Understanding Acute Myeloid Leukaemia (AML)

A guide for patients, carers and families
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The Leukaemia Foundation values feedback from patients, their families, carers and health care professionals working with people with blood disorders. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact the General Manager – Support Services at info@leukaemia.org.au

February 2012
INTRODUCTION

This booklet has been written to help you and your family understand more about acute myeloid leukaemia (also known as 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, such as clinical trials 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. These are highlighted in italics. Their meaning is explained in the booklet and/or in the glossary of terms at the back of the booklet.

In some parts of the booklet we have provided additional information you may wish to read on selected topics. This information is presented in the shaded boxes. 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.

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 the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, 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 free support services to patients and their carers, family and friends. This support may be offered over the telephone, face to face at home, hospital or at the Foundation’s office or accommodation centres, depending on the location 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.

The Leukaemia Foundation funds leading research into better treatments and cures for leukaemias, lymphomas, myeloma and related blood disorders. Through its National Research Program, the Foundation has established the ALLG Leukaemia and Lymphoma Tissue Bank at the Princess Alexandra Hospital, and the Leukaemia Foundation Research Laboratory at the Queensland Institute for Medical Research. In addition, the Foundation funds research grants, scholarships and fellowships for talented researchers and health professionals.
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. They can offer individual support and care to you and your family when it is needed.

Support Services may include:

**Information**

The Leukaemia Foundation has a range of booklets, fact sheets and other resources that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from the website (www.leukaemia.org.au). Translated versions (in languages other than English) of some booklets and fact sheets are also available from our website.

**Education & support programs**

The Leukaemia Foundation offers you and your family AML-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 well being.
**Emotional support**

A diagnosis of AML can have a dramatic impact on a person’s life. At times it can be difficult to cope with the emotional stress involved. The Leukaemia Foundation’s Support Services staff can provide you and your family with much needed support during this time. They may refer you or a loved one to a specialist health professional eg psychologist if required.

**Online discussion forum**

The Foundation has established an on-line information and support group for people living with leukaemia, lymphoma, myeloma, or a related blood disorder. Registration is free and participants can remain anonymous, see www.talkbloodcancer.com

**Telephone discussion forums**

This support service enables anyone throughout Australia who has or has had AML to share their experiences, provide tips, education and support others in a relaxed forum. Each discussion is facilitated by a member of the Leukaemia Foundation Support Services Team who has a background in haematology nursing (ph 1800 620 420).

**Accommodation**

Some patients and carers need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation 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.

**Transport**

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

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

**Contacting us**

The Leukaemia Foundation provides services and support in every Australian state and territory. Every person’s experience of living with these blood cancers and disorders is different. Living with leukaemias, lymphomas or myeloma and related blood disorders is not easy, but you don’t have to do it alone. Please call **1800 620 420** (Freecall) 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
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 *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. In later life, it is limited to the hips, ribs and breastbone (sternum). Some of 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 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-loid’) stem cells develop into red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets.  

Lymphoid (‘lim-foi’d’) stem cells develop into two other types of white cells called T-cells and B-cells.

**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 stem cells in the bone marrow to produce different types of blood cells.

These days some 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.
**Blood**

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

**Blood cells**

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

<table>
<thead>
<tr>
<th>Plasma</th>
<th>60%</th>
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| Blood cells | 40% |

- **The normal haemoglobin range for a man is approximately 130 - 170 g/L**
- **The normal haemoglobin range for a woman is approximately 120 - 160 g/L**

Red cells are by far the most numerous blood cell 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 approximately 40 – 52% |
| The normal range of the haematocrit for a woman is approximately 36 – 46% |

**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 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 blood transfusion may be given to restore the red cell numbers and therefore the haemoglobin to more normal levels.
White cells

White cells, also known as leukocytes, fight infection and are involved in inflammation. There are different types of white cells that fight infection together and in different ways.

<table>
<thead>
<tr>
<th>Cell Type</th>
<th>Function and Characteristics</th>
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<tbody>
<tr>
<td>Neutrophils</td>
<td>Kill bacteria and fungi</td>
</tr>
<tr>
<td>Eosinophils</td>
<td>Kill parasites</td>
</tr>
<tr>
<td>Basophils</td>
<td>Work with neutrophils to fight infection</td>
</tr>
<tr>
<td>Monocytes</td>
<td>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.</td>
</tr>
<tr>
<td>T-cells</td>
<td>Kill viruses, parasites and cancer cells; produce cytokines</td>
</tr>
<tr>
<td>B-cells</td>
<td>Make antibodies which target microorganisms</td>
</tr>
</tbody>
</table>

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

The normal total adult white cell count varies between 3.7 and 11 x 10⁹/L

Neutropenia

Neutropenia is the term used to describe a lower than normal neutrophil count. If your neutrophil count is less than 1(1x10⁹) you are at increased risk of developing more frequent and sometimes severe infections.

The normal adult neutrophil count varies between 2.0 and 7.5 x 10⁹/L
**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 (e.g. by a cut) the platelets gather at the site of injury, stick together and form a plug to help stop the bleeding.

\[
\text{The normal adult platelet count varies between 150 - 400 x 10^9/L}
\]

**Thrombocytopenia**
Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops below 10-20 (10-20 x 10^9/L - depending on your institutions policy) you are at risk of spontaneously bleeding, and tend to bruise easily. Platelet transfusions are sometimes given to bring the platelet count back to a safe level.

Alternatively, drugs such as tranexamic acid may be prescribed to help mesh existing platelets together more tightly in situations where the platelet count is dangerously low. If you are on drugs which block platelet function, such as aspirin or non-steroidal anti-inflammatory drugs, you should ask your doctor if it is safe to continue taking these drugs.

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 cell type.
**Children**

In children, some normal blood cell counts vary with age. If your child is being treated for leukaemia 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.

In children, some normal blood cell counts vary with age (see table below).

<table>
<thead>
<tr>
<th>Normal range of blood values for children</th>
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<tr>
<td></td>
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<tr>
<td><strong>Haemoglobin g/L</strong></td>
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<tr>
<td>---------------------</td>
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<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>White cell count</strong></td>
</tr>
<tr>
<td><strong>Platelets x 10⁹/L</strong></td>
</tr>
<tr>
<td><strong>Neutrophils x 10⁹/L</strong></td>
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WHAT IS LEUKAEMIA?

Leukaemia is the general name given to a group of cancers that usually 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 do not mature as they are supposed to. Because they have not matured properly, these cells are unable to function properly. Most cases of leukaemia originate in developing white cells.

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, 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, and 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.
Acute leukaemias develop and progress quickly and need to be treated as soon as they are diagnosed. Acute leukaemias affect very immature blood cells, preventing them from maturing properly. Chronic leukaemias develop slowly, during the early stages of disease, and progress slowly over weeks or months. Chronic leukaemias generally involve an accumulation of more mature but abnormal white cells.

Leukaemia can also be either myeloid or lymphoid. The terms myeloid and lymphoid 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 (myelocytic, myelogenous or granulocytic) leukaemia. When leukaemia starts somewhere in the lymphoid cell line it is called lymphocytic (or lymphoblastic or lymphatic) leukaemia. (See figure (stem cell lines) page 9)

Therefore, there are four main groups 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.

* There are separate Leukaemia Foundation booklets that provide more details about types of chronic leukaemia
Each year in Australia around 3,000 adults and 270 children are diagnosed with leukaemia.

Of these, around 870 are diagnosed with the type of leukaemia called acute myeloid leukaemia (AML), a relatively rare type of cancer more common in adults.

Acute lymphoblastic leukaemia (ALL) is diagnosed in 320 Australians each year and is more common in children than in adults. ALL is the most common type of cancer in children aged 0 to 14 years.

Overall, chronic leukaemias are more common in adults than acute leukaemias. They rarely occur in children. Chronic lymphocytic leukaemia (CLL) is diagnosed in around 1000 Australians each year and chronic myeloid leukaemia (CML) in 270 Australians each year (Australian Institute of Health and Welfare December 2010).
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. As the bone marrow cannot function properly, it is unable to 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. The abnormal blast cells (leukaemic blasts) eventually spill out into the blood stream and can accumulate in various organs such as 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 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.

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 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. 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 public concern that living near high-voltage power lines may increase the risk of developing leukaemia. There is, however, no clear evidence to date 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’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.

