



Leukaemia  
Foundation

VISION TO CURE  
MISSION TO CARE

# Acute Lymphoblastic Leukaemia (ALL) in adults

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*A guide for patients and families*



1800 620 420



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



# Contents

Acknowledgements	4
Introduction	5
The Leukaemia Foundation	6
Acute lymphoblastic leukaemia	10
What is leukaemia?	16
How common is it and who gets it?	19
Causes	19
Symptoms	20
Diagnosis	22
Treating ALL	30
Commonly used prognostic terms	33
Body image, sexuality and sexual activity	46
Complementary therapies	48
Nutrition	48
Exercise	48
Making treatment decisions	49
Information and support	50
Useful internet addresses	52
Glossary of terms	53

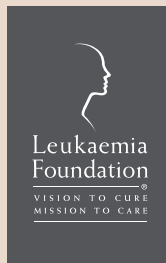
# Acknowledgments

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

The Leukaemia Foundation values feedback from people affected by ALL 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](mailto:info@leukaemia.org.au)

**June 2015**



# Introduction

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

A diagnosis of ALL may leave many of you feeling shocked, anxious, and confused. That is quite understandable as you will probably have never heard of ALL before and you will find that most people you talk with have not heard of it either.

A great deal of information can be found on the internet but some of this may be confusing and difficult to understand, and much of it may not apply to your situation. It is hoped that this booklet will help you begin to understand your disease a little better.

Please remember that the information in this booklet is written in very general terms. Your disease is unique to you. The treatment you will be offered will be decided only after your doctors make a definite diagnosis on the type of ALL you have and fully assess your disease status. This booklet is written to supplement any information given to you by your doctors and the rest of your treatment team.

You may not feel like reading this booklet from cover to cover. It may be useful to look at the list of contents and read the sections that you feel most useful at the time.

Some medical terms have been used that may not be familiar to you. See the back of this booklet for a glossary of terms.

Some of you may require more information than the booklet covers. We have therefore included internet addresses that may be useful. Your doctors and nurses may also give you written information as you proceed through diagnosis and treatment.

It is not the intention of this booklet to recommend any particular form of treatment. Your treating doctor will discuss your particular medical circumstances with you at all times.

# 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 corporations 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 ALL 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 are health professionals who 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 and 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, DVDs, fact sheets, newsletters, 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](http://www.leukaemia.org.au)).

### ***Education and support programs***

The Leukaemia Foundation offers you and your family 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 ALL 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 Blood Cancer Support 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 e.g. psychologist if required.



### ***Blood buddies***

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

### ***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. When our accommodation facilities are full, the Foundation may be able to subsidise external accommodation.

### ***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.

*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 ALL is different. Living with ALL 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](mailto:info@leukaemia.org.au)** or visit **[www.leukaemia.org.au](http://www.leukaemia.org.au)**

## *Acute lymphoblastic leukaemia*

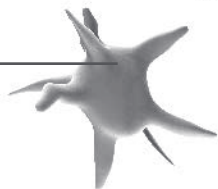
*In this section of our booklet we provide a brief overview of ALL. It is important to point out that the information provided here is of a general nature and may not necessarily apply to the specific type or severity of disease you or your loved one has.*

ALL 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.

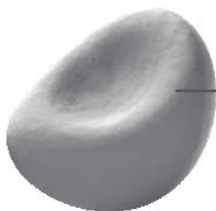
### *Platelets*

Support blood clotting to stop bleeding



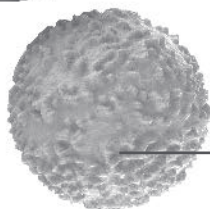
### *Red Blood Cells*

Carry oxygen for the body to produce energy



### *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.

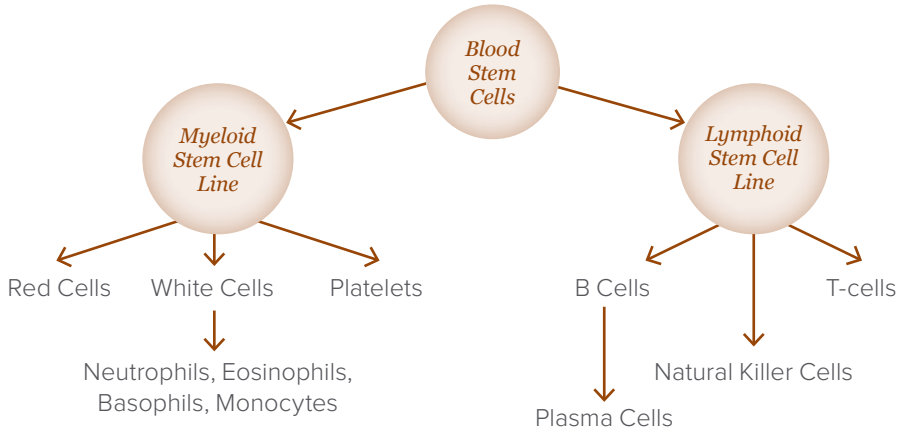
The main workers at the factory are the *stem cells*. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of red cells, white cells and platelets. All blood cells need to be replaced because they have limited life spans.

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:



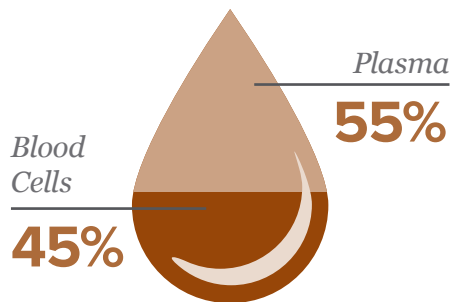
## Growth factors and cytokines

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 the straw coloured fluid part of the blood 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% 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

	 <b>Men</b>	 <b>Women</b>
<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 <sup>9</sup> /L	
<i>Neutrophils (neut)</i>	2.0 – 7.5 × 10 <sup>9</sup> /L	
<i>Platelets (Plt)</i>	150 – 400 × 10 <sup>9</sup> /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.

*Regular washing of my hands has become part of my new normal.*

## *What is leukaemia?*

*Leukaemia is the general name given to a group of cancers that develop in the bone marrow. Under normal conditions the bone marrow contains a small number of immature blood cells, sometimes called blast cells. These immature blood cells mature and develop into red cells, white cells and platelets, which are eventually released into the blood stream.*

Leukaemia originates in developing blood cells, which have undergone a malignant change. Instead of maturing properly these cells grow and multiply and interfere with normal blood cell production in the bone marrow. Most cases of leukaemia originate in developing white cells. In a small number of cases, leukaemia develops in other blood-forming cells, for example in developing red cells or developing platelets.



## What are the different 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.

### **Acute leukaemias**

Acute leukaemias develop and progress quickly and therefore need to be treated as soon as they are diagnosed. Acute leukaemias affect very immature blood cells, preventing them from maturing properly.

### **Chronic leukaemias**

In chronic leukaemias there is an accumulation of more mature but abnormal white cells. Chronic leukaemias can occur at all ages but they are rarely seen in children.

Leukaemia can also be either myeloid or lymphoid. The terms myeloid and lymphoid refer to the types of cell lineage in which the leukaemia first started (see diagram on page 12).

### **Lymphoid leukaemias**

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 lymphoblastic, lymphocytic, or lymphatic leukaemia.

Therefore, 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.

## *Acute lymphoblastic leukaemia (ALL)*

*ALL is a type of cancer that affects immature lymphocytes developing in the bone marrow.*

Under normal condition these cells grow and mature into specialised white cells called B-cells and T-cells. In ALL, they multiply in an uncontrolled way, quickly crowding the bone marrow, and interfering with normal blood cell production. Because the bone marrow is unable to make adequate numbers of red cells, normal white cells and platelets, people with ALL become more susceptible to anaemia, recurrent infections and to bruising and bleeding easily.

Excessive numbers of these abnormal lymphocytes, known as lymphoblasts, leukaemic blasts or leukaemic cells, spill out of the bone marrow and circulate around the body in the bloodstream. From here they can accumulate in various organs including the lymph nodes, spleen, liver and central nervous system (brain and spinal cord).

## How common is it and who gets it?

Each year in Australia around 3,200 adults and over 250 children are diagnosed with leukaemia. Of these about 150 adults and 175 children (0 to 14 years) are diagnosed with ALL. ALL is the most common type of childhood leukaemia, and the most common childhood cancer. In adolescents and young adults, ALL is most commonly diagnosed between the ages of 15 and 25 years. The percentage of all acute leukaemias due to ALL falls with age; most (but obviously not all) acute leukaemias in adult patients are acute myeloid leukaemia. Overall, ALL is more common in males than in females.

The characteristics of ALL differ greatly between children and adults. These days with treatment, the majority of children with ALL can be cured of their disease. In adults, cure rates are more variable.

## Causes

Many people who are diagnosed with ALL 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 in most cases the cause of ALL remains unknown. We do know that it is not contagious. You cannot 'catch' ALL by being in contact with someone who has it.

Like other types of leukaemia, ALL is thought to arise from an acquired mutation (or change) in one or more of the genes that normally control the growth and development of blood cells. This change (or changes) will result in abnormal growth. The original mutation is preserved when the affected stem cell divides and produces a 'clone'; that is, a group of identical cells all with the same defect. Why gene mutations occur in the first place remains largely unknown. There are likely to be a number of, as yet, unidentified factors involved. As ALL progresses it is possible that new clones can develop, which acquire new genetic abnormalities.

In very rare cases, exposure to very large doses of radiation, or certain drugs used to treat other forms of cancer may increase the risk of ALL. Rarely, certain types of viral infections may play a role in the development of some types of ALL.

*It was such a scary thing to be told I had cancer at my young age.*

## Symptoms

*Because ALL develops quickly, people are usually only unwell for only a short period of time before they are diagnosed (days or weeks). The most common symptoms of ALL are caused by a shortage of normal blood cells in the circulating blood.*

### Anaemia

A low haemoglobin level in the blood 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 purple 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 ALL don't have enough normal white blood cells, particularly neutrophils, 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.

## Bone pain

Bone and/or joint pain is common and results from the marrow being crowded with leukaemic cells.

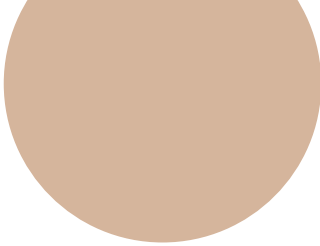
## Other symptoms

Other symptoms of ALL may include swollen lymph nodes, chest pain and abdominal discomfort due to a swollen spleen or liver.

Some people, particularly those with T-cell ALL, may experience chest pain and shortness of breath due to swollen lymph nodes in the chest. This is known as a mediastinal mass.

Occasionally, leukaemic cells can accumulate in the skin causing a rash.

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

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

Your doctor will take your full medical history, asking questions about your general health and any illness or surgery you have had in the past. They will conduct a careful physical examination looking for any signs of disease, such as an enlarged spleen, liver or lymph nodes, and take a routine blood test to check your blood count.

