



Leukaemia
Foundation

VISION TO CURE
MISSION TO CARE

Acute Myeloid Leukaemia (AML)

A guide for patients and families



1800 620 420



leukaemia.org.au

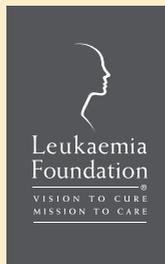
Acknowledgments

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People who have experienced AML as a patient or carer, Leukaemia Foundation blood cancer support staff, haematology nursing staff and clinical haematologists.

The Leukaemia Foundation values feedback from people affected by AML and the health care professionals working with them. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact the Head of Blood Cancer Support at info@leukaemia.org.au

June 2015



Introduction

This booklet has been written to help you and your family to understand more about AML.

Some of you may be feeling anxious or a little overwhelmed if you or someone you care for has been diagnosed with AML. 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 which you may not be familiar with. Their meaning is explained in the booklet and/or in the glossary of terms at the back of the booklet.

Some of you 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 treating hospital.

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

Finally, we hope that you find this booklet useful and we would appreciate any feedback from you so that we can continue to serve you and your families better in the future.

The Leukaemia Foundation

The Leukaemia Foundation is Australia's peak body dedicated to the care and cure of patients and families living with leukaemia, lymphoma, myeloma and related blood disorders.

Since 1975, the Foundation has been committed to improving survival for patients and providing much needed support. The Foundation does not receive direct ongoing government funding, relying instead on the continued and generous support of individuals and corporate supporters to develop and expand its services.

The Foundation provides a range of support services to patients at no cost. This support may be offered over the telephone, face to face or online depending on the geographical and individual needs. Support may include providing information, patient education seminars and programs that provide a forum for peer support and consumer representation, practical assistance, accommodation, transport and emotional support/counselling.

The Leukaemia Foundation also funds leading research into better treatments and cures for AML and related blood disorders. The Foundation supported the establishment of the ALLG Discovery Centre at the Princess Alexandra Hospital, and the Leukaemia Foundation Research Unit at the Queensland Institute for Medical Research. The Foundation also funds research grants, scholarships and fellowships for talented researchers and health professionals as part of its national research program.



Foundation staff with health professional qualifications provide patients and their families with information and support across Australia.

Support Services

The Leukaemia Foundation has a team of highly trained and caring Support Services staff with qualifications and experience in nursing or allied health that work across the country.

We can offer individual support and care to you and your family when it is needed.

Support Services may include:

Information

The Foundation has a range of booklets, DVDs, fact sheets and other resources that are available at no cost. These can be ordered via the form at the back of this booklet or downloaded from the website.

Education & Support programs

The Leukaemia Foundation offers you and your family disease-specific and general education and support programs throughout Australia. These programs are designed to empower you with information about various aspects of diagnosis and treatment and how to support your general health and wellbeing.

Emotional support

A diagnosis of AML can have a dramatic impact of a person's life. At times it can be difficult to cope with the emotional stress involved. The Leukaemia Foundation's blood cancer support staff can provide you and your family with much needed support during this time.



Blood Buddies

This is a program for people newly diagnosed with AML to be introduced to a trained 'buddy' who has been living with AML for at least two years, to share their experience, their learning, and to provide some support.

Transport

The Foundation also assists with transporting people to and from hospital for treatment. Courtesy cars and other services are available in many areas throughout the country.

Accommodation

Some people need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation's staff can help you to find suitable accommodation close to your hospital or treatment centre. In many areas, the Foundation's fully furnished self-contained units and houses can provide a 'home away from home' for you and your family.

With the cost of hospital car parking and how difficult it can be to find a car park, the Foundation's transport service has made my hospital visits so much easier.

The health system can feel so big and overwhelming. Sometimes I don't even know what questions to ask to get what I need. The Foundation's staff help by pointing me in the right direction.

Practical assistance

The urgency and lengthy duration of medical treatment can affect everyday life for you and your family and there may be practical things the Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for people who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

Advocacy

The Leukaemia Foundation is a source of support for you as you navigate the health system. While we do not provide treatment recommendations, we can support you while you weigh up your options. We may also provide information on other options such as special drug access programs, and available clinical trials.

Contacting us

The Leukaemia Foundation provides services and support in every Australian state and territory. Every person's experience of living with AML is different. Living with AML is not always easy, but you don't have to do it alone. Please call **1800 620 420** to speak to a local support service staff member or to find out more about the services offered by the Foundation. Alternatively, contact us via email by sending a message to **info@leukaemia.org.au** or visit **www.leukaemia.org.au**

Leukaemias

In this section of our booklet we provide a brief overview of leukaemia. It is important to point out that the information provided here is of a general nature and may not necessarily apply to the specific type or severity of disease you or your loved one has.

AML occurs in cells that originate in the bone marrow and are defined by the uncontrolled growth of faulty cells.

To best understand these cancers we first need to understand the bone marrow, stem cells and blood.

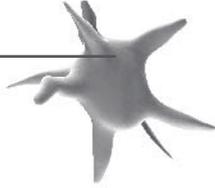
Red Blood Cells

Carry oxygen for the body to produce energy



Platelets

Support blood clotting to stop bleeding



White Blood Cells

Form part of the immune system



Getting to know your bone marrow, stem cells and blood

Bone marrow

Bone marrow is the spongy tissue that fills the cavities inside your bones. Most of your blood cells are made in your bone marrow.

The process by which blood cells are made is called *haematopoiesis*. There are three main types of blood cells; red cells, white cells and platelets.

As an infant, haematopoiesis takes place at the centre of all bones. In later life, it is limited mainly to the hips, ribs and breast bone (sternum). Some of you may have had a bone marrow biopsy taken from the bone at the back of your hip (the iliac crest).

You might like to think of the bone marrow as the blood cell factory.

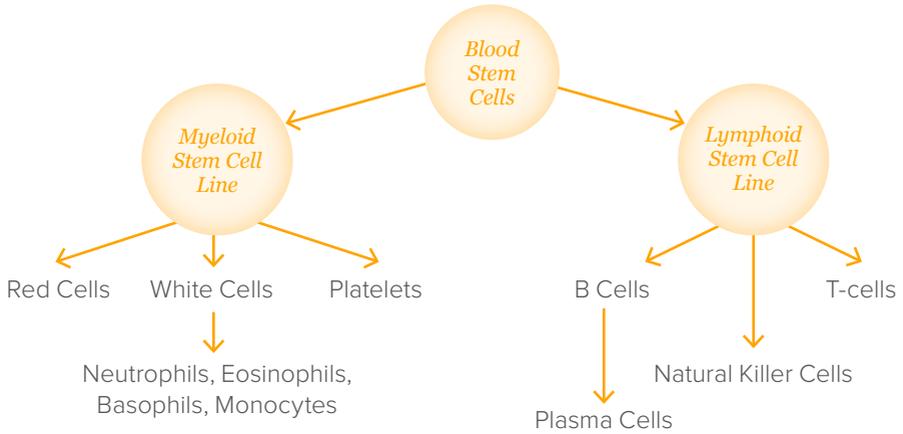
The main workers at the factory are the *stem cells*. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of red cells, white cells and platelets. All blood cells need to be replaced because they have limited life spans.

There are two main families of stem cells, which develop into the various types of blood cells.

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

Lymphoid ('lim-foid') stem cells develop into other types of white cells including T-cells, B-cells and Natural Killer Cells.

Blood cell formation:



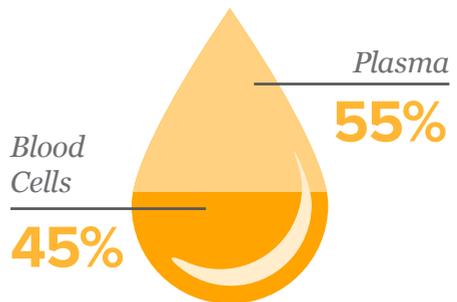
Growth factors and cytokines

All normal blood cells have a limited lifespan in the circulation and need to be replaced on a continual basis. This means that the bone marrow remains very active throughout life. Natural chemicals circulating in your blood called growth factors, or cytokines, control this process of blood cell formation. Each of the different blood cells is produced from stem cells under the guidance of a different growth factor.

Some of the growth factors can now 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 certain white cells, including *neutrophils*, while erythropoietin (EPO) stimulates the production of red cells.

Blood

Blood consists of blood cells and plasma. Plasma is a straw-coloured fluid that blood cells use to travel around your body and also contains many important proteins and chemicals.



Blood cells

Red cells and haemoglobin

Red cells contain haemoglobin (Hb) which gives the blood its red colour and transports oxygen from the lungs to all parts of the body. The body uses this oxygen to create energy.

Haematocrit

About 99 per cent of all blood cells in circulation are red blood cells. The percentage of the blood that is occupied by red blood cells is called the haematocrit. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

Anaemia

Anaemia is a reduction in the number of red cells or low haemoglobin. Measuring either the haematocrit or the haemoglobin will provide information regarding the degree of anaemia.

If you are anaemic you may feel rundown 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 blood transfusion may be given to restore the red blood cell numbers and therefore the haemoglobin to more normal levels.

Normal ranges for adults:

	 Men	 Women
<i>Haemoglobin (Hb)</i>	130 – 170 g/L	120 – 160 g/L
<i>Haematocrit (Hct)</i>	40 – 52%	36 – 46%
<i>White cell count (WBC)</i>	3.7 – 11.0 × 10 ⁹ /L	
<i>Neutrophils (neut)</i>	2.0 – 7.5 × 10 ⁹ /L	
<i>Platelets (Plt)</i>	150 – 400 × 10 ⁹ /L	

White cells

White cells, also known as leukocytes, fight infection. The following is a list of some of the different types of white cells:

Neutrophils: Mainly kill bacteria and remove damaged tissue. Neutrophils are often called the first line of defence when infections occur. They are often the first white blood cell at the site of infection and attempt to destroy the foreign pathogen before it becomes a problem to the body.

Eosinophils: Mainly kill parasites

Basophils: Mainly work with neutrophils to fight infection

Monocytes: Mainly work with neutrophils and lymphocytes to fight infection; they also act as scavengers to remove dead tissue. These cells are known as monocytes when found in the blood, and called macrophages when they migrate into body tissue to help fight infection.

B-cells: Mainly make antibodies that target micro-organisms, particularly bacteria.

T-cells: Mainly kill viruses, parasites and cancer cells and produce cytokines which can recruit other cells to make antibodies which target micro-organisms.

These white cells work together to fight infection as well as having unique individual roles in the fight against infection.



Neutropenia

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than $1 (1 \times 10^9/L)$, you are at an increased risk of developing more frequent and sometimes severe infections.

Platelets

Platelets are cellular fragments that circulate in the blood and play an important role in clot formation. They help to prevent bleeding.

If a blood vessel is damaged (for example by a cut) the platelets gather at the site of the injury, stick together and form a plug to help stop the bleeding. They also release chemicals, called clotting factors that are required for the formation of blood clots.

Thrombocytopenia

Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops too low, you are at an increased risk of bleeding and tend to bruise easily. Each treatment centre will have their own guidelines on the specific platelet count level when interventions may need to be taken. Platelet transfusions are sometimes given to return the platelet count to a safer level.

To reduce infections, regular washing of my hands has become part of my new normal.

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.

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 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, normal white cells and platelets you can become fatigued, more susceptible to infections, and you may bleed and bruise more easily.

The leukaemic blasts often spill out of the bone marrow into the blood stream, where they can be detected using a simple blood test.

Sometimes leukaemia spreads from the blood to other organs including the lymph nodes (glands), spleen, liver, central nervous system (brain, spinal cord or spinal fluid), skin and testes.

Acute leukaemia develops and progresses quickly and therefore needs to be treated as soon as it is diagnosed.

What is chronic leukaemia?

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

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

When leukaemia starts somewhere in the myeloid cell line it is called myeloid (or myelogenous) leukaemia.

When leukaemia starts somewhere in the lymphoid cell line it is called lymphocytic (or lymphoblastic) 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 Australia around 3,200 adults and 250 children are diagnosed with leukaemia.

Of these around 900 adults and around 50 children are diagnosed with the type of leukaemia called acute myeloid leukaemia (AML).

AML is a relatively rare type of cancer but it is the most common type of acute leukaemia diagnosed in Australian adults, with the incidence rising sharply with increasing age over 60. AML can also affect children but it more commonly occurs in adults, with over half those affected over the age of 60 at diagnosis.



Acute myeloid leukaemia (AML)

Acute myeloid leukaemia (AML) is a type of cancer that increases the number of immature myeloid blood cells. 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 and to bruising and bleeding easily. The abnormal blast cells (leukaemic blasts) eventually spill out into the blood stream and can accumulate in various organs like the spleen and liver.

Causes

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 their 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.

The bone marrow produces about 100 billion circulating blood cells each day. Dividing blast cells are prone to acquiring errors in the DNA code, which must also be copied into each new cell. These errors accumulate with age, therefore making older people more prone to diseases like AML, which develops from the accumulation of DNA errors in critical genes controlling cell growth, survival and division.

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 DNA which normally controls 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 like AML. These include the survivors of the nuclear bombs in Japan and those exposed to radiation following the Chernobyl nuclear power plant disaster in the Ukraine. More commonly, people who have previously received radiation therapy for the treatment of another cancer may also develop what is called therapy-related AML.

Genetic factors

Although AML is commonly not inherited, genetic factors may play a role in its development. Some congenital disorders are associated with the development of AML. These include Down's syndrome, Bloom's syndrome and Fanconi's 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. These familial forms of AML should be suspected when there are several first-degree family members affected and may be diagnosed using DNA sequencing technologies in specialised centres.

Chemicals

Exposure to high levels of benzene over a long period of time may increase the risk of some blood cancers like 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 per cent of all adult cases of AML are linked to smoking.

Pre-existing blood disorders

People with pre-existing blood disorders including myelodysplastic disorders and myeloproliferative neoplasms have an increased risk of developing secondary AML.

Symptoms

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 flat pinhead sized spots may appear on the skin, especially on the legs. These are called petechiae ('pe-tee-chi-a') 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, coughing, urinary tract infections (frequent passing of urine with a sensation of burning) and often fevers.

Other symptoms

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. So, most people with these symptoms don't 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 properly.



Diagnosis

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) or full blood examination (FBE). 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.

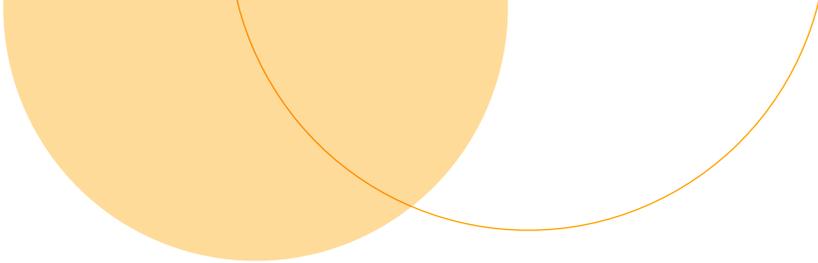
Most people with AML have a low red cell count, low haemoglobin level, low neutrophils and a low platelet count. Many of the white blood cells may be abnormal leukaemic blast cells. The presence of leukaemic blast cells in your blood suggests that you have AML. A diagnosis of AML needs to be confirmed 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 your 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, less commonly, 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 per cent of blast cells but this can increase to between 20 per cent and 100 per cent in people with AML.

The bone marrow biopsy may be done whilst a hospital inpatient or in a hospital day unit under local anaesthesia or, in selected cases, under a short general anaesthetic in theatre. Most commonly, a mild sedative and a pain-killer is given beforehand by mouth or intravenously and the skin is numbed using a local anaesthetic, which is given as an injection under the skin. The injection takes a minute or two, and you should feel only a mild stinging sensation. Patients are usually asked to fast for several hours beforehand if sedation is planned.



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'. The first instance of the bone marrow aspirate may be associated with a sharp pain. 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, you should take a family member or friend along who can take you home. A small dressing or plaster over the biopsy site can be removed a couple of days later. 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 you have, the likely course of your 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 mostly found in the leukaemic cells.

Molecular tests

More recently, certain molecular tests are commonly performed which detect mutations predictive of prognosis, especially in patients with a ‘normal’ cytogenetic profile. Such tests may include FLT3, NPM1 and CEBPA mutation testing. These mutations are also acquired in the leukaemic cells.

Following treatment, you will need another bone marrow examination to assess how well your disease is responding. The goal of therapy is to achieve a ‘complete remission’ which is defined as less than 5 per cent of blasts in the bone marrow and recovery of normal blood counts.

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
- lactate dehydrogenase (LDH) level (LDH is an enzyme, which is usually raised in AML)
- coagulation tests (to see if your blood is clotting properly)
- HIV and hepatitis infection tests
- Uric acid (this level may increase when leukaemia treatment is started).
- Imaging tests
- chest x-ray (to detect a chest infection or any other abnormalities)
- electrocardiogram (ECG) and either an echocardiogram (cardiac ultrasound) or gated heart pool scan (to see how well your heart is working).

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

Waiting around for tests can be both stressful and boring. 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.

Types of AML

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.

The World Health Organisation classifies AML into more than 20 different subtypes based on the appearance of the leukaemic cells under the microscope, clinical features, cytogenetic and molecular information. This information also provides more reliable information regarding the likely course (prognosis), of a particular subtype of AML, and the best way to treat it.

One of the most important factors in predicting prognosis in AML is the genetic make-up of the leukaemic cells. Certain cytogenetic 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 (APML or M3). APML is treated differently to other types of AML, and usually has the best overall prognosis.