Chemicals

Exposure to high levels of benzene over a long period of time may increase the risk of some blood disorders 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. Approximately 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 myelofibrosis have an increased risk of developing AML.
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 flat pinhead sized spots may appear on the skin, especially on the legs. These are called petechiae (‘pe-teechi-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.

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.

**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 examination

The first step in diagnosing AML requires a simple blood test called a 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 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 biopsy

A bone marrow biopsy involves taking a sample of bone marrow, usually from the back of the iliac crest (hip 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 in the haematologist’s rooms, clinic or a hospital bed under local anaesthesia or, in selected cases, under a short general anaesthetic in theatre. Most commonly, a mild sedative and a pain-killer are given beforehand by mouth or into a vein 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. 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 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’.

As you might feel slightly drowsy afterwards, it may be useful to take a family member or friend along who can take 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 gene mutation 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 only found in the leukaemic cells.

**Gene mutation tests**

Recent scientific evidence from clinical trials has shown that, in addition to the information provided by cytogenetic tests, it is possible to find distinct mutations in several important genes in AML cells in some patients. These genes, including Flt3, CEBPA and NPM1, are critical for the development of normal white blood cell precursors, and when affected by mutations, appear important in causing AML. In almost all cases, these gene mutations are not inherited, but are acquired by bone marrow cells during life for reasons not yet understood. Detection of these mutations can be done on leukaemia cells by a special DNA test.

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

In some cases, you may be asked for your consent to allow storage of excess bone marrow material in a “Tissue Bank” for future leukaemia research.

**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

**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 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. 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 average prognosis, although new information regarding recently discovered mutations may provide a more accurate prognosis for people in this group into the future.

Some subtypes of AML are associated with specific symptoms. For example, in some subtypes of AML (acute myelo/monocytic), leukaemic cells can spread from the blood stream into other parts of the body like the gums, causing swelling and discomfort. Acute promyelocytic leukaemia (APML or 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 patients a better chance of being cured of their disease with treatment than others. As we mentioned above, the genetic make-up of the leukaemic cells is the most important factor in predicting prognosis in AML. Other factors include the person’s age, their white cell count at diagnosis, the history of a pre-existing 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, NPM, and CEBPA. The presence of some of these mutations may lead to a better prognosis, whilst others may indicate 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

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 5 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.
TREATING AML

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.

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. 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 5 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 post-remission, post-induction or consolidation therapy.

**Induction therapy**

Induction therapy commonly involves the use of a combination of chemotherapy drugs. The best combination is still uncertain, and the choice of drugs will depend on each patient’s circumstances. In one commonly used combination, cytarabine (also known as standard dose cytosine, or ara-C) is given each day for seven days together with an anthracycline (for example, daunorubicin or idarubicin) each day for three days. Another chemotherapy drug called Etoposide (VP-16) may also be used, usually in addition to the above drugs. In some cases high-dose cytarabine (also known as high-dose ara-C, HIDAC) is given with other chemotherapy drugs as induction therapy.

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. 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).
ATRA is not a chemotherapy drug. It is actually a derivative of vitamin A, which works by making the immature promyelocytes (the identifiable leukaemic cells in APML) mature properly. This drug is now used in combination with standard chemotherapy to induce a remission. A newer drug called arsenic trioxide is now routinely used in the treatment of APML.

In most cases you will need to be admitted to hospital for induction chemotherapy.

**Consolidation (Post Remission) Therapy**

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

One approach to consolidation therapy involves using similar chemotherapy drugs to those used for induction therapy, usually in shorter courses repeated one or more times. Alternatively, more intensive consolidation treatment with multiple courses of high-dose cytarabine may be given, especially in younger patients. In some cases, where there is a high risk that the leukaemia will relapse, patients may be offered even more intensive chemotherapy followed by a stem cell transplant.

**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 only offered if your doctor feels that the benefits to you outweigh the risks.

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.

*There are separate Leukaemia Foundation booklets called ‘Understanding Autologous Blood Stem Cell Transplants - A guide for patients and families’ and ‘Understanding Allogeneic Blood Stem Cell Transplants - A guide for patients and families’ that provide more details on these types of treatments.
Due to the potential toxicities of this type of treatment, some older patients may be offered a reduced-intensity or “mini”-transplant. An alternative source of donor cells when an adult source cannot be found is called 'cord' stem cells. These cells are collected from the donated umbilical cords of new born babies.

Another option involves collecting your own stem cells, 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.

**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, bone marrow and reproductive organs. 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 managed 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 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 some 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 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 10 to 14 days after 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 Granulocyte – Colony Stimulating Factor (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).

**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, 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 mouthwashes that contain alcohol as this may increase mouth soreness.

**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.

**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 certain things that you can do to make yourself feel more comfortable.

Avoiding the use of heat or chemicals, only using a soft hairbrush, and using 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 airconditioned 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. 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, 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 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 does 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.

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. Many people however 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 instead of, or 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.
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. It is important however 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. See www.leukaemia.org.au or email info@leukaemia.org.au
“How can I help with blood cancer research?”

The Australasian Leukaemia and Lymphoma Group (clinical trials research group) has established a national Leukaemia and Lymphoma Tissue Bank at the Princess Alexandra Hospital in Brisbane. The Tissue Bank is a temperature controlled facility for storing clinical tissue samples to be used in approved research into leukaemia, lymphoma, myeloma and related blood disorders. Current research focuses on understanding the development of cancers, why different patients respond differently to current treatments and more effective therapies, especially those being assessed in clinical trials. The clinical tissue samples used for this research come from blood and bone marrow samples from patients’ routine testing and from samples taken for monitoring during clinical trials.

In order to donate your blood and/or bone marrow samples to the Tissue Bank you will need to sign a consent form at the time of your diagnosis. This can be obtained from your clinician. Be assured, donating does not involve any additional procedures, it simply involves saving and storing in the Tissue Bank any excess blood or bone marrow extracted during your routine tests. Samples are also welcomed from relapsed patients at re-diagnosis.

The donation of your tissue sample is an invaluable way to support blood cancer research and could bring us closer to finding a cure. Tissues from blood cancer patients are precious materials for researchers because these cancers are relatively rare and are vital for finding cures. For further information on the ALLG Leukaemia and Lymphoma Tissue Bank go to www.leukaemia.org.au/web/research/tissuebank.php
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 there 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

• Leukaemia Foundation
  www.leukaemia.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.bmtinfonet.org

• Cancer Council of Australia
  www.cancer.org.au

• Cancer Voices Australia
  www.cancervoiceaustralia.org.au

• Clinical Trials
  www.australiancancertrials.gov.au

• Leukaemia Foundation On-line Support Group
  www.talkbloodcancer.com

• Leukemia & Lymphoma Society of America
  www.leukemia.org

• Leukaemia Research Fund (UK)
  www.beatbloodcancers.org

• 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/cancerinfo
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 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 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 leukaemias, lymphomas, myeloma and related blood disorders.

You can help by making a donation. Please fill out the form below or visit www.leukaemia.org.au to make your gift online.

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Please send to:
The Leukaemia Foundation
GPO Box 9954
in your capital city.
Please send me a copy of the following information booklets:

- Eating well: a practical guide for people living with leukaemias, lymphomas & myeloma
- Living with Leukaemias, Lymphomas, Myeloma & Related Disorders, Information and Support
- Understanding Leukaemias, Lymphomas, Myeloma & Related Disorders
- Understanding Acute Lymphoblastic Leukaemia in Adults
- Understanding Acute Lymphoblastic Leukaemia in Children
- Understanding Acute Myeloid Leukaemia
- Understanding Autologous Transplants
- Understanding Amyloidosis
- Understanding Autologous Transplants
- Understanding Chronic Lymphocytic Leukaemia
- Understanding Chronic Myeloid Leukaemia
- Understanding Hodgkin Lymphoma
- Understanding non-Hodgkin’s Lymphomas
- Understanding Myelodysplastic Syndrome
- Understanding Myeloma
- Understanding Myeloproliferative Disorders
- Young Adults with a Blood Cancer

Or information about:

- The Leukaemia Foundation’s Support Services
- Regular salary deduction scheme
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Please send to:
Leukaemia Foundation, GPO Box 9954, In Your Capital City
or Freecall 1800 620 420
or email: info@leukaemia.org.au

Further information is available on the Leukaemia Foundation’s website
www.leukaemia.org.au
Understanding Acute Myeloid Leukaemia (AML)

A guide for patients, carers and families

February 2012