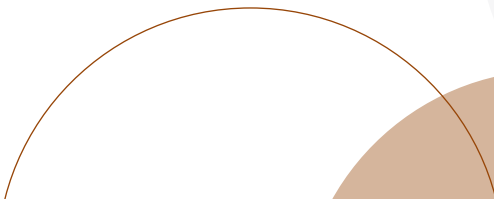
## Full blood count

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

Many people with ALL have a low red cell count, a low haemoglobin level and a low platelet count. Most will also have a high white cell count with large numbers of abnormal leukaemic blast cells (lymphoblasts) in the circulating blood.

The presence of blast cells in the bloodstream suggests that you have leukaemia. A small percentage of patients may not have lymphoblasts detected in their blood at diagnosis. In all cases, the diagnosis will need 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 observe the stage of your ALL and how it is responding to treatment.



## Bone marrow examination

A bone marrow examination (or 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 ALL is confirmed by the presence of an excessive number of blast cells in the bone marrow.

Under normal circumstances the bone marrow contains a small proportion of normal or healthy blast cells, usually less than five per cent. This proportion can increase to between 20 per cent and 95 per cent in people with ALL.

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

## Bone marrow biopsy

The bone marrow examination may be done in the haematologist's rooms or clinic under local anaesthesia or, in selected cases, under a short general anaesthetic in a day procedure unit. A mild sedative and a pain-killer is given beforehand and the skin is numbed using a local anaesthetic (this is given as an injection under the skin).

The injection takes a minute or two, and you should feel only a mild stinging sensation. After allowing time for the local anaesthetic to work, a 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 the 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 afterwards. A small dressing over the biopsy site can be removed the next day. There may be some mild bruising or discomfort, which usually is managed effectively with paracetamol. More serious complications such as bleeding or infection are very rare.

## Immunophenotyping (‘im-u-no-feen-o-typing’)

Immunophenotyping looks at special markers called antigens found on the surface of blast cells to determine the exact subtype of leukaemia you have and therefore the best way to treat it. This test is done on a machine called a flow cytometer and the test is called flow cytometry.

## Cytogenetic (‘cy-to-gen-etic’) and molecular genetic 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. Standard cytogenetic tests involve growing ALL cells from the blood or bone marrow and examining the chromosomes under the microscope.

## Antigens

Antigens are anything that can stimulate your body to produce antibodies.

Antigens, which are commonly named as CD (cluster of differentiation) antigens followed by a number (eg CD20), act like flags identifying the type and origin of a cell and distinguish it from other cells in a given sample.

Recognition of particular CD antigens is useful in distinguishing between normal and leukaemic cells and determining the type of cell in which the leukaemia originated (B-cell ALL or T-cell ALL), and the point at which this cell stopped developing properly in the bone marrow.



## Chromosome changes

Certain cytogenetic changes, such as missing, extra or abnormal chromosomes help to confirm the specific sub-type of ALL you have, and which treatment is likely to be most effective.

These chromosomal changes are only found in the leukaemic cells. They are not usually passed down from parent to child (inherited). Instead, they tend to be acquired over time. An example of this is the Philadelphia (Ph) chromosome, found in some leukaemic cells.

This abnormal chromosome is formed when part of chromosome 9 (the ABL gene) breaks off and attaches itself to part of chromosome 22 (the BCR gene) in a process known as translocation.

This translocation t(9;22) produces the new fusion gene BCR-ABL which in turn releases excess amounts of an enzyme called tyrosine kinase. Tyrosine kinase continually signals the bone marrow to make too many abnormal blood cells.

The Ph chromosome is the most common chromosomal abnormality seen in adults with ALL, occurring in 25 to 30 per cent of all adult patients. Its frequency increases with age and is as high as 50 per cent in people over the age of 50 years.

Ph chromosome positive (Ph+) ALL is treated with oral drugs called tyrosine kinase inhibitors and used in combination with chemotherapy. In suitable patients, an allogeneic (donor) stem cell transplant may be considered.

## Other genetic tests

Sometimes a more sensitive test can be performed to detect chromosomal abnormalities called FISH (fluorescent in situ hybridisation). Depending on the situation, even more sensitive molecular genetic tests (for example polymerase chain reaction or PCR) can be used to assess how well your disease has responded to treatment. These tests are capable of measuring very small numbers of left-over (residual) leukaemic cells not normally visible under the microscope.

Together, immunophenotyping, cytogenetic and molecular tests can provide more information about the exact type of disease you have, its likely response to treatment and the best way to treat it.

### **Minimal residual disease**

The presence of residual disease during or after your treatment may give the doctor some indication of the likelihood of disease progression or future relapse (return of the original disease). Using this highly sensitive technology, subtle changes in your disease can be detected earlier and where necessary treated earlier, or different forms of treatment may be recommended.

*I seemed to be having so many tests. I just wanted to know what was wrong inside my body. The waiting and the unknown were the worst part for me.*

## 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 x-rays. Blood tests may include kidney function tests, liver function tests and coagulation tests, to see if your blood is clotting properly.

A small sample of the cerebro-spinal fluid (CSF) that surrounds your brain and spinal cord is also collected, during a procedure called a lumbar puncture. This fluid is tested in the laboratory to check for the presence of leukaemic cells within the central nervous system.

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

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 ALL

*ALL is not a single disease. It is the name given to a group of leukaemias that develop in the lymphoid cell line in the bone marrow. Depending on the type of abnormal lymphocyte present, ALL can be broadly classified into two main groups:*

- ALL that arises in developing B-cells
- ALL that arises in developing T-cells

The current World Health Organization's classification system for ALL uses additional information, obtained from more specialised laboratory techniques, like immunophenotyping and cytogenetic tests, to classify ALL precisely. The diagnosis of different subtypes of ALL depends on the presence or absence of distinct cell surface markers.

## Pre-B-cell ALL

Between 75 to 80 per cent of adult ALL arises in B-cells in the early stages of development in the bone marrow. In these cases the affected cells share several characteristics with normal immature B-cells. The disease is therefore called precursor B-cell ALL or Pre-B-cell ALL.

## B-cell ALL

B-cell ALL arises in more mature developing lymphocytes. This type of ALL is less common accounting for around three to five per cent of all adult cases.

B-cell ALL cells often (but not always) spread to areas outside the blood and bone marrow such as in the abdomen, head, and neck regions. Involvement of the central nervous system is common. B-cell ALL is sometimes called Burkitt-like or Burkitt type ALL. It resembles another disease called Burkitt's lymphoma, a rare aggressive type of non-Hodgkin's lymphoma.

People diagnosed with B-cell ALL are commonly treated with similar drugs to those used to treat this lymphoma.

## T-cell ALL

In around 20 to 25 per cent of cases ALL arises in developing T-cells. This type of ALL can be further classified as early, mid or late thymocyte T-cell ALL, depending on the maturity of the affected cell.

T-cell ALL commonly presents with a high white blood cell count and may involve the central nervous system at diagnosis. In many cases, leukaemia has spread to the chest where a swollen thymus (gland) produces a collection known as a mediastinal mass.



# *Treating ALL*

The treatment chosen for your disease depends on a number of 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. However, remember that no two people are the same.

In helping you to make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

The principal aim of treatment in ALL is to destroy all the leukaemic cells in your body, allow the bone marrow to function normally again and, where possible, cure your disease.

Because it progresses quickly, treatment needs to begin as soon as possible after ALL is diagnosed.

## **Standard therapy**

Standard therapy refers to a type of treatment that is commonly used in particular types and stages of the 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**

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.

*My treatment started so quickly after my diagnosis. I was so scared but thankful that they were treating me straight away. I wanted to get on top of this thing inside of me.*

## Types of treatment

### 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 is the main form of treatment given for ALL. The dose, timing and types of the drugs used will vary depending on the particular disease involved, your age and general health, and the treatment protocol (plan of treatment) you are following.

Chemotherapy is usually given as 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 rest periods in between. This is to allow your body time to recover from the side-effects.

Chemotherapy is given in many different ways in the treatment of ALL. Some drugs are given in tablet form (orally) but most are injected into a vein

(intravenously or IV). IV drugs are usually given through a special line called a central venous catheter (or central line). This 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. 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.

Chemotherapy is also given intrathecally (into the spinal fluid) through a lumbar puncture, to either treat or prevent the spread of leukaemic cells into the central nervous system (CNS - brain and spinal cord).

### Cortico-steroid therapy

Cortico-steroids are hormones produced naturally by the body. They can also be made in the laboratory. These drugs play an important role in the management of leukaemia. Prednisolone and dexamethasone are examples of cortico-steroids commonly used in the treatment of ALL. These drugs work by directly killing leukaemic cells as well as enhancing the effects of chemotherapy.

## Central nervous system (CNS) treatment and prophylaxis

Leukaemic cells are sometimes found in the CNS (brain and spinal cord) at the time of diagnosis. In other cases ALL reappears or relapses within this area at a later stage. Because the blood supply to the CNS is different from the blood supply to other parts of the body, this area can act as a 'sanctuary site' or hiding spot for leukaemic cells. Here the cells can grow and multiply beyond the reach of standard chemotherapy drugs, which normally travel throughout the rest of the body in the blood stream.

CNS treatment and prophylaxis (protection) will be given at various stages throughout your treatment. This usually involves injections of methotrexate and/or other chemotherapy drugs directly into the spinal fluid (intrathecal injection), through a lumbar puncture. Some types of intravenous chemotherapy and cortico-steroid therapy also provide valuable protection for the CNS. On rare occasions, radiation therapy to the head (cranial irradiation) is also used.





## Commonly used prognostic terms

### **Cure**

This means that there is no evidence of leukaemia and no sign of it re-appearing, even after many years.

### **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, the blood count has returned to normal, and no cytogenetic abnormalities can be detected.

The majority of adults with ALL will achieve a complete remission. It does not, however, necessarily imply that the ALL is permanently cured. The ALL cells may still be present, but in a low number below the limit of detection by the various laboratory tests available.

Recent advances in flow cytometry and molecular testing appear to be better able to define which patients in 'complete remission' (using less sensitive criteria such as microscopic and cytogenetic evaluation) actually have a high or low chance of cure with normal chemotherapy.

This particularly applies to childhood ALL. There are ongoing studies in adult ALL to try and see whether these tests are also useful in this age group. The term commonly used for these tests is measuring the level of 'minimal residual disease' or MRD.

The length of time that a remission lasts may vary from person to person, and the leukaemia may well re-appear (relapse) over time.

### **Resistant or refractory disease**

This means that the leukaemia is not responding to treatment.

### **Relapse**

The leukaemia has re-appeared.

## Phases of treatment

Treatment for ALL can be divided into three phases:

1. Induction therapy
2. Post-remission (consolidation) therapy
3. Maintenance therapy

### *Induction therapy*

Soon after you are diagnosed your doctor will need to begin an intensive course of treatment to bring about, or induce, a remission. The goal of this treatment is to destroy any detectable leukaemic cells in your blood and bone marrow and allow your bone marrow to function normally again. You will need to be admitted to hospital for this first phase of treatment.

Commonly used chemotherapy drugs in this phase of treatment include: vincristine, cyclophosphamide and an anthracycline drug (daunorubicin, or adriamycin). Other drugs like corticosteroids (prednisolone) are also used. CNS therapy also begins at this stage.

While you are having induction therapy you may also be given a drug called allopurinol or occasionally a similar drug called rasburicase. 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 the kidneys excrete these products safely.

Usually the administration of induction chemotherapy and the recovery of the bone marrow from this treatment takes about four weeks. At the end of this time you will undergo another bone marrow biopsy and testing to assess whether you are in remission or not. These tests include microscopic examination, cytogenetics and, in some patients where applicable, flow cytometry and molecular tests.

The majority of patients (around 80 per cent) will achieve an initial remission following induction therapy. However, in a small number of people, the disease does not respond to treatment as expected (e.g. the blasts cell count in your marrow does not normalise or flow cytometry or molecular tests suggest there is significant residual leukaemia) and you may be said to have resistant or refractory disease. In these cases the doctor may recommend a more intensive form of therapy to treat your disease more effectively.

*It was quite hard being diagnosed as a young person. I couldn't do the things I enjoyed with my friends.*

People with Ph+ disease may also be treated with tyrosine kinase inhibitors (TKIs) such as imatinib or dasatinib, during the induction and post-remission phases of their treatment. These drugs are a relatively new class of drugs that work by targeting the bcr-abl protein, thereby blocking the leukaemia-causing effects of tyrosine kinase. Higher remission rates have been reported using a combination of imatinib or dasatinib and chemotherapy.

### ***Post-remission (consolidation) therapy***

Soon after induction therapy finishes, more treatment is required to help destroy any left over disease in your body. We know that just one cycle of chemotherapy is rarely sufficient to get rid of all the leukaemia cells, even in those patients who achieve remission. This is important because it helps to prevent the disease from re-appearing (relapsing) or spreading to the central nervous system (brain and spinal cord) in the future.

This second phase of treatment is called post remission therapy, consolidation therapy or intensification.

The type of consolidation therapy chosen for you will depend on your estimated risk of relapse in the future, in other words, the 'risk group' to which you belong. Consolidation therapy usually involves 'blocks' of treatment over several months. This often includes several courses of more intensive chemotherapy (intensification) to help reduce left over disease to a minimum (minimum residual disease).

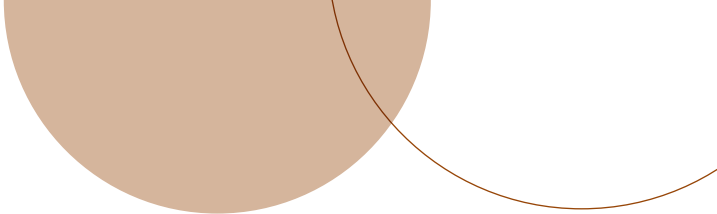
Because of the high risk that ALL will relapse in the future, some people may be offered even more intensive treatment followed by a stem cell transplant, to more effectively treat their disease.

### ***Prognosis and risk-based therapy***

A prognosis is an estimate of the likely course of a disease and whether it is likely to relapse in the future. It provides some guidance regarding the chances of curing the disease or controlling the disease for a given time.

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.

Certain factors (known as prognostic factors) give some patients a better chance of being cured of their disease with treatment than others. At diagnosis these include your age, the exact type of disease you have and your white cell count.



The genetic make-up of the leukaemic cells is an important factor in predicting prognosis and the likelihood of cure in ALL. For example, certain cytogenetic changes are associated with a less favourable prognosis than others. Leukaemic cells with less than the normal number of chromosomes present (hypodiploidy) have historically been associated with a poorer prognosis using standard therapy.

Another important prognostic factor is how well your disease responds to initial treatment, that is, how quickly you achieve a remission and how much disease is left over in your body after this initial treatment.

Taking these and other factors into consideration, you will be categorised as having 'standard-risk' or 'high-risk' ALL. This ensures that the most appropriate and effective 'risk-based' therapy can be chosen for you. For example, more intensive therapy may be more beneficial than standard therapy for some people who belong to the high-risk group. Intensive therapy may help to reduce your risk of future relapse and therefore increase your overall chances of survival.

Although the majority of people treated for ALL will achieve a remission, a significant proportion will relapse over time.

### ***Maintenance therapy***

Maintenance therapy is designed to help keep your disease in remission and prevent it from reappearing (relapsing) in the future. Common maintenance protocols involve chemotherapy tablets (some taken daily, others weekly) and possibly blocks of injections of chemotherapy with courses of cortico-steroids.

This phase of treatment usually lasts for several months for up to two years, during which time you will be treated as an outpatient. However sometimes, depending on the type of chemotherapy being given or your general health, you may need to be admitted to hospital.

### ***Stem cell transplantation***

People in very good health, deemed strong enough to withstand the rigors of therapy, and who have a suitably matched donor, may be offered an allogeneic (donor) stem cell transplant when they have achieved their first remission from ALL. This involves the use of very high doses of chemotherapy (with or without radiotherapy), which kills the normal marrow cells as well as, hopefully, any ALL cells that have survived thus far. The term used for this intense treatment is 'myeloablative'. This is followed by an infusion of stem cells, which have been donated by a suitably matched donor.

This form of treatment may reduce the chance of relapse in both standard and high-risk ALL and improve the overall chance of cure. Whether you will be offered a transplant will depend on a number of factors, predominantly the risk of relapse you are estimated to have if treated with chemotherapy alone, together with your tolerability of the chemotherapy you will receive. This risk will vary between different people so the advice from your doctor will be very specific to your circumstances. Due to the potential toxicities of this type of treatment it is not generally suitable for older patients (over 65 years).

A newer approach involves using lower and therefore less toxic doses of chemotherapy and radiotherapy. This is called a reduced intensity, non-myeloablative, or mini-allogeneic (mini-allo) stem cell transplant. This may be suitable for selected older patients and those with certain health problems who would benefit from, but might not be able to tolerate, a conventional donor

transplant. Using this approach, less intensive doses of chemotherapy are used to treat disease in the bone marrow and suppress the patient's immune system sufficiently for it to accept the new, donated healthy stem cells. Meanwhile it is hoped that the donor's immune system will attack and destroy any left over disease.

A stem cell transplant is usually only offered if your doctor feels that it will be of benefit to you. You will be able to discuss with your doctor if a transplant is a suitable treatment option in your case.

### **Relapsed disease**

Finding out that your leukaemia has relapsed can be devastating, but there are usually ways of getting it back under control. The treatment of relapsed disease depends on a number of factors including the duration of the remission and the site at which the disease has reappeared. Other factors are also considered including your age and the genetic characteristics of the relapsed leukaemic cells.



A relapsed disease may be treated with similar drugs to those initially used to treat leukaemia, or in some cases different drugs. You may also be invited to take part in a clinical trial to test new and experimental treatments for ALL. In some circumstances, people who respond to chemotherapy for relapse may be considered for a stem cell transplant.

### ***ALL in adolescents and young adults***

Recent studies suggest that adolescents and young adults may have better outcomes using paediatric treatment protocols, which traditionally have been more intensive than adult protocols. Trials are currently under way to determine if these more intensive protocols could improve outcomes for adults aged between 18-40. You should ask your doctor if this type of treatment may be best for your particular circumstances.

## **Clinical trials**

Clinical 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. In addition, clinical trials often give people access to new therapies not yet funded by governments.

Any medication you have ever taken only exists because people were prepared to test them in clinical trials previously.

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 informed consent. Talk to your doctor as they can guide you in making the best decision for you.



# Side-effects of treatment

## 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.

*Loving life and all it has to offer, quirks and all, is what kept me going and continues to keep me going.*

## Effects on the bone marrow

ALL 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

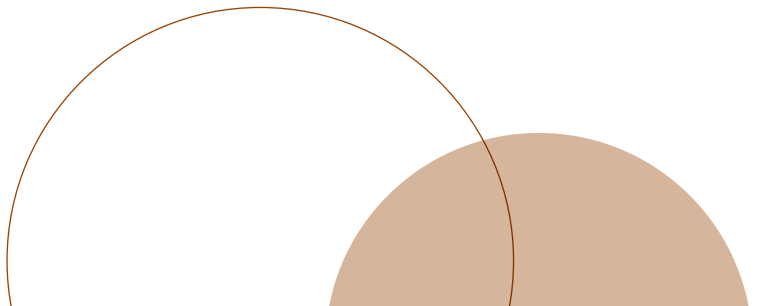
The point at which your white blood cell count is at its lowest is called the nadir. This is usually expected 10 to 14 days after having your chemotherapy. During this time you will be at a higher risk of developing an infection. At this stage you will also be neutropenic, which means that your neutrophil 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. This is called a rigor. 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).





## Nausea and vomiting

Nausea and vomiting are often associated with chemotherapy and some forms of radiotherapy. However these days, 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. 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.

## 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.

## 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.

## Diarrhoea/constipation

Chemotherapy can cause some damage to the lining of your bowel wall. This can lead to cramping, wind, bloating 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.

Other types of chemotherapy may cause severe constipation, so it is 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 people, the thought of losing their 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 hair-brush 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.

## 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

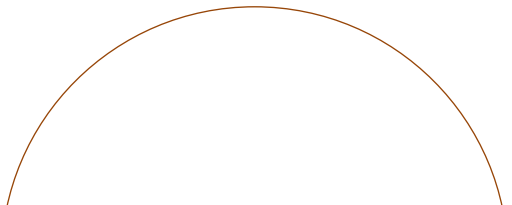
before starting any treatment that might impact on your fertility. In some cases however, people are not suitable for sperm banking when they are first diagnosed because they are too ill and therefore unable to produce the sperm in sufficient quantity or quality.

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 two to three weeks. Once the eggs are collected they are



then fertilised with your partner's sperm and stored to be used at a later date. Your unfertilised eggs can also be collected and stored in a similar manner (egg storage).

Ovarian tissue storage - this is still a fairly new approach to protecting your fertility. It involves the removal and storage, at a very low temperature, of some ovarian tissue (cryopreservation). This is performed as a day procedure, via a laparoscopy (keyhole surgery to the abdomen). It is hoped that at a later date the eggs contained in this tissue can be matured, fertilised and used to achieve a pregnancy.

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 for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of these methods. 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.

As early menopause can also be associated with other long-term health issues, including accelerated bone loss, 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. Look Good...Feel Better is a free community service that runs programs on how to manage the appearance-related side-effects of cancer treatments. You might like to visit their website at [www.lgfb.org.au](http://www.lgfb.org.au) or **free call them on 1800 650 960.**

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

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.



## Side-effects of cortico-steroids

The types of side-effects seen with cortico-steroids depend largely on how long they are used for, and the dose given. If you are using them for a short time you may notice that your appetite increases or you may feel more restless than usual. Some people find it more difficult to get to sleep at night and sleeping tablets or other natural therapies are sometimes recommended.

Cortico-steroids can cause a rise in the blood sugar. Diabetics may find they need more of their diabetes medication while they are taking these drugs and some people who are not normally diabetic may require treatment to keep their blood sugar at acceptable levels.

It is important to keep a check on the blood sugar and keep a diary of the levels and the amount of diabetic medication being taken. Diabetics will already know how to do this. People whose blood sugar only goes up when they are on cortico-steroids may be given information on diet and taught how to measure their blood sugar and adjust their medication. Blood sugar levels usually return to normal once the steroids are finished.

Many of the side-effects of cortico-steroids are temporary and should pass once you finish taking them. Long-term use of cortico-steroids may cause some other effects such as fluid retention and an increased susceptibility to infections. Aching joints such as the knees and hips have also been reported. However, these effects are not common as most people with ALL do not require prolonged steroid therapy.

Remember to tell your doctor and nurses about any side-effects you are having as they can usually suggest ways to help you.

*My steroids would keep me up at night and seemed to increase my anxiety levels. They also made me so hungry, I couldn't seem to stop eating.*

## 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 ALL. They should not be used instead as an alternative to medical treatment for ALL. It is important to realise that no complementary or alternative treatment alone has proven to be effective against ALL. 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 dietitian who can advise you on planning a 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 treatment you are having.

## 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 ALL. 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 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 other questions, 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.

*My treatment has finished but I know I need to continue to work hard to stay well. I worked with my haematologist to develop a tailored wellness plan to give myself the best chance of beating this disease for ever.*

*We are not alone on the journey with ALL – support is available and real. There are many ways to connect with others: support group meetings, phone support, seminars run by the Foundation, written materials or internet forums.*

## *Information and support*

*People cope with a diagnosis of ALL 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 a loved one.*

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.

There may be an ALL support group in your state or territory. You may wish to contact the Leukaemia Foundation in your state for more information.

If you have a psychological or psychiatric condition please inform your doctor and do not 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. Ask your treatment centre if a social worker is available to discuss these issues.

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.



## *Useful internet addresses*

### ***Leukaemia Foundation***

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

### ***Leukaemia Foundation of Queensland***

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

### ***American Cancer Society***

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

### ***Australian Bone Marrow Donor Registry***

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

### ***Australian Clinical Trial's Registry***

[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)

### ***Bone & Marrow Transplant Information Network (USA)***

[www.bmtinfont.net.org](http://www.bmtinfont.net.org)

### ***Cancer Council of Australia***

[www.cancercouncil.com.au](http://www.cancercouncil.com.au)

### ***Leukemia & Lymphoma Society (USA)***

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

### ***Look Good ... Feel Better program***

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

### ***Macmillian Cancer Support (UK)***

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

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

[www.cancer.gov/about-cancer](http://www.cancer.gov/about-cancer)

# Glossary of terms

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## **Alopecia**

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

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## **Anaemia**

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

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## **Antibodies**

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

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## **Antiemetic**

A drug which prevents or reduces feelings of sickness.

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## **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. 'Antigen' is also the general term used to describe proteins found on the surface of all body cells. Here, antigens act like flags identifying different types of cells.

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## **Blood count**

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

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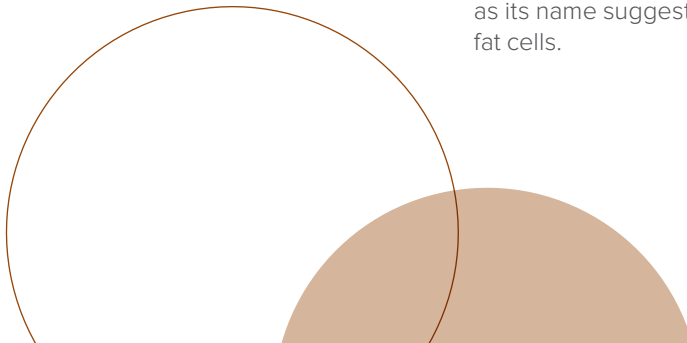
## **B-cell**

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

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## **Bone marrow**

The tissue found at the center of many flat or big bones of the body. Active or red bone marrow contains stem cells from which all blood cells are made and in the adult this is found mainly in the bones making up the axial skeleton – hips, ribs, spine, skull and breastbone (sternum). The other bones contain inactive or (yellow) fatty marrow, which, as its name suggests, consists mostly of fat cells.



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## Cancer

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

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## Cannula

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

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## Central venous catheter (CVC)

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

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## Chemotherapy

Single drugs or combinations of drugs which may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some common side-effects including hair loss and a sore mouth. Most side-effects are temporary and reversible.

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## Chromosomes

Chromosomes are made up of coils of DNA (deoxyribonucleic acid). DNA carries all the genetic information for the body in sequences known as genes. There are approximately 40,000 genes on 23 different chromosomes. The chromosomes are contained within the nucleus of a cell.

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## 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 standard technology.

In people with leukaemia this means that 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.

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### **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.

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### **Cure**

This means that there is no evidence of disease and no sign of it reappearing, even after many years.

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### **Cytogenetic tests**

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.

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### **Disease progression**

Where the disease is getting worse on or off treatment.

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### **Growth factors**

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

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### **Haemopoiesis**

The formation of blood cells.

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### **Haematologist**

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

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### **Hickman catheter**

A type of central venous catheter used for patients undergoing intensive treatment such as bone marrow or peripheral blood cell transplantation. It may have a single, double or triple tube (or lumen).

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### **High-dose therapy**

The use of higher than normal doses of chemotherapy to kill off resistant and/or residual (left over) cancer cells that have survived standard-dose therapy.

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### **Immune system**

The body's defence system against infection and disease.

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### **Immunophenotyping**

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

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## Leukaemia

A 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 take over the bone marrow often causing a fall in blood counts. If they spill out into the bloodstream however they can cause very high abnormal white cell counts.

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## Leukaemic blasts

Abnormal immature blood cells that 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.

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## Lymph nodes or glands

Structures found throughout the body, for example in the neck, groin, armpit and abdomen, which contain both mature and immature lymphocytes. There are millions of very small lymph glands in all organs of the body.

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## Lymphatic system

A vast network of vessels, similar to blood vessels, that branch out into all the tissues of the body. These vessels carry lymph, a colourless watery fluid that carries lymphocytes, specialised white cells that protect us against disease and infection. The lymphatic system is part of the body's immune system.

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## Lymphocytes

Specialised white cells that help defend 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.

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## 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.

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## Malignancy

A term applied to tumours characterised by uncontrolled growth and division of cells (see cancer).

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## Mucositis

Inflammation of the lining of the mouth and throat, which also can extend to the lining of the whole gastrointestinal tract (stomach and intestines).

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## Myeloid

Term used to describe a pathway of maturation of blood cells in the bone marrow. Red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets are derived from the myeloid stem cell line.

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## Neutropenia

A reduction in the number of circulating neutrophils, an important type of white cell. Neutropenia is associated with an increased risk of infection.

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## Neutrophils

Neutrophils are the most common type of white cell. They are needed to mount an effective fight against infection, especially bacteria and fungi.

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## Pathologist

A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.

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## PICC line

Peripherally inserted central venous catheter (see central venous catheter) inserted in the middle of the forearm.

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## Philadelphia (Ph) chromosome

An abnormal chromosome formed when part of chromosome 9 breaks off and attaches itself to chromosome 22.

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## Prognosis

An estimate of the likely course of a disease.

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## Radiotherapy (radiation therapy)

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

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## Relapse

The return of the original disease.

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## Resistant or refractory disease

This means that the disease is not responding to treatment.

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## Remission

When there is no evidence of disease detectable in the body. This is not the same as a cure as relapse may still occur.

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## Spleen

An organ that accumulates lymphocytes, acts as a reservoir for red cells for emergencies, and destroys blood cells at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It cannot normally be felt on examination unless it is enlarged. It is often enlarged in diseases of the blood – this is known as hypersplenism.

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## Splenomegaly

Another term used to describe an enlarged spleen.

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## Standard therapy

The most effective and safest therapy currently being used.

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## Stem cells

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

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### **Stem cell transplant**

General name given to bone marrow and peripheral blood stem cell transplants. These treatments 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 serious diseases.

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### **T-cell**

A type of white cell involved in controlling immune reactions.

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### **White cells**

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

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### **X-ray**

A form of radiation used in diagnosis and treatment.



# 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](http://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	
Address	
Postcode	
Phone	Mobile
Email	

I enclose my gift of (please tick box)

\$30  \$50  \$75  \$100  \$250 Other \$

I wish to make a regular monthly donation of \$

Commencing on

/ / \*

\*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:

Visa  MasterCard  Diners  Amex

Card Number

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Expiry Date	/	CVV
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Cardholder's Name
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Signature
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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](http://www.leukaemia.org.au/privacy)



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

Leukaemia, Lymphoma, Myeloma, MDS, MPN and related blood disorders

Acute Lymphoblastic Leukaemia in Adults (ALL)

Acute Lymphoblastic Leukaemia in Children (ALL)

Acute Myeloid Leukaemia (AML)

Amyloidosis

Chronic Lymphocytic Leukaemia (CLL)

Chronic Myeloid Leukaemia (CML)

Hodgkin Lymphoma

Non-Hodgkin Lymphoma (NHL)

Myelodysplastic Syndrome (MDS)

Myeloma

Myeloproliferative Neoplasms (MPN)

Eating Well

Living with Leukaemia, Lymphoma, Myeloma, MDS, MPN and related blood disorders

Allogeneic Stem Cell Transplants (also called Bone Marrow Transplants)

Autologous Stem Cell Transplants

Young Adults with a Blood Cancer

My Haematology Diary

### Books for children:

Tom has Lymphoma

Joe has Leukaemia

Ben's Stem Cell Transplant

Jess' Stem Cell Donation

### Or information about:

The Leukaemia Foundation's Support Services

Giving at work

Monthly giving program

National fundraising campaigns

Volunteering

Receiving our newsletters

Leaving a gift in my will

Name

Address

Postcode

Phone

Mobile

Email



**POST TO** The Leukaemia Foundation, Reply Paid 9954 in your capital city



**PHONE** 1800 620 420



**EMAIL** [info@leukaemia.org.au](mailto:info@leukaemia.org.au)



**FURTHER INFORMATION ONLINE** [www.leukaemia.org.au](http://www.leukaemia.org.au)







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*

## *Contact us*



1800 620 420



GPO Box 9954, IN YOUR CAPITAL CITY



[info@leukaemia.org.au](mailto:info@leukaemia.org.au)



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



**Leukaemia  
Foundation**

VISION TO CURE  
MISSION TO CARE