



Leukaemia  
Foundation

VISION TO CURE  
MISSION TO CARE

# CHRONIC MYELOID LEUKAEMIA

A guide for patients and families



1800 620 420



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



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The Leukaemia Foundation values feedback from people affected by CML and the healthcare professionals working with them. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact us at **[info@leukaemia.org.au](mailto:info@leukaemia.org.au)**.

**June 2017**

# INTRODUCTION

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

Some of you may be feeling anxious or a little overwhelmed if you or someone you care for has been diagnosed with CML. This is normal.

Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family.

Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor, or specialist nurse.

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

We have used some medical words and terms which you may not be familiar with. Their meaning is explained in the booklet and/or in the glossary of terms at the back of the booklet.

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

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

We hope you find this booklet useful and we would appreciate any feedback from you so that we can continue to help you and your family in the future.

# THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life.

It exists only because of the generous and ongoing support of the Australian community.

Each year, the Leukaemia Foundation helps more than 750 families from regional and rural Australia by providing free accommodation in our capital cities so they can access life-saving treatment at major hospitals.

Our transport service helps thousands get to and from medical appointments, driving more than one million kilometres each year to ensure people get the medicines they need to beat their blood cancer.

The Leukaemia Foundation also provides counselling, comprehensive information, education and support programs and financial assistance to help the 60,000 Australians who are currently living with a blood cancer.

The Leukaemia Foundation also funds researchers who are working tirelessly to discover safer and more effective treatments that will save lives and help people lead a better quality of life.

Supporters ensure the Leukaemia Foundation can continue to give those impacted by blood cancer a strong voice, advocating for change and ensuring all Australians who need them have easy access to the very best blood cancer treatments.



*Leukaemia 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 staff with qualifications and experience in nursing or allied health who work across the country.

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

***Support Services may include:***

### ***Information***

The Leukaemia Foundation has a range of booklets, DVDs, fact sheets and other resources that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from **[leukaemia.org.au](http://leukaemia.org.au)**.

### ***Education & Support programs***

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

### ***Emotional support***

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



### **Blood Buddies**

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

### **Telephone discussion forums**

This service enables anyone throughout Australia who has or has had CML to share their experiences, provide tips, and receive education and support in a relaxed forum. Each discussion is facilitated by a member of the Leukaemia Foundation support team who is a trained health professional.

### **Accommodation**

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

### **Transport**

The Leukaemia 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 Leukaemia 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 Leukaemia 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 Leukaemia Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for patients who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

### **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 free services and support across Australia. Every person's experience of living with CML is different. It's not always easy, but you don't have to do it alone.

Please call **1800 620 420** to speak to a support staff member or to find out more about the services the Leukaemia Foundation offers.

Alternatively, contact us via email on **[info@leukaemia.org.au](mailto:info@leukaemia.org.au)** or visit **[leukaemia.org.au](http://leukaemia.org.au)**.

## CML

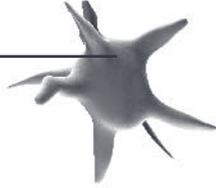
Chronic myeloid leukaemia (CML) is a type of leukaemia that affects the blood and bone marrow.

In CML the bone marrow produces too many white cells, called granulocytes. These cells (sometimes called blasts or leukaemic blasts) gradually crowd the bone marrow, interfering with normal blood cell production.

To understand CML and its effect on our body, we first need to understand the cells involved and where they are formed. For this, we need to understand the bone marrow and the cells that are formed there – the blood cells.

### *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.

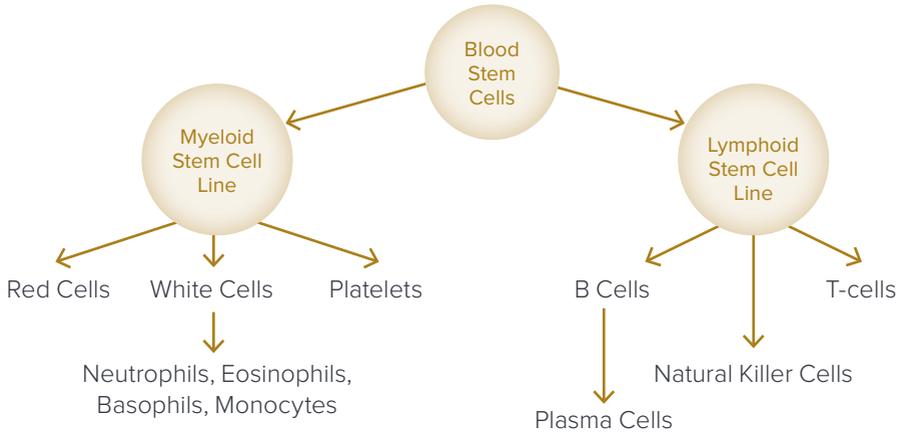
The main workers at the factory are the stem cells. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of red cells, white cells and platelets. All blood cells need to be replaced because they have limited life spans.

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:



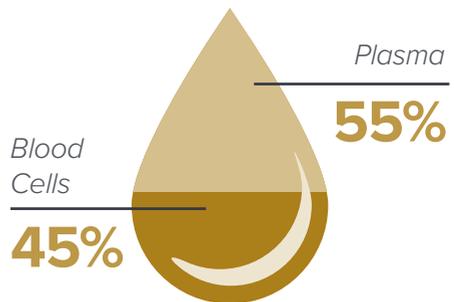
## Growth factors and cytokines

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 a straw-coloured fluid that blood cells use to travel around your body and also contains many important proteins and chemicals.



## Blood cells

### Red cells and haemoglobin

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

### Haematocrit

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

### Anaemia

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

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

## Normal ranges for adults:

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

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



### **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.

## **Normal ranges for children:**

	<b>1 month</b>	<b>1 year</b>	<b>3 years</b>	<b>5 years</b>	<b>9 years</b>	<b>16 years</b>
<i>Haemoglobin g/L</i>	102-130	104-132	107-136	110-139	113-143	115-165 (f) 130-180 (m)
<i>White cell count x10<sup>12</sup>/L</i>	6.4-12.1	5.4-13.6	4.9-12.8	4.7-12.3	4.7-12.2	3.5-11
<i>Platelets x10<sup>12</sup>/L</i>	270-645	205-553	214-483	205-457	187-415	150-450
<i>Neutrophils</i>	0.8-4.9	1.1-6.0	1.7-6.7	1.8-7.7	1.8-7.6	1.7-7.0

If your child is having a transplant you can ask your doctor or nurse for a copy of their blood results which should include the normal values for each blood type for a male or female child of the same age.

## WHAT IS LEUKAEMIA?

Leukaemia is the general name given to a group of cancers that develop in the bone marrow. 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 bloodstream.

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.

# WHAT IS CML?

**CML is a type of leukaemia where the bone marrow produces too many white cells called granulocytes (neutrophils, eosinophils and basophils).**

These white cells normally help the body to fight infection and disease. In CML, these cells are faulty and do not function normally. They spill out of the bone marrow, circulate around the body in the bloodstream and accumulate in various organs such as the spleen and liver.

CML usually presents as a relatively slow-growing disease (called chronic phase) but in the absence of effective treatment it can change into a more aggressive type of disease (accelerated or blast phase) where the bone marrow produces an excessive number of immature granulocytes, known as blast cells or leukaemic blasts.

These cells are produced rapidly and crowd the bone marrow and prevent it from making adequate numbers of red cells, normal white cells and platelets. The main aim of treatment is to prevent CML from progressing into this more aggressive phase.

## How common is CML and who gets it?

CML is uncommon; each year in Australia around 330 people are diagnosed with this condition. CML can occur at any age but it is more common in adults over the age of 40 years, who account for nearly 70% of all cases. CML is slightly more common in men than women and is rarely diagnosed in children.

# THE PHASES OF CML

CML is recognised as having three distinct stages or phases: the chronic phase, accelerated phase, and blast (crisis) phase.

## Chronic phase

More than 90% of people are diagnosed in the early chronic phase of CML. Without treatment the disease usually progresses slowly. The proportion of blast cells in the bone marrow and blood is low (five per cent or less). Most people are generally well at this stage and have few, if any, troubling symptoms. In fact, often the diagnosis of CML is picked up on a routine blood test performed for another reason.

Without treatment, chronic phase usually lasts between three to five years before progressing to the more aggressive forms of the disease. However, for most patients receiving current treatment the duration of the chronic phase is prolonged indefinitely, with most expected to have a normal life expectancy.

Regular blood tests are performed during treatment for chronic phase CML to monitor your health and to see how well the CML is responding to treatment.

## Accelerated phase

Uncommonly, people may present with more advanced and rapidly growing CML, which is called accelerated phase. This phase may also occur in the few people who do not respond well to drug therapy for chronic phase.

In the accelerated phase, the blood counts become increasingly abnormal and the proportion of blast cells increases in the bone marrow and blood.

Treatment during the accelerated phase of disease usually involves finding the most appropriate drug therapy, but may sometimes include stem cell transplantation. In patients whose CML has progressed while on drug treatment, a switch to a more effective drug will usually be required.

*I had a blood test before starting my new job. I was shocked to be told I had CML. I didn't even have any symptoms.*

## Blast (crisis) phase

When CML is poorly controlled, it can transform into a very rapidly progressing disease resembling acute leukaemia. This is known as the blast phase or crisis. The risk of this happening in patients with chronic phase CML overall is generally less than 5%; it is less than 1% in those with an excellent response to drug therapy.

In rare cases patients may present with blast phase disease, without knowing that they might have had chronic phase CML previously.

Blast crisis is characterised by a rapid increase in the number of blast cells in the bone marrow and blood (usually 30% or more) and by the development of more severe symptoms.

Normal blood cell production is impaired and severe shortages of normal blood cells leads to an increased susceptibility to bleeding, infections and anaemia. Blast cells may accumulate in various parts of the body including the spleen, which can become rapidly enlarged, the lymph nodes, skin and central nervous system (brain and spinal cord).

In about two thirds of blast phase cases, CML transforms into a disease resembling acute myeloid leukaemia (AML)\*. In the remainder, the transformed disease resembles acute lymphoblastic leukaemia (ALL)\*. In a small number of cases, the blast cells are said to be undifferentiated or mixed.

Information regarding the type of blast cell involved is important because it helps to guide decisions regarding the most effective treatment for your disease.

Treatment during blast phase of disease is intensive and usually involves intravenous chemotherapy in combination with the most appropriate CML-specific drug (discussed later in this booklet). If this is successful, some younger patients may then be considered for a bone marrow transplant from a donor.

\* *The Leukaemia Foundation has separate booklets called: Acute myeloid leukaemia (AML) - A guide for patients and families, and Acute lymphoblastic leukaemia (ALL) - A guide for patients and families*

*It used to really bother me that I didn't know how I got my CML. I guess I will never know and I'm finally ok with that.*

## WHAT CAUSES CML?

Like other types of leukaemia, CML is thought to arise from the chance development of a mutation (or change) in one or more of the genes that normally control the growth and development of blood cells.

Within a cell the genes, which control all aspects of cell growth and survival, are located on chromosomes within part of the cell called the nucleus. Each nucleus contains 46 chromosomes. Almost all people with CML have a distinctive genetic abnormality known as the **Philadelphia (Ph) chromosome**.

This is an abnormal chromosome 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 an overactive, abnormal enzyme (part of a group of enzymes called tyrosine kinases) called *bcr-abl*. This signals the cell to divide repeatedly, leading to an excess of leukaemic cells in the blood and bone marrow.

No one knows exactly what causes the CML mutation to occur in most patients. In the vast majority of cases it is a chance, unlucky event. Rarely, excessive exposure to a chemical called benzene or to very high doses of radiation may be involved; the risk is increased in survivors of the Hiroshima and Chernobyl disasters. The Ph chromosome is found only in blood cells and bone marrow cells; it is not found in eggs or sperm, nor in saliva. It is not passed down from parent to child and is not contagious.

## WHAT ARE THE SYMPTOMS OF CML?

Most people are diagnosed during the chronic phase of CML and have few, if any, symptoms. In these cases CML is often picked up incidentally during a routine blood test or physical examination. Initial symptoms may be vague and non-specific, becoming more pronounced if the disease progresses.

In CML the spleen enlarges as the leukaemic cells grow within it. Symptoms of an enlarged spleen (splenomegaly) are common and include: feelings of discomfort or pain in the upper left-side of the abdomen; pressure on the stomach causing a feeling of fullness; indigestion or a loss of appetite. In some cases the liver may also be enlarged (hepatomegaly).

Other symptoms may include headaches, fevers, excessive sweating at night, increased bleeding, unintentional weight loss and those symptoms related to anaemia (lack of red cells) such as:

- » persistent tiredness and fatigue
- » weakness
- » shortness of breath with minimal exercise
- » looking pale.



# HOW IS CML DIAGNOSED?

## Blood test

CML is usually first suspected when a blood test shows a high white cell count. There are various types of white cells, but the pattern of which white cells are increased usually leads to the suspicion of CML versus other blood diseases. Usually the GP who discovers this then refers the person to a blood specialist called a haematologist.

As well as a high white cell count, the blood test may show anaemia (low red blood cells) or a higher than normal number of platelets. Platelets help the blood to clot but in CML they may not function properly, increasing the risk of easy bruising and bleeding.

If the results of your blood tests suggest CML, a small sample of bone marrow will need to be examined to help confirm the diagnosis and to provide important additional information about the disease.

## Bone marrow examination

A bone marrow examination (also called a marrow biopsy) involves taking a sample of bone marrow, usually from the bone at the back of the pelvis (called the iliac crest) and sending it to the laboratory for examination under the microscope.

The bone marrow examination is generally performed in a day procedure unit. A mild sedative and a pain-killer is given beforehand and the skin is numbed using a local anaesthetic given as an injection under the skin.

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 known as a 'bone marrow aspirate'. The needle is then 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 of the sedation, it is recommended that patients should be taken home by a family member or friend. A small dressing over the biopsy site can be removed the next day. There may be some mild bruising or discomfort, which can usually be managed effectively with paracetamol. More serious complications such as bleeding or infection are very rare.

## **Bone marrow analysis: cytogenetic and molecular genetic tests**

The marrow in CML is filled with large numbers of mature and immature white cells and platelets; the diagnosis is confirmed by detection of the Ph chromosome or the bcr-abl gene in the bone marrow cells.

Detection of the Ph chromosome is performed in a specialised 'cytogenetic' laboratory. Cytogenetic tests provide information about the genetic make-up of the leukaemic cells, in other words, the number, structure and abnormalities in the chromosomes present.

A different technique called polymerase chain reaction (PCR) can detect presence of the bcr-abl gene. This test is also used to assess the response to therapy as it can measure levels of bcr-abl in the blood.

## **Other tests**

Other tests are usually done at diagnosis to provide information about the patient's general health including the functioning of kidneys, liver and other vital organs. These may include a combination of blood tests and a chest x-ray and an ECG. These tests are important because they help to select the best treatment for you. They can also be compared with later results to assess how the treatment is tolerated.

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.

# PROGNOSIS

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

If you have CML your overall prognosis will depend on a number of factors. These include how well you are physically, the nature of your disease at diagnosis and, most importantly, how well your disease responds to treatment.

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.

The Sokal scoring system provides an initial estimate of the likelihood of CML (in chronic phase) responding well to therapy. This system takes different prognostic factors into account including age, spleen size, and platelet and peripheral blood blast cell count at diagnosis. These factors are given individual scores, which are then tallied to give an overall score. Depending on the score, you are regarded as being in either the low, intermediate or high-risk group.

The likelihood of achieving the desired response to treatment (i.e. very low bcr-abl levels) has been closely correlated to the Sokal score i.e. more people in the low risk group (with a low score) will achieve excellent responses to treatment than those in the high-risk group.

Having said that, the Sokal score is not entirely predictive as even in the high risk group some individuals will respond very well. In fact, the most important thing is how well the CML responds to treatment based on bcr-abl in blood tests.

An ideal response is a bcr-abl less than 10% at 3 months, less than 1% at 6 months and less than 0.1% at 12 months. At the very least, it is essential that all patients achieve a bcr-abl of less than 10% by 6 months and less than 1% by 12 months, which are values associated with a low risk of disease progression. If initial drug therapy does not achieve these responses, then changes may be made to ensure that you are receiving the best possible treatment at all times for your particular situation.

*Meeting with others going through similar issues helps make it more of a shared experience rather than just an individual struggle.*

## Responding to treatment: commonly used terms

### **Complete cytogenetic response (CCR)**

The Ph chromosome cannot be detected using standard laboratory tests. Bcr-abl is usually less than, or equal to, 1% at this point.

### **Major molecular response (MMR)**

Bcr-abl is less than or equal to 0.1%. We aim to reach this level as early as possible because we know that once this level is achieved and maintained, the likelihood of progressing into a more serious form of CML such as accelerated phase or blast crisis is minimal. Patients who achieve MMR are largely protected against progression to accelerated or blastic phases, with very rare exceptions.

### **Complete molecular response (CMR)**

This refers to the situation when no bcr-abl can be detected i.e. the value is 0%. However, this does not necessarily mean that the CML has completely disappeared as there may still be some residual disease in very small amounts, which the test is not able to detect.

### **Treatment-free remission or 'cure'**

This means that there is no evidence of leukaemia after a period of ceasing CML therapy. Some patients who have achieved and consistently maintained (usually for a minimum of two years)

undetectable levels of bcr-abl have been offered participation in clinical studies to investigate whether treatment can be stopped under medical supervision and intensive monitoring. Observations of these patients over a longer period of time is needed, but in some of these patients CML has not reappeared after a number of years and they may be cured.

Ceasing medications should only be attempted as part of a clinical trial or with close medical monitoring, as more frequent monitoring of your disease is required during this time.

### **Mutations**

Development of a mutation is suspected when the CML starts to lose response to therapy, as evidenced by a rising bcr-abl. These mutations can be detected by a specialised molecular test called mutation analysis. This may show mutations that cause resistance to one drug but not another. Switching treatment is often needed based on the results of this test.

An alternative cause of rising bcr-abl is not taking the medication regularly at the prescribed dose. Non-adherence is the most common cause of loss of control of the disease, and increases the risk of developing a mutation.

# TREATING CML

The treatment chosen for your CML largely depends on the phase of your disease and your general health.

Virtually all people with CML will be treated with drugs called tyrosine kinase inhibitors or TKIs. A tyrosine kinase is an enzyme that sends signals to enhance cell growth. As mentioned, the bcr-abl enzyme is overactive in CML and leads to excessive growth of malignant CML cells. TKIs work by blocking the activity of bcr-abl, thereby preventing the growth and proliferation of leukaemic cells.

The three TKIs in Australia funded on the PBS are imatinib, nilotinib and dasatinib. These drugs predominantly inhibit cancerous cells that have the Ph chromosome and have minimal effects on normal blood cells.

The most common decision to be made at diagnosis is which of the three available TKI drugs is most suited to you. This will vary from person to person and haematologists need to consider all the information available about an individual patient before making a recommendation.

Whilst these drugs are usually very effective at controlling the disease, most people are required to take these medicines for life in order to keep the disease under control. Only a minority of patients may be 'cured' by TKI therapy and are able to safely stop taking them. People with well-controlled CML are expected to have a normal life expectancy.

In a very small number of patients, a stem cell transplant (often called a bone marrow transplant) from a matched donor may be considered. This is usually only considered in patients who do not respond well to TKI therapy and have progressive CML. This treatment, while offering the prospect of cure, carries serious risks and requires a suitably matched donor, hence it is not used as a first choice therapy.

Promising new and experimental treatments are being developed for CML all the time. Some of these treatments are currently being used in clinical trials in Australia and other parts of the world. Your doctor will be able to discuss with you all of the treatment options suitable for you.

*We are all different.  
My doctor had to consider all other  
aspects of my health before deciding  
on which TKI I should use.*

## Standard therapy

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

## Clinical trials

These 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 may give people access to new therapies not yet funded by governments.

If you are considering taking part in a clinical trial make sure that you understand the reasons for the trial and what it involves for you. You also need to understand the benefits and risks of the trial before you can give your informed consent. Talk to your doctor who can guide you in making the best decision for you.

## *Informed consent*

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

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

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

## Chronic phase CML

In chronic phase CML, treatment is aimed at controlling the disease, prolonging this phase and delaying or preventing the onset of symptoms and complications.

### *Initial treatment at diagnosis*

It takes one to two weeks to get approval to start therapy with a TKI drug. In the interim, patients with very high white cell counts at diagnosis may be given a short course of chemotherapy tablets called hydroxyurea to reduce the CML count.

Most people tolerate hydroxyurea very well. It does not usually cause nausea or significant hair loss, although it can cause dry skin or a rash.

## Tyrosine kinase inhibitors (TKIs)

### *Imatinib*

The first clinically available TKI was a drug called imatinib mesylate (imatinib). It made a huge leap forward in the effectiveness of how CML was treated and replaced stem cell transplants as the best treatment approach.

Imatinib produces rapid control of the blood count in most patients with chronic phase CML and leads to a high rate (60% after 5 years) of major molecular responses (i.e. substantial lowering of bcr-abl levels), thus controlling the disease and reducing the probability of progression to blast phase for the majority of people.

A minority (approx. 20%) of people with CML will not respond to imatinib initially (in the first three to six months of treatment) OR will respond to imatinib but lose their response and require other therapy. Another reason for replacing imatinib with another drug is side-effects, which occur in approximately 15% of patients.

People who tolerate imatinib well and achieve a major molecular response are likely to have a normal life expectancy, although very few patients have received imatinib for longer than 15 years, so we don't yet know the stability of the response to this drug beyond this time. However, there is currently no evidence to suggest that these patients will not continue to respond to imatinib beyond this time frame.

As imatinib was the first TKI medication used for people with CML, we know more about its long term use and its side-effects than the other TKIs. This long term usage data has given confidence to doctors and patients and imatinib is therefore currently the most commonly used TKI therapy for people with CML in Australia.

### *Possible side-effects*

Side-effects are usually mild and vary from person to person and according to the dose given. They can be unpleasant but most are temporary and improve with time. It is important that people report any side-effects as many of them can be treated successfully, reducing any unnecessary discomfort.

Side-effects of imatinib and treatment can be:

- 1. nausea and vomiting:** this can be prevented by taking imatinib with the largest meal of the day with a large glass of water; imatinib should NOT be taken on an empty stomach.
- 2. fatigue:** this is not uncommon and is often subtle enough that patients can continue their normal daily activities. In some patients, however, it can be profound and require switching to another TKI drug.
- 3. fluid retention and swelling:** puffiness around the eyes is common with imatinib. Some patients on imatinib put on some weight due to fluid retention. This tends to stabilise after a few months and usually does not require treatment.
- 4. muscle cramps:** these can be a problem in some patients and may require medication, often magnesium tablets, to reduce the severity.
- 5. an itchy skin rash:** this happens occasionally and usually responds to topical ointment and temporarily stopping the drug. A persistent rash is rarely a reason to permanently stop the drug.
- 6. diarrhoea:** this may require medication such as Gastrostop (loperamide) to overcome. If severe (which is uncommon), it may require stopping imatinib.

- 7. a temporary reduction in the number of white cells, platelets and red cells:** this is a rare side-effect, and is usually mild. In severe cases blood transfusions may be required for a few weeks, and it may be necessary to stop imatinib temporarily.

Imatinib interacts with many other drugs which may interfere with the effectiveness of imatinib by increasing or decreasing its concentration in your blood. These include some prescription and over-the-counter drugs (including herbal remedies and St John's Wort) and grapefruit juice (and fruits from the same family). These should be avoided.

Your imatinib medication box should have an information sheet inserted – please ensure you read this for more information about product safety. It is important that people taking imatinib speak to their doctor before using any other drugs or supplements.

It is recommended that women do not become pregnant while taking imatinib as it may affect the developing baby. You or your partner should use an effective form of contraception. It is possible, however, for women with CML to have children but it is very important to discuss this with the treating haematologist well in advance. In addition, it is not known if the imatinib passes into the breast milk and hence breastfeeding is not recommended.

Many people with CML have been able to have healthy children. Please ensure you speak with your doctor if you are considering conceiving to ensure you have the best advice on how to do this safely.

In men, imatinib may have an effect on sperm count in some cases. Men may wish to store sperm prior to commencing CML treatment. There is no evidence of any increased risk of abnormalities in babies fathered by men taking imatinib. It is important that you don't stop taking imatinib unless you are instructed to do so by your doctor. To be effective imatinib needs to be taken every day.

### **Nilotinib**

Nilotinib has a similar mode of action to imatinib. It is effective in some people who have become resistant to imatinib as well as newly-diagnosed patients. People who experience side-effects from imatinib usually do not have similar side-effects when taking nilotinib.

Nilotinib is a tablet taken in the morning and evening. It is very important that nilotinib is taken on an empty stomach – no food should be eaten for two hours before AND one hour after taking each dose.

Most people have only mild side-effects with nilotinib, although some people have more troubling side-effects. The more common side-effects include fatigue, rash, itching, nausea and constipation. Less commonly, nilotinib can cause anaemia, a low platelet count, or a low white blood cell count.

Nilotinib can cause an abnormal heart rhythm called QT prolongation in a small number of people. This risk is increased by an imbalance of the electrolytes in the blood (low potassium and magnesium levels) and taking other medications that also cause QT prolongation. Your doctor will monitor this carefully.

Around 1% of people taking nilotinib will develop pancreatitis, a condition with inflammation and swelling of the pancreas, often accompanied by abdominal pain and vomiting. If pancreatitis is caused by nilotinib a different TKI should be used.

People taking nilotinib also appear to have a higher risk of blocked arteries (which may lead to heart attacks and strokes), especially those taking higher doses. In a recent study blocked arteries occurred in 7.5% of people after five years of taking 300mg of nilotinib twice per day, and in 13.4% of people taking 400mg twice per day.

The mechanism behind this is not fully understood. Therefore, nilotinib may not be the preferred TKI medication in patients with other risk factors for heart disease and strokes such as diabetes, high blood pressure and high cholesterol.

Nilotinib can cause an increase in blood sugar levels on both diabetics and non-diabetic patients and in cholesterol levels and these should be monitored closely whilst taking this drug.

It is recommended that you or your partner use a suitable form of contraception while taking nilotinib as this drug may harm the developing baby. Mothers are advised not to breastfeed while taking nilotinib.

### ***Dasatinib***

Dasatinib is also a tyrosine kinase inhibitor, with activity in newly diagnosed disease as well as disease resistant to imatinib. It is a tablet that is swallowed once daily and can be taken with or without a meal. It comes in 100mg, 50mg or 20mg tablets. The usual daily dose is 100mg per day, but lower doses may be effective in older patients.

Generally dasatinib is well-tolerated, although some people have troubling side-effects. These include diarrhoea, easy bruising and bleeding, and fatigue. The most significant side-effect is the development of fluid in the space around the lungs, called a pleural effusion, which may lead to a persistent dry cough and shortness of breath. This side-effect is more common in elderly patients.

If identified early, pleural effusion can be well-managed. This may require treatment with a steroid medicine (prednisolone), temporarily stopping dasatinib (usually with restarting the medication at a lower dose), or occasionally a procedure to drain the fluid from the chest. Those with lung disease, or the elderly, should be monitored closely.

Very rarely dasatinib can cause a condition called pulmonary hypertension which can result in excess pressure on the heart and symptoms including shortness of breath. This can sometimes be diagnosed using an ultrasound of the heart (called an echocardiogram). If detected, dasatinib needs to be stopped permanently.

It is recommended that you or your partner use a suitable form of contraception while taking dasatinib. Mothers are advised not to breastfeed while taking dasatinib.

# ADHERENCE TO TREATMENT

Adherence, also commonly called compliance, to treatment for CML is very important for the drugs to work effectively. If there is not enough drug in the body, it is possible that the CML cells may become resistant (via a process called mutation).

Some mutations do not respond well to TKIs, making treatment much more difficult. It is therefore very important that you take your medication every day, and not make any changes to your treatment without discussing it first with your haematologist.

Research has shown that the faster the medications reduce bcr-abl levels to undetectable levels, the better the outcome is long term. Therefore adherence to therapy is particularly important in the first two years of treatment. Unfortunately, this is also the time that side-effects are most prevalent. To get the best out of your therapy, work closely with your treating team to manage your side-effects, to best enable you to adhere to the full dose of medications prescribed.

*It can be so tempting to take a couple of days off therapy to help me feel a little better. When I heard what the consequences can be I decided it wasn't worth the risk.*

# MANAGING SIDE-EFFECTS

Remember that no two people are the same. In helping to make the best treatment decision about any side-effects you may experience, your doctor will consider the specific details of your situation.

Potential side-effects	Potential remedies
<p><b>Eyes:</b></p> <p>Swelling; excessive watery or dry eyes; bleeding in whites of eyes</p>	<p>Avoid high sodium (salt) foods</p> <p>Prescription steroid eye drops</p> <p>Elevate head off the bed or use an extra pillow</p> <p>Mild diuretic</p> <p>No treatment available for bleeding whites of eyes – avoid heavy lifting/straining</p>
<p><b>Fluid retention</b></p> <p>Common in hands, feet, legs and occasionally around heart and lungs</p>	<p>Avoid high sodium (salt) foods</p> <p>Diuretics (which promote urination) and steroids may be prescribed</p> <p>Elevation of affected area</p> <p>Regular exercise</p> <p>For pleural effusion (fluid around the lungs), a dose reduction and/or temporarily ceasing the drug may be required</p>
<p><b>Nausea and vomiting</b></p>	<p>Take imatinib with at least 240ml of water and additional bland food</p> <p>Anti-nausea drugs may be required</p> <p>Take a record of what you ate each time you felt sick. Some foods such as spicy or fatty foods may cause an upset stomach for you when taking a TKI</p> <p>Take imatinib after or during a substantial meal</p> <p>Take nilotinib on an empty stomach, two hours after and one hour before food</p> <p>Take dasatinib with or without food</p>

Potential side-effects	Potential remedies
<b>Heartburn</b>	<p>Avoid overeating and spicy foods</p> <p>Reduce caffeine and alcohol consumption</p> <p>Remain upright or sitting for one to two hours after taking TKI</p> <p>Antacids two hours before/after imatinib or dasatinib – NOT recommended for use with nilotinib</p> <p>H2 blockers or proton pump inhibitors not recommended when taking dasatinib or nilotinib</p>
<b>Diarrhoea</b>	<p>Avoid sorbitol, mannitol, maltitol (common ingredients in 'sugar-free' foods)</p> <p>Psyllium seed – increases fibre</p> <p>Anti-diarrheal medications e.g. loperamide (gastrostop). May need to lower dose or cease drug if bad</p> <p>Drink plenty of fluid</p>
<b>Muscle cramps</b>	<p>Often helped by taking electrolyte replacements such as: calcium, potassium (especially if on diuretics), magnesium.</p> <p><b><i>Refer to your haematologist before commencing these electrolyte replacements:</i></b></p> <p>Tonic water (low dose quinine) may prove effective</p> <p>Adequate hydration</p> <p>Stretching the muscle</p> <p>Gentle non-weight bearing exercise</p> <p>Heat packs and massage</p> <p>Ibuprofen</p>
<b>Muscle/joint/bone pain</b>	<p>Usually resolves within days to weeks</p> <p>May be relieved by non-steroidal anti-inflammatory drugs</p> <p>Short-term opioids may be required</p> <p>Consider interaction of TKI with drugs to lower cholesterol (called statins)</p>

Potential side-effects	Potential remedies
<b>Skin problems</b>	<p>Dry/itching skin – apply moisturising lotion after bathing; don't use soap-based materials, use baking soda in bath water; may require a steroidal cream</p> <p>Rash – may require temporarily stopping the drug, steroid cream and oral prednisone if severe; antihistamines may be appropriate; hypoallergenic moisturiser/body products</p> <p>Skin tears/abrasions – protect skin with clothing (long sleeves)</p> <p>Sun sensitivity – slip, slop, slap! Sunburn with TKIs can be severe</p>
<b>Fatigue</b>	<p>Check for anaemia and thyroid function</p> <p>Moderate regular exercise</p> <p>Rest before you are exhausted</p> <p>Take a daily nap if you need it</p> <p>Meditation and yoga may be helpful</p> <p>Reduce stress</p> <p>Cognitive behaviour therapy can increase feeling of wellbeing</p>
<b>Birth defects</b>	<p>Do not become pregnant while taking TKIs</p> <p>If you are considering having a baby, speak with your doctor to discuss your options. Interferon may be the drug of choice during pregnancy</p>
<b>Constipation</b>	<p>Increase fruits and vegetables in diet</p> <p>Drink plenty of fluids</p> <p>Stool softeners and laxatives may be required</p> <p>Increase insoluble fibre intake</p> <p>20-30 mins of gentle exercise per day</p>

Potential side-effects	Potential remedies
<p><b>Changes in status of diabetes and cholesterol</b></p>	<p>Pay extra attention to a healthy diet</p> <p>Increase exercise and try to lose weight for those overweight</p> <p>Have cholesterol and blood sugar checked regularly, especially in those at risk of heart disease and stroke</p> <p>Some cholesterol medications are not compatible with TKIs. Be sure to discuss this with your doctor and pharmacist</p>
<p><b>Bleeding</b></p>	<p>Notify your doctor or dentist of your condition if you need any operations or procedures</p>
<p><b>Chest pain, stroke-like symptoms</b> (loss of vision, inability to move limbs, loss of speech, inability to walk properly) and <b>claudication</b> (pain in the legs on walking)</p>	<p>Chest pain and stroke-like symptoms are medical emergencies. Get in touch with your doctor immediately. If there is any delay in speaking with your doctor, call an ambulance</p> <p>Claudication (pain in calves that develops after walking a distance) may indicate blockages in the leg arteries, and should be reported to your doctor</p> <p>To prevent blocked arteries causing heart attacks, strokes and claudication, it is important to maintain a healthy diet and a healthy body weight, keep blood sugar and cholesterol normal, increase exercise, and above all – smokers should quit</p>
<p><b>Shortness of breath</b> (on dasatinib)</p>	<p>A possible sign of pleural effusion – a potential dangerous side-effect that must be reported immediately</p> <p>A diuretic medication may be used</p> <p>In more severe cases the fluid may be drained and steroids used</p>

## Interferon alpha

Interferon alpha used to be standard treatment for CML before imatinib was developed. These days it is not used very often. It may still have a role in a minority of cases (e.g. during pregnancy), and researchers are investigating whether it provides an extra benefit when combined with a TKI.

Interferon alpha is given as a small injection under the skin. It can have significant side-effects including flu-like symptoms: chills, fevers, aches and pains and weakness. It can also cause other unpleasant symptoms such as nausea, loss of appetite and depression. These symptoms are usually temporary. Your doctor or nurse will explain any side-effects you might experience if you are having this form of treatment and how they can be managed.

## Chemotherapy

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxics (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells.

Chemotherapy for CML in chronic phase usually involves hydroxyurea, a drug which can be taken in tablet or capsule form at home and has been found to be very effective at controlling a high white cell count. On the other hand, people in accelerated or blast phase CML may benefit from more intensive anti-leukaemia therapy.

If you are having chemotherapy your doctor and nurse will tell you about the side-effects you might experience and how they can be best managed.

## Accelerated and blast phase

Some people already have advanced disease at diagnosis, whilst others may experience disease progression to accelerated and blast phases. These are both uncommon.

In these advanced phases, treatment is aimed at re-establishing the chronic phase of CML, and reducing any troublesome symptoms. There are several treatment options which may be used depending on your particular circumstances.

*I find the biggest side-effect on a day-to-day basis is tiredness and it is hard for people to understand why I need to rest and be in bed early. I look fine, but I am extremely tired.*

**Accelerated phase disease:** usually a stronger TKI (e.g. nilotinib or dasatinib) is preferred.

**Blast phase disease:** a combination of a TKI with intensive chemotherapy is usually necessary. This commonly involves the use of a combination of chemotherapy drugs given intravenously (into a vein).

The drugs chosen are tailored to treat the type of leukaemic transformation which has occurred (acute myeloid leukaemia (AML) or acute lymphoblastic leukaemia (ALL). This treatment is given in hospital and the side-effects can be more severe.

Not everyone is suitable for this form of treatment, especially if they are elderly or not well enough to tolerate the potential side-effects. In younger, fitter patients a stem cell transplant may be necessary. Treatments to reduce symptoms of CML may include blood transfusions, antibiotics and other drugs to help keep you as well and as comfortable as possible during this time.

## Stem cell transplant\* (bone marrow transplant)

An allogeneic (donor) stem cell transplant currently offers the chance of curing CML but has significant side-effects in many patients. It is generally used only for people in whom the CML has not responded well to TKI therapy or for those rare patients who present with or develop accelerated or blast phase disease. Around 10 people will receive a stem cell transplant for CML in Australia each year.

A transplant involves giving very high doses of chemotherapy, sometimes in combination with radiotherapy, in an attempt to completely destroy the abnormal stem cells in your bone marrow.

These cells are then replaced with healthy stem cells which have been donated, usually from a brother or sister who has the same tissue type as yours. In some cases the donor is not a family member, but has a similarly matched tissue type. This type of transplant is called a matched unrelated donor transplant (MUD) or volunteer unrelated donor transplant (VUD).

\* *The Leukaemia Foundation also has a booklet called: Allogeneic Transplants - A guide for patients and families.*

## HOW DO I KNOW IF THE TREATMENT IS WORKING?

Regular blood tests will indicate how well your CML treatment is working.

At first, you will need a blood test at least every one to two weeks for the first month. This is to make sure that the high white blood cells that were found at diagnosis are returning to normal and that your platelets and haemoglobin levels are satisfactory. They will also monitor for some of the side-effects of therapy.

After this time blood tests are needed less frequently, usually every four to six weeks for a few months and then every three months. If treatment is working as planned, the white cell count should return to normal within four weeks, and the bcr-abl should fall to less than 10% by three months. The next crucial time-point is at six months, when the

bcr-abl value is ideally less than 1%. At 12 months the value should be <0.1% (i.e. a major molecular response or MMR).

In general, bcr-abl values are then tested every three to four months for the rest of your life. The ideal situation is obtaining a very low, stable bcr-abl value of <0.1% which is associated with only a very low risk of losing control of the CML.

If the bcr-abl level starts to rise significantly your doctor will check that you have been taking the medication regularly, and that you have not started any other medications that might interfere with your TKI. If this is not an issue, you will have another blood test called a mutation analysis.

Sometimes the leukaemic cells undergo slight changes called mutations which can affect how well the treatment works. The results of the mutation analysis can help your doctor decide whether a different TKI may be better for you.

*I was worried that my fatigue wasn't improving so my TKI must not be working on me. I now know I can still have symptoms or side-effects while my CML is being treated successfully.*

## Treatment for relapsed and resistant CML

Despite optimal treatment and the best efforts of both the patient and the doctor, a minority of people still develop disease progression. This may be slow or relatively rapid.

Rapid transformation from chronic phase to either blast phase or accelerated phase disease can occur unexpectedly, usually in people with previously less than ideal responses to TKI therapy. It often indicates development of a highly resistant mutation.

Finding out that your CML has transformed or developed a highly resistant mutation can be devastating. It is important to remember that there are still several options for treating the disease and getting it back under control. These may include a stem cell transplant, a clinical trial drug, or a newer TKI drug, such as ponatinib. Ponatinib may be effective against many mutations.

**Slow progression:** some patients experience a loss of previously achieved treatment response (i.e. bcr-abl going up instead of going down), or they never achieve a satisfactory treatment response (i.e. the bcr-abl does not decrease with treatment as expected) but the chronic phase CML remains. This scenario is more common than the rapid progression. In many such cases, switching to an alternative TKI may result in improvements.

Promising new and experimental approaches to the treatment of CML are being developed all the time. Some of these treatments are currently being used in clinical trials in Australia and other parts of the world. Your doctor will be able to discuss with you all of the treatment options suitable for you.

# SUPPORTIVE THERAPIES

Supportive care plays an important role in the treatment of many people with CML. This involves making every effort to improve your quality of life, by relieving any symptoms you might have and by preventing and treating any complications that arise from your disease or treatment.

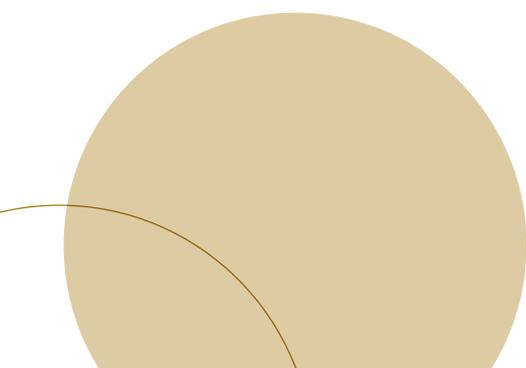
Blood transfusions, antibiotics, careful attention to side-effects, psychological support and appropriate use of complementary therapies are all important elements of supportive care.

## Antibiotics

Serious infections occur very rarely in people with CML. Don't hesitate to contact your doctor or hospital if you develop any of the following signs of infection so that you can be treated appropriately, with antibiotics and other drugs if necessary:

- » A temperature of 38°C and/or an episode of shivering (where you shake uncontrollably)
- » Coughing or shortness of breath with a fever
- » A sore throat and/or a head cold
- » Passing urine frequently or a stinging pain when passing urine
- » If you are feeling generally unwell.

A number of antibiotics can interact with CML medications so it's important that your GP knows what CML medication you are taking in order to check for any potential interactions before prescribing an antibiotic.



### **Other indications to see your doctor in addition to routine appointments:**

- » if you are bleeding (for example blood in your urine, stools, sputum, bleeding gums or a persistent nose bleed) or bruising very easily
- » if any surgery is planned. Advice may be required from your haematologist to ensure that the surgery is completed successfully without problems due to your disease or its treatment.

## **Complementary therapies**

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

Complementary therapies should 'complement' or assist with recommended medical treatment for CML. **They should not be used instead of, or as an alternative to, medical treatment.** It is important to realise that no complementary or alternative treatment alone has proven to be effective against CML. It is also important that you inform your doctor if you are using any complementary or

alternative drug therapies, or remedies, in case they cause any problems with your disease, or its medical treatment.

## **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 treatments you are having.

People with CML should avoid grapefruit as it can interact with TKIs.

## BODY IMAGE

It is likely that the diagnosis and treatment of CML will have some impact on how you feel about yourself as a man or a woman and as a 'sexual being'.

Fatigue, skin changes, and fluid retention 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 [lgfb.org.au](http://lgfb.org.au) or Freecall them on 1800 650 960.



# INFORMATION AND SUPPORT

People cope with a diagnosis of CML 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.

In addition to this, waiting for test results and then having to make decisions about choosing and proceeding with the recommended treatment can be very stressful. Some people do not feel that they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given, or that they are being rushed into making a decision.

It is important that you feel you have enough information about your illness and all of the treatment options available, so that you can make your own decisions about which treatment to have.

It is best for people 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 haematological diseases. Some people find it useful to talk with other patients and family members who understand the complexity of feelings and the kinds of issues that come up for people living with an illness of this nature.

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

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.

*Learn about your disease and become a partner with your medical team, rather than a patient.*

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 and that information can often help to take away the fear of the unknown.

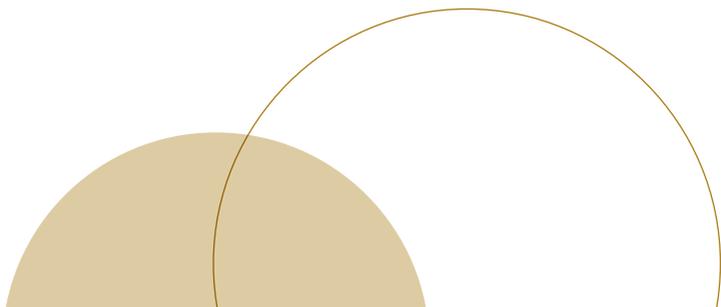
If you feel that you need some psychological support in addition to that from your doctor and your family and friends, please let your doctor know so that you can be referred to someone with expertise in this area.

There may be a CML support group near you. You may wish to contact the Leukaemia Foundation for more information.

Many people are concerned about the social and financial impact of their

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. However, it is important to realise that most people with CML return to normal function after an initial period of adjustment to the new diagnosis and therapy. Most working age people are able to do full time work or look after their family, whilst those who are retired continue to enjoy their previous activities.

There are a variety of programs designed to help ease the emotional and financial strain created by cancer. The Leukaemia Foundation is there to provide you and your family with information and support to help you cope during this time. Contact details for 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)

***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 Cancer Clinical Trials***

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

***Clinical Trials Registry (US)***

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

***Blood & Marrow Transplant Information Network***

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

***Cancer Council of Australia***

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

***CML Advocates Network***

[www.cmladvocates.net](http://www.cmladvocates.net)

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

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

***Bloodwise (UK)***

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

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

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

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

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

# GLOSSARY OF TERMS

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## Accelerated phase

A phase of CML more advanced than chronic phase disease but less severe than blastic phase. In accelerated phase, a patient might have an enlarged spleen, too many or too little platelets, and a greater number of immature cancer cells called blasts in the bone marrow and blood. This is now very rarely seen, thanks to the availability of effective treatment.

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## Acute leukaemias

Rapidly progressing cancers of the blood and bone marrow, usually of sudden onset and characterised by uncontrolled growth of immature blood cells which crowd the bone marrow and spill out into the bloodstream.

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## Acute myeloid leukaemia (AML)

A rapidly progressing cancer of the blood and bone marrow. AML affects developing blood cells on the myeloid cell line, usually white blood cells. It is more common in adults than in children.

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## Allogeneic stem cell transplant

The transplant of blood stem cells from one person to another. The donor is usually the patient's sister or brother, or an unrelated volunteer donor.

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

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## Antiemetic

A drug used to prevent or reduce feelings of sickness (nausea) and vomiting.

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## Autologous stem cell transplant

A type of stem cell transplant using blood stem cells collected from the patient's own bone marrow. These cells are collected and stored in advance, at an early disease stage. They are returned to the patient at a later stage, to rescue the function of their bone marrow, after they have received high doses of chemotherapy to destroy their disease.

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### **Blast crisis (blastic phase, blastic transformation)**

CML presenting at a late stage, when the disease has progressed. Patients at this phase of the disease are usually sicker and have identifiable immature cancer cells in the blood called blasts. This is now very rarely seen, thanks to the availability of effective treatment.

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### **Blood count**

Also called a full blood count (FBC) or a complete blood count (CBC). 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 centre 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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### **Bone marrow aspirate (BMA)**

A procedure that involves removing a small sample of bone marrow fluid for examination in the laboratory. The fluid is drawn, under local or general anaesthetic, usually from the back of the hip or occasionally from the breastbone.

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### **Bone marrow biopsy (BMB)**

A procedure that involves removing a small core of bone marrow for examination in the laboratory. The biopsy (or trephine) is taken under local or general anaesthetic from the back of the hip.

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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 and drugs to enter the bloodstream.

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### Central venous catheter (CVC)

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

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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 (mucositis). Nausea and vomiting are also common, but nowadays are largely preventable with modern anti-nausea medication. 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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### Chronic leukaemias

A group of cancers that affect the blood and bone marrow. Chronic leukaemias usually develop gradually and slowly progress, particularly in the early stages of disease. The leukaemia is called chronic because the leukaemic cells are more mature than those found in acute leukaemia. Chronic leukaemias are sometimes diagnosed by chance, during a routine blood test.

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### Chronic myeloid leukaemia (CML)

A type of leukaemia which is an initially slow growing (indolent) disease where the bone marrow produces too many white cells. Without treatment over time, CML usually transforms into acute leukaemia, a more aggressive type of disease where the bone marrow produces large numbers of abnormal immature granulocytes, known as blast cells or leukaemic blasts. CML is also called chronic myelogenous or chronic granulocytic leukaemia (CGL).

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### Clinical trial

A controlled and carefully monitored assessment of new forms of treatment. Trials can vary in design and size from small-scale trials of experimental treatments to large national trials that compare subtle variations in current therapies. The patient will be informed and will always be given the option not to join, or not without detriment to their treatment when their treatment is part of a trial.

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## Clone

A population of genetically identical cells arising from a single parent cell.

Leukaemia is believed to be a clonal disease, that is, all the leukaemia cells may originate from one abnormal cell.

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## Complete molecular response

When there is no evidence of disease detectable in the body. Note this is not always equivalent to a cure as relapse may still occur.

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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 the disease reappearing, even many years later.

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## Cytogenetic tests

The study of the genetic makeup of the cells, in other words, the structure and number of chromosomes present. Cytogenetic tests are commonly 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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## Dasatinib

A relatively new drug used to treat chronic myeloid leukaemia and other Philadelphia chromosome positive (Ph+) leukaemias. Dasatinib is classified as a tyrosine kinase inhibitor. It works by targeting the abnormal bcr-abl gene thereby blocking the leukaemia-causing effects of the enzyme tyrosine kinase.

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## DNA (deoxyribonucleic acid)

Molecules found in the centre of the cell that carry all the genetic information for the body. There are four different chemical compounds of DNA (bases) arranged in coded sequences called genes, which determine an individual's inherited characteristics.

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## Echocardiogram

A special ultrasound scan of the heart.

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## Electrocardiogram (ECG)

Recording of the electrical activity of the heart.

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## Genes

Collections of DNA. Genes direct the activity of cells. They are responsible for the inherited characteristics that distinguish one individual from another. Each person has an estimated 100,000 separate genes.

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## Granulocytes

A family of white blood cells that contains granules in their cytoplasm (neutrophils, eosinophils and basophils). They protect the body by seeking out and destroying micro-organisms.

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## Growth factors and cytokines

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 stem cell transplantation.

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## Haemoglobin

The iron containing pigment in red blood cells, which carries oxygen to all the body's tissues.

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## Haematopoiesis

The processes involved in blood cell formation.

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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 (leftover) cancer cells that have survived standard-dose therapy.

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## Imatinib mesylate

A relatively new drug used to treat chronic myeloid leukaemia and other Philadelphia chromosome positive (Ph+) leukaemias. Imatinib is classified as a tyrosine kinase inhibitor. It works by targeting the abnormal bcr-abl gene, thereby blocking the leukaemia-causing effects of the enzyme tyrosine kinase.

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## Immune system

The body's defence system against infection and disease.

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## Immunocompromised

When someone has decreased immune function.

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## Interferons

A family of natural proteins produced by the immune system, which play an important role in fighting infection and disease. Interferons can also be produced in the laboratory and have been found to be effective in the treatment of some blood and bone marrow cancers and related diseases.

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## Leukaemia

A cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal blood cells. These cells take over the bone marrow, often causing a fall in blood counts. However, if they spill out into the bloodstream 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 can also spill out into the bloodstream and accumulate in other organs.

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## Leukopheresis (leucopheresis)

A procedure that uses a special machine called a 'cell separator' to separate and remove white blood cells from the circulation before returning the remainder of the blood to the patient. Leukopheresis is the technique used to collect stem cells from the blood for use in a stem cell transplant. It is also sometimes used to reduce a dangerously high white cell count.

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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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## Lymphocytes

Specialised white blood cells involved in defending the body against disease and infection. There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. They are also called B-cells and T-cells.

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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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## Matched unrelated donor (MUD) transplant

An allogeneic stem cell transplant where the donor is unrelated to the patient, but with a similarly matched tissue type. Also called voluntary unrelated donor (VUD) transplant.

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### **Mini allogeneic (mini allo stem cell transplant)**

An allogeneic stem cell transplant involving the use of reduced dose (instead of high-dose) chemotherapy and/or radiotherapy. Also known as a non-myelo-ablative, or reduced intensity transplant.

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### **Mucositis**

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

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### **Mutation**

A change in the DNA code of a cell, caused for example by exposure to hazardous chemicals or copying errors during cell division. If mutations affect normal cell function this can lead to the development of disease due to the loss of normal function or the development of abnormal functions of that cell.

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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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### **Myeloproliferative neoplasms**

A group of disorders characterised by the over-production of blood cells by the bone marrow. One or more of the cell families (red, white, platelets or support tissue) may be involved and treatment varies depending on the type and severity of the disease. Includes chronic myeloid leukaemia, polycythemia rubra vera, essential thrombocythemia and idiopathic myelofibrosis.

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### **Neutropenia**

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

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### **Neutrophils**

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

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### **Nilotinib**

A relatively new drug used to treat chronic myeloid leukaemia and other Philadelphia chromosome positive (Ph+) leukaemias. Nilotinib is classified as a tyrosine kinase inhibitor. It works by targeting the abnormal bcr-abl gene thereby blocking the leukaemia-causing effects of the enzyme tyrosine kinase.

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### **Oncologist**

General term used for a specialist doctor who treats cancer by different means, e.g. medical, radiation, surgical oncologist.

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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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## Peripheral blood stem cell collection

The collection of stem cells from the circulating bloodstream.

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## Petechiae

Red or purple flat pinhead sized spots on the skin, especially on the legs. They are caused by tiny bleeds under the skin, usually as a result of a severe shortage of platelets.

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## Peripherally inