 5 percent, removing them completely from the circulating blood and returning the blood count to normal. This is the first phase of treatment for AML and it is known as induction therapy.

Once a remission has been achieved more treatment is needed to help prevent the leukaemia from reappearing, and in many cases to try to achieve a cure. This second phase of treatment is called post-remission, post-induction or consolidation therapy.

### INDUCTION THERAPY

Induction therapy commonly involves the use of a combination of chemotherapy drugs. In one commonly used combination, a chemotherapy drug called cytarabine (also known as cytosine arabinoside, or ara-C) is given each day for seven days together with an anthracycline drug (for example, daunorubicin or idarubicin) each day for three days. Another chemotherapy drug called etoposide (also known as VP-16) may also be used. In some cases high-dose cytarabine (also known as high-dose ara-C, HIDAC) is given alone or with other chemotherapy drugs as induction therapy.

These drugs are usually given as intravenous (IV) infusions through a central venous catheter (or central line). A central venous catheter is a special line inserted through the skin, into a large vein in your arm, neck or chest. Once it's in place, chemotherapy and any other IV drugs can be given through the line and blood tests can also usually be taken from the line without the need for frequent needle pricks. There are several different kinds of central lines used; some are intended for short-term use while others can remain in place for months or even years. Examples of lines used include Hickman lines, Groshong lines and PICC lines.

While you are having induction therapy you may also be given a drug called allopurinol. This is not a chemotherapy drug. It is used to help prevent a build-up of waste products of the destroyed leukaemic cells and to help your kidneys excrete them safely.

### CONSOLIDATION THERAPY

Once remission has been achieved, some form of consolidation therapy is given to reduce the risk of the leukaemia coming back. The type of consolidation treatment used will depend on several factors including the type of disease involved, how well the disease responded to induction therapy, your age and your general health.

One approach to consolidation therapy involves using similar chemotherapy drugs to those used as induction therapy, at the same or higher doses. In some cases, where there is a high risk that the leukaemia will relapse, patients may be offered even more intensive therapy followed by a stem cell transplant.

### TREATMENT OF ACUTE PROMYELOCYTIC LEUKAEMIA (APML)

The treatment of acute promyelocytic leukaemia (also known as APML or AML M3) differs from the treatment of other types of acute leukaemia because it involves the use of a drug called all-trans retinoic acid (ATRA). ATRA is not a chemotherapy drug, it is a derivative of Vitamin A which works by making the immature promyelocytes (the identifiable leukaemic cells in APML) mature properly. This drug is used alone or in combination with chemotherapy to induce a remission. In most cases you will need to be admitted to hospital for induction chemotherapy.

## NON-INTENSIVE TREATMENT / TREATMENT FOR OLDER ADULTS

The best quality of life for people with AML is generally achieved by getting the leukaemia into remission. This is so that normal bone marrow function and blood counts can be restored. It is common in older adults for the cytogenetic and/or molecular test results to predict that remission is unlikely to be achieved with intensive chemotherapy, or that poor health makes this intensive treatment too dangerous. If this is the case, intensive induction chemotherapy may not be considered appropriate and a decision made to consider non-intensive or low dose chemotherapy as an alternative.

These treatments are usually considered palliative, with the aim of slowing down the growth of the leukaemia without causing too many side effects. Cure is not a realistic goal with this treatment. The chemotherapy is given as an outpatient and is generally well tolerated. Examples of this include low dose Ara-C or cytarabine (usually given twice daily as an injection under the skin for 10 days, repeated every 6 weeks) or hydroxyurea (taken orally to control a rising leukaemia cell count in the blood). Some people may respond very well to these treatments and have a prolonged period of disease control.

### **Stem cell transplantation**

For some people very high doses of chemotherapy or radiotherapy are needed to more effectively treat their AML. As a side effect of these treatments, normal bone marrow and blood stem cells are also destroyed and need to be replaced afterwards. In these cases a bone marrow or peripheral blood stem cell transplant is used.

A stem cell transplant is usually only offered if your haematologist feels that it will be of benefit to you.

Younger patients who have a suitably matched donor may be offered an allogeneic (donor) stem cell transplant when they have achieved their first remission from AML. This involves the use of very high doses of chemotherapy, with or without radiotherapy, followed by infusion of blood stem cells which have been donated by a suitably matched donor. Due to the potential toxicities of this type of treatment it is not generally suitable for older patients.

Another option involves collecting your own stem cells, usually from your blood stream, storing them and then giving them back after you have received high doses of chemotherapy. This type of treatment is called an autologous stem cell transplant. It may be more suitable for older patients and those who do not have a suitable donor.

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

## Relapsed disease

Finding out that your leukaemia has relapsed can be devastating, but there are usually ways of getting it back under control.

Relapse is most likely in patients with 'bad-risk' cytogenetic or molecular markers. Relapsed AML tends to be more resistant to treatment than the original disease.

The time of relapse is significant. Patients who relapse a long time after therapy have a better chance of responding to re-treatment and tend to have a higher incidence and duration of second remissions. During this period they will be considered for a transplant if they have not already received one.

Age is another important factor in determining the success of re-treatment. The chances of successful re-induction and a reasonable prospect of a disease free time is better in young patients and gets poorer with increasing age.

Most relapses occur within the first two years. Although the chance of relapse becomes progressively less with time, particularly once all treatment has been completed, late relapses can occur.

## Palliative care

If a decision is made not to continue with anti-cancer treatment (chemotherapy and radiotherapy) for leukaemia there are still many things that can be done to help people to stay as healthy and comfortable as possible for a time.

Palliative care is aimed at relieving any symptoms or pain a person might be experiencing as a result of their disease or its treatment, rather than trying to cure or control it.

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

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

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

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

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

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

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

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

## Side effects of chemotherapy

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

The type of side effects and their severity varies from person to person, depending on the type of chemotherapy used and how an individual responds to it. There is no doubt that side effects can be very unpleasant at times but it's good to remember that most of them are temporary and reversible. It is important that you report any side effects you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

### EFFECTS ON THE BONE MARROW

As mentioned previously, AML prevents your bone marrow from functioning properly and producing adequate numbers of red blood cells, normal white blood cells and platelets. Chemotherapy also temporarily affects the bone marrow's ability to produce adequate numbers of blood cells. As a result, your blood count (the number of white cells, platelets and red cells circulating in your blood) will generally fall within a week of treatment. The length of time it takes for your bone marrow and blood counts to recover mainly depends on the type of chemotherapy given.

Your **platelet count** may also be affected and you may become thrombocytopenic (a reduction in the number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time it is helpful to avoid sharp objects in your mouth such as chop bones or potato chips as these can cut your gums. Using a soft toothbrush also helps to protect your gums. In many cases a transfusion of platelets is given to reduce the risk of bleeding until the platelet count recovers.

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

The point at which your **white cell count** is at its lowest is called the nadir. This is usually expected early on after having your chemotherapy, during which time you will be at a higher risk of developing an infection. At this stage you will also be neutropenic, which means that your neutrophil count is low. Neutrophils are important white blood cells that help us to fight infection. While your white blood cell count is low you should take sensible precautions to help prevent infection. These include avoiding crowds, avoiding contact with people with infections that are contagious (for example colds, flu, chicken pox) and only eating food that has been properly prepared and cooked.

Your doctor and nurse will advise you on how to reduce your risk of infection while your white cell count is low.

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

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

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

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

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

### NAUSEA AND VOMITING

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

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

#### CHANGES IN TASTE AND SMELL

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

#### MUCOSITIS

Mucositis, or inflammation of the lining of the mouth and throat, is a common and uncomfortable side effect of chemotherapy and some forms of radiotherapy. It usually starts about a week after the treatment has finished and goes away once your blood count recovers, usually a couple of weeks later. During this time your mouth and throat could get quite sore. Oral pain relief and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger pain killers might be needed.

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

#### BOWEL CHANGES

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

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

## HAIR LOSS

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

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



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

Look Good ... Feel Better is a free community service that runs programs on how to manage the appearance-related side effects of cancer treatments. The beauty therapists who run these programs give useful advice and demonstrations on how to manage hair loss including the use of hats, wigs, scarves or turbans. You might like to find out more or register for a workshop, call 0800 865 432.