Other cytogenetic 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, neither 'good' nor 'bad-risk' cytogenetic changes are found. People with 'normal' cytogenetics have also traditionally been regarded as having an 'intermediate' prognosis, although new information regarding recently discovered mutations within the genes may change this prognosis.

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

Prognosis

A prognosis is an estimate of the likely course of a disease and the chance of it being cured or controlled.

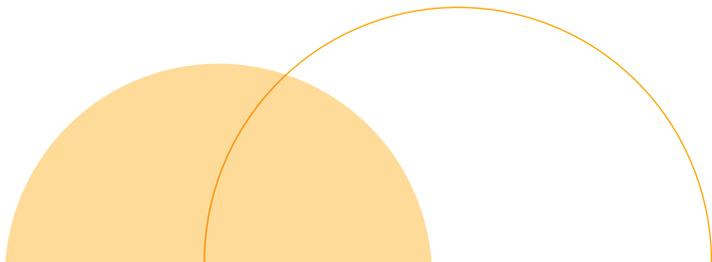
Certain factors (known as prognostic factors) give some patients a better chance of being cured of their disease with treatment than others. Age is the most important factor in AML survival, with outcomes substantially inferior in patients over the age of 60. As we mentioned above, the genetic make-up of the leukaemic cells is also an important factor in predicting prognosis in AML.

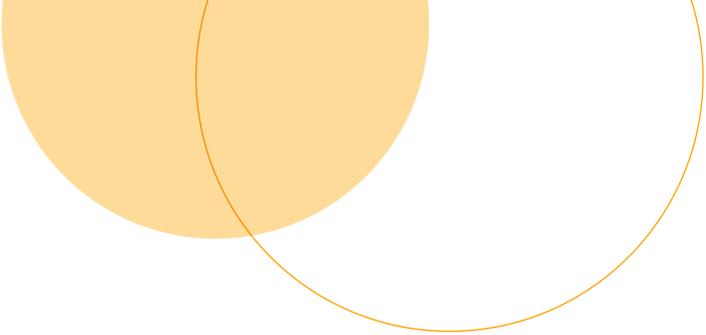
Other factors include the white cell count at diagnosis, the history of a pre-existing malignant blood disorder or the use of chemotherapy or radiotherapy to treat another type of cancer in the past.

Mutations within the genes of the leukaemia cells may also be important factors in determining prognosis. These mutations are not able to be seen on standard cytogenetics, and require complex testing such as polymerase chain reaction (PCR). An example of genes that mutations have been discovered in include FLT3, NPM1, and CEBPA. The presence of some of these mutations may lead to a better prognosis, whilst others may lead to a worse prognosis. New mutations are continuously being discovered, and our understanding of the importance of these mutations is improving.

In general, older people have a poorer prognosis, related in part to the increased complications and lesser effectiveness of intensive chemotherapy.

Your doctor 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

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 younger people with 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 the microscope. The proportion of blast cells in the marrow has been reduced to less than five per cent. There are no blast cells present in the circulating blood and the blood count has returned to normal.

The length of time that a remission lasts varies from person to person.

Relapse

The leukaemia has reappeared in the blood, bone marrow or sometimes the skin or other organs.

Resistant or refractory disease

This means that the leukaemia is not responding to treatment.





Treatment

The treatment chosen for your disease depends on several factors including the exact type of leukaemia you have, your age, other prognostic factors and your general health.

Information gathered from hundreds 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 however 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.

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 been proven to be safe and effective in a given situation.

Clinical trials (also called research studies) test new treatments or 'old' 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. Clinical trials often give people access to new therapies not yet funded by governments.

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 also need to understand the benefits and risks of the trial before you can give your informed consent. Talk to your doctor who can guide you in making the best decision for you.

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
- post-remission therapy (e.g. consolidation therapy or stem cell transplantation).

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. 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.

In the first place, chemotherapy is given to bring about, or induce, a remission. This means reducing the proportion of blast cells in the marrow to less than five per cent, removing them totally 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 given to help prevent the leukaemia from reappearing, and in many cases to try to achieve a cure. This second phase of treatment is called consolidation therapy.

Induction therapy

Induction therapy commonly involves the use of a combination of chemotherapy drugs. In one commonly used combination, cytarabine (also known as cytosine arabinoside, or ara-C) is given each day for seven days together with an anthracycline antibiotic (for example, daunorubicin or idarubicin) each day for three days. In some cases high-dose cytarabine (also known as high-dose ara-C, HIDAC) may be given to younger patients.



These drugs are usually given as intravenous infusions through a special line called 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. This is often done under imaging guidance in radiology or a vascular procedures room. Once in place, chemotherapy and other 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.

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 breakdown products of the destroyed leukaemic cells and to help your kidneys excrete them safely.

Acute promyelocytic leukaemia (APML or M3)

The treatment of acute promyelocytic leukaemia (APML or 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) and arsenic. ATRA and arsenic are not chemotherapy drugs. ATRA is actually a derivative of vitamin A and together with arsenic, work by making the immature promyelocytes (the identifiable leukaemic cells in APL) mature properly. These drugs are often used in combination to induce a remission. In some patients, additional chemotherapy may be used.

Post-remission therapy

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

One approach to post-remission therapy involves using similar chemotherapy drugs to those used in induction therapy, at the same or higher doses (high-dose cytarabine). In some cases, where there is a high risk that the leukaemia will relapse, intensive chemotherapy is followed by a stem cell transplant.

Stem cell transplantation

For some people very high doses of chemotherapy or radiotherapy are needed to cure, or 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 doctor 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. An alternative source of donor cells when an adult source of compatible stem cells cannot be found is (umbilical) cord stem cells.

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.

For me fatigue is my worst side effect. It is more than just feeling tired and it is hard to explain to others how it feels.

Side-effects of chemotherapy

Chemotherapy kills cells that multiply quickly, such as leukaemic 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 we 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 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.

Platelets

Your platelet count may also be affected by your disease and by the chemotherapy you are receiving and you may become thrombocytopenic (a reduction in the number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time it is helpful to avoid sharp objects in your mouth such as 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.

Red cells

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

White cells

The point at which your white blood cell count is at its lowest is called the nadir. This is usually expected within a week of having your chemotherapy. During this time you will be at a higher risk of developing an infection. At this stage you will also be neutropenic, which means that your neutrophil count is low.

Neutrophils are important white blood cells that help us to fight infection. While your white blood cell count is low you should take sensible precautions to help prevent infection. These include avoiding crowds, avoiding close 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.

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 drug like 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).

When to call the doctor...

It is important that you contact your doctor or the nursing team 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 higher (even if it returns to normal) and/or an episode of uncontrolled shivering (a rigor)
- bleeding (or bruising), for example blood in the urine, blood in bowel motions, coughing up blood, bleeding gums or a persistent nose bleed
- prolonged nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- diarrhoea, stomach cramps or severe constipation
- persistent coughing or shortness of breath
- a new rash, reddening of the skin, itching
- a persistent headache
- a new severe pain or persistent unexplained soreness
- any cut or injury
- any persistent pain, swelling, redness or pus.

It is important to realise that there can be many unscheduled admissions to hospital, for the management of side effects, throughout your treatment.

Nausea and vomiting

Nausea and vomiting are often associated with chemotherapy and some forms of radiotherapy. These days however, thanks to significant improvements in anti-sickness (anti-emetic) drugs, nausea and vomiting are generally very well controlled. You will be given anti-sickness drugs before and for a few days after your chemotherapy treatment. Be sure to tell the nurses and doctors if the anti-emetics are not working for you and you still feel sick.

There are many different types of anti-emetics that can be tried. A mild sedative may also be used to help stop you feeling sick. This will help you to relax but it might make you a little sleepy.

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.

Avoiding strong or offensive smells and taking the prescribed anti-sickness drugs as recommended by the nurse and doctor should also help.

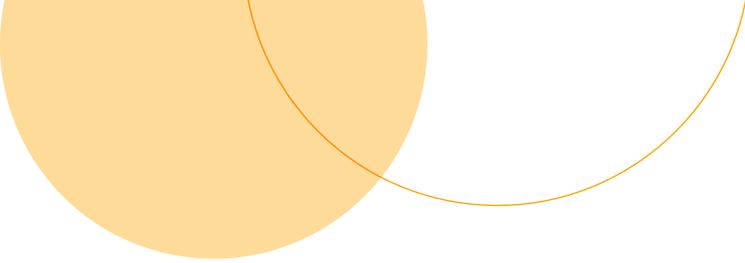
Changes in taste and smell

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, throat or gut 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. Soluble paracetamol and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger pain killers might be needed.

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 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 you will be given some medication to help stop the diarrhoea and/or the discomfort you may be feeling.

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

It is important not to push or manipulate haemorrhoids as this could result in a shower of bacteria entering your bloodstream.

Hair loss

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

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 volunteer 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 visit their website at www.lgfb.org.au or free call them on 1800 650 960.

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 well being and it also may help to reduce your fatigue. It is important to listen to your body and rest when you are tired.



Fertility

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

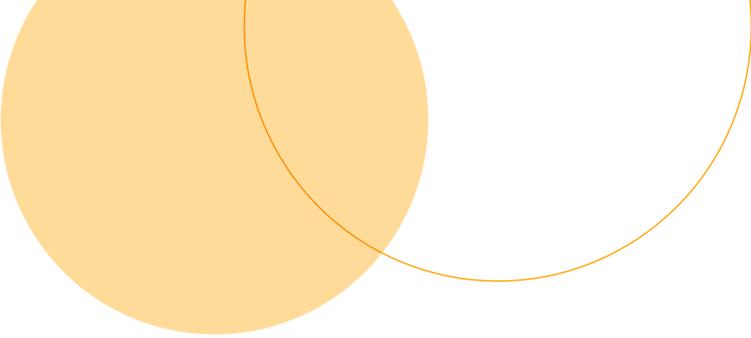
In women, some types of chemotherapy and radiotherapy can cause varying degrees of damage to the normal functioning of the ovaries. In some cases this leads to menopause (change of life) earlier than expected. In men, sperm production can be impaired for a while but the production of new sperm may become normal again in the future. There are some options for preserving your fertility, if necessary, while you are having treatment for leukaemia.

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, people are not suitable for sperm banking when they are first diagnosed because they are too ill 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.





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 having drugs to stimulate your ovaries to produce a number of eggs, so that more than one egg can be collected. This process takes some time. Once they 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. 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, egg storage and ovarian tissue storage are techniques which remain under investigation. They have not yet been proven to be successful in allowing women to bear children.

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 the methods are still quite experimental and for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of them. Some are time consuming and costly while others may simply not be acceptable to you or your partner. In addition, 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. It is important that you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you or refer you to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

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. As we mentioned previously, Look Good...Feel Better is a free community service that runs programs on how to manage the appearance-related side-effects of cancer treatments.

During treatment you may experience a decrease in libido (your body's sexual urge or desire) sometimes without there being any obvious reason. It may take some time for things to return to 'normal'. It is perfectly reasonable and safe to have sex while you are on treatment or shortly afterwards, but there are some precautions you need to take.

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.

Partners are sometimes afraid that sex might in some way harm the patient. This is not likely as long as the 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.

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 not considered standard medical therapies. However, 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 your disease and 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.

There is a separate Leukaemia Foundation booklet called 'Eating Well: a practical guide for people living with leukaemias, lymphomas and myeloma', that provides more detail.

Exercise

Exercise is being utilised more often in wellness centres and treatment centres to help to maintain muscle mass, fine motor skills, reduce fatigue and boredom, and improve treatment recovery times. Speak with your treatment centre about appropriate exercise for you. You may wish to request a referral to an exercise physiologist for guidance.

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 going to see your doctor make a list of the questions you want to ask. It is handy to keep a notebook or some paper and a pen handy 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 helps to bring a family member or a friend along who can write down the answers to your questions, prompt you to ask others, be an extra set of ears or simply be there to support you.

Your treating doctor (haematologist) will spend time discussing with you and your family 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.



Clinical trials

These trials (also called research studies) 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. Clinical trials often give people access to new therapies not yet funded by governments.

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 also need to understand the benefits and risks of the trial before you can give your informed consent. Talk to your doctor as they can guide you in making the best decision for you*.

Informed consent

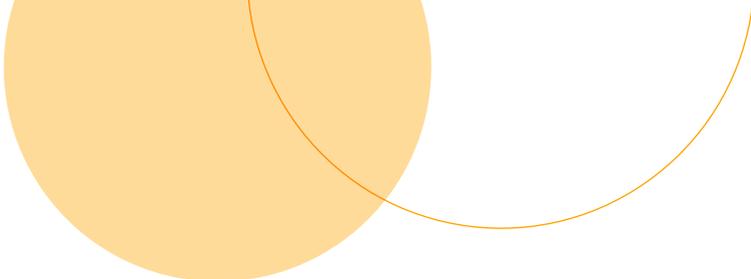
Giving an informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you are happy that you have adequate information to make such a decision.

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.

** You can also refer to the information sheets about clinical trials on our website. There are also questions that you can ask your doctor. See www.leukaemia.org.au*





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 that of loved ones.

It is worth remembering that information can often help to take away the fear of the unknown. It is best for patients and families to speak directly to their doctor regarding any questions they might have about their 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 blood and bone marrow 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 an illness of this nature.

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.

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, doing the banking and taking care of children.

There are a variety of programs designed to help ease the emotional and financial strain created by blood cancers and related disorders. The Leukaemia Foundation is here to provide you and your family with information and support to help you cope during this time. Contact details for your state office of the Leukaemia Foundation are provided on the back of this booklet.

** There is a separate Leukaemia Foundation booklet called 'Living with Leukaemias, Lymphomas, Myeloma & Related Disorders'. This booklet addresses the impact of the diagnosis, family matters, support, survivorship, and other general issues around treatment.*

Useful internet addresses

There is an enormous amount of information about AML available on the internet. Many of these sites are based in the United States, United Kingdom or Europe and the quality of information provided on these sites is enormously variable.

For this reason, it is important to use reputable and up-to-date sites and to discuss information that you have gained from these sites with your doctor and other members of your health care team.

Leukaemia Foundation

www.leukaemia.org.au

Leukaemia Foundation of Queensland

www.leukaemiaqld.org.au

American Cancer Society

www.cancer.org

Australian Bone Marrow Donor Registry

www.abmdr.org.au

Australian Centre for Grief and Bereavement

www.grief.org.au

Bone & Marrow Transplant Information Network

www.bmtinfolnet.org

Cancer Council of Australia

www.cancer.org.au

Cancer Voices Australia

www.cancervoicesaustralia.org.au

Clinical Trials

www.australiancancertrials.gov.au

Leukemia & Lymphoma Society (US)

www.lls.org

Leukaemia Research Fund (UK)

www.bloodwise.org.uk

Look Good ... Feel Better program

www.lgfb.org.au

MacMillan Cancer Support (a UK cancer information site)

www.macmillan.org.uk

National Cancer Institute (USA)

www.cancer.gov/about-cancer

Glossary of terms

Alopecia

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

Anaemia

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

Antibodies

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

Antiemetic

A drug which prevents or reduces feelings of sickness (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 by producing antibodies.

Aplastic anaemia

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

B-cell

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

Blast cells

Immature blood cells normally found in the bone marrow.

Blood count

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

Bone marrow

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

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 line 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 per cent. There are no blast cells present in the circulating blood and the blood count has returned to normal.

Computerised axial 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.

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.

Haematologist

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

Hickman catheter

A type of central venous catheter (see p48) 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 suppression

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

Immune system

The body's defense 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/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 glands 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 disorders

Also known as myelodysplastic syndromes (MDS). These are a group of blood diseases that affect normal blood cell production in the bone marrow.

Myelofibrosis

A disorder in which the bone marrow becomes replaced by fibrous tissue and is unable to produce adequate numbers of blood cells.

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.

Paroxysmal nocturnal haemoglobinuria

A rare disorder characterised by an increased breakdown of red cells. This tends to occur at night leading to the appearance of dark or red urine, usually in the morning.

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 per cent. 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). It is inserted in the middle of the forearm. PICCs 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.

Standard therapy

The most effective and safest therapy currently being used.

Stem cells

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

T-cell

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.



Making a donation



The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemia, lymphoma, myeloma and related blood disorders. The Foundation receives no ongoing government support and relies on the generosity of the community to support our Vision to Cure and Mission to Care.

How can I give?



ONLINE www.leukaemia.org.au



PHONE 1800 620 420



POST (complete this form or enclose cheque/money order and return)

The Leukaemia Foundation, Reply Paid 9954 in your capital city

Name

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Postcode

Phone

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I enclose my gift of (please tick box)

\$30

\$50

\$75

\$100

\$250

Other \$

I wish to make a regular monthly donation of \$

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*You can cancel at any time by calling 1800 620 420.

My cheque/money order made payable to the Leukaemia Foundation is enclosed.

I wish to pay with my credit card and my details are included below:

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Card Number

Expiry Date

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Cardholder's Name

Signature

Your privacy is important to us. That is why we treat your personal information with confidence. To learn more about how and why we collect and use any personal or sensitive information about you, please view our Notification Statement at www.leukaemia.org.au/privacy

This information booklet is produced by the Leukaemia Foundation and is one in a series on leukaemia, lymphoma, myeloma, MDS, MPN and related blood disorders.

Copies of this booklet can be obtained from the Leukaemia Foundation in your state by contacting us.

The Leukaemia Foundation is a not-for-profit organisation that depends on donations and support from the community. Please support our work.

June 2015

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