## FATIGUE

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

## FERTILITY

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

Some types of chemotherapy and radiotherapy may cause a temporary or permanent reduction in your fertility. Standard treatment for AML often leaves patients infertile, however, it is important to be aware that this is not always the case and some people are able to become parents in the future. Adequate contraception should always be used. It is very important that you discuss any questions or concerns you might have regarding your future fertility with your doctor before you commence treatment.

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

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

### **Protecting your fertility - Men**

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

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

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

### Protecting your fertility - Women

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

**Embryo storage** - this involves collecting your eggs, usually after taking drugs to stimulate your ovaries to produce a number of eggs, so that more than one egg can be collected. This process takes at least several weeks and this can be a problem if your treatment needs to start immediately. Once the eggs are collected they are then fertilised with your partner's sperm and stored to be used at a later date. Your unfertilised eggs can also be collected and stored in a similar manner (egg storage).

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

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

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

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

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

### EARLY MENOPAUSE

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

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

## MENSTRUATION

Cancer treatment can also affect your periods. You may find your periods stop or become irregular. You may be prescribed a birth control pill to stop your periods. This prevents heavy bleeding and blood loss when your platelets are low. It is best to use pads instead of tampons if you are menstruating as this will reduce the risk of infections. Always let your doctor or nurse know if you are having your period and if there are any changes to your cycle. If appropriate, he or she may be able to refer you to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

## **BODY IMAGE, SEXUALITY AND SEXUAL ACTIVITY**

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

During treatment you may experience a decrease in libido, which is your body's sexual urge or desire, sometimes without there being any obvious reason. It may take some time for things to return to 'normal'. It is perfectly reasonable and safe to have sex while you are having treatment or shortly afterwards, but there are some precautions you need to take. It is usually recommended that you or your partner do not become pregnant as some of the treatments given might harm the developing baby. As such, you need to ensure that you or your partner uses a suitable form of contraception. Condoms (with a spermicidal gel) offer good contraceptive protection as well as protection against infection or irritation. Your partner may be worried that sex might in some way harm you. This is not likely as long as your partner is free

from any infections and the sex is relatively gentle. Finally, if you are experiencing vaginal dryness, a lubricant can be helpful. This will help prevent irritation. Using a condom is also important to protect your partner from chemotherapy drugs that can be excreted in body fluids in the first few days after they are administered.

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



## COMPLEMENTARY THERAPIES

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

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

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

## NUTRITION

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

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



## MAKING TREATMENT DECISIONS

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

Before your appointment with your haematologist, make a list of the questions you want to ask. It may be useful to keep a notebook or some paper and a pen by your bedside as many questions are thought of in the early hours of the morning.

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

Your doctor will spend time with you and your family discussing what he or she feels is the best option for you. Feel free to ask as many questions as you need to, at any stage. You are involved in making important decisions regarding your wellbeing. You should feel that you have enough information to do this and that the decisions made are in your best interests. Remember, you can always request a second opinion if you feel this is necessary. However, it is important not to delay starting treatment for AML as this disease progresses rapidly without treatment and can quickly become life-threatening.

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

### Interpreting services

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

There are resources available from Leukaemia & Blood Cancer New Zealand in languages other than English.



## INFORMATION AND SUPPORT

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

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

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

Many people are concerned about the social and financial impact of the diagnosis and treatment on their families. Normal family routines are often disrupted and other members of the family may suddenly have to fulfil roles they are not familiar with, for example, cooking, cleaning, and taking care of children.

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

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



## USEFUL INTERNET ADDRESSES

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

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

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

[www.leukaemia.org.nz](http://www.leukaemia.org.nz)

[www.lifebloodlive.org.nz](http://www.lifebloodlive.org.nz)

### **Cancer Society of New Zealand**

[www.cancernz.org.nz](http://www.cancernz.org.nz)

### **Leukaemia Foundation of Australia**

[www.leukaemia.org.au](http://www.leukaemia.org.au)

### **American Cancer Society**

[www.cancer.org](http://www.cancer.org)

### **MacMillan Cancer Support (A UK cancer information site)**

[www.macmillan.org.uk](http://www.macmillan.org.uk)

### **Leukemia & Lymphoma Society of America**

[www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org)

### **Leukaemia & Lymphoma Research (UK)**

[www.llresearch.org.uk](http://www.llresearch.org.uk)

### **National Cancer Institute (USA)**

[www.cancer.gov/cancerinfo](http://www.cancer.gov/cancerinfo)

## GLOSSARY OF TERMS

### **Alopecia**

Hair loss. Usually temporary when due to chemotherapy or radiotherapy treatment.

### **Anaemia**

Deficiency of red blood cells which results in a reduced level of the oxygen carrying pigment, haemoglobin, in the blood. 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 (nausea) and vomiting.

### **Antigen**

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

### **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.

### **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.

### **Blood count**

A routine blood test that measures the number and type of cells circulating in the blood.

### **Cancer**

A disease characterised by uncontrolled production, accumulation and maturation of cells; often called malignant disease or neoplasm. Cancer cells grow and multiply, eventually causing a mass of cancer cells known as a tumour.

### **Cannula**

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

**Central venous catheter (CVC)**

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

**Chemotherapy**

Treatment using anti-cancer drugs. Single drugs or combinations of drugs may be used to kill and prevent the growth of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and therefore causes some common side effects including hair loss, nausea and vomiting, and mucositis. The side effects of chemotherapy are usually temporary and reversible.

**Complete remission**

Anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology. In people with leukaemia this means that proportion of blast cells in the marrow has been reduced to less than five percent. There are no blast cells present in the circulating blood and the blood count has returned to normal.

**Computer assisted tomography (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**

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

**Disease progression**

This means that the disease is getting worse despite treatment.

**Echocardiogram**

A special ultrasound scan of the heart.

**Electrocardiogram (ECG)**

Electrical trace of the heart.

**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. For example G-CSF (granulocyte colony stimulating factor).

**Haemopoiesis**

The formation of blood cells. Also referred to as haematopoiesis.

**Haematologist**

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

**Hickman line**

A type of central venous catheter (see above) sometimes used for patients undergoing intensive treatment including bone marrow or peripheral blood cell transplantation. 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.

**Immune system**

The body's defense system against infection and disease.

**Immune suppression**

The use of drugs to reduce the function of the immune system.

**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 / or 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 millions of very small lymph nodes in all organs of the body.

**Lymphoid**

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

**Lymphocytes**

Specialised white 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.

**Malignancy**

(See cancer)

**Mucositis**

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

**Myelodysplastic syndromes**

These are a group of blood diseases that affect normal blood cell production in the bone marrow.

**Myeloid**

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.

**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.

**Prognosis**

An estimate of the likely course of a disease.

**Radiotherapy (radiation therapy)**

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

**Relapse**

The return of the original disease.

**Resistant or refractory disease**

This means that the disease is not responding to treatment.

**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.

**Stem cells**

Stem cells are primitive blood cells that can give rise to more than one cell type. There are many different types of stem cell in the body. Bone marrow (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 (haemopoietic or blood stem cell transplant)**

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.

**Standard therapy**

The most effective and safest therapy currently being used.

**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.

**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.

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

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

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| <input type="checkbox"/> Dictionary of Terms   | <input type="checkbox"/> Acute Lymphoblastic Leukaemia in Adults   |
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Send to: Leukaemia & Blood Cancer New Zealand  
 PO Box 99182, Newmarket, Auckland 1149  
 Phone: 09 638 3556 or 0800 15 10 15  
 Email: [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz)

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



# Acute Myeloid Leukaemia

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

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**7. Any other comments?**

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

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

## Contact details of Haematology Centres throughout NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road Whangarei	(09) 430 4100
North Shore Hospital	Shakespeare Road Takapuna	(09) 486 1491
Auckland Hospital	Park Road Grafton	(09) 379 7440
Starship Hospital	Park Road Grafton	(09) 379 7440
Middlemore Hospital	Hospital Road Otahuhu	(09) 276 0000
Waikato Hospital	Pembroke Street Hamilton	(09) 839 8899
Thames Hospital	Mackay Street Thames	(07) 868 6550
Tauranga Hospital	Cameron Road Tauranga	(07) 579 8000
Hastings Hospital	Omahu Road Hastings	(06) 878 8109
Rotorua Hospital	Pukeroa Street Rotorua	(07) 348 1199
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
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



our mission is to care, our vision is to cure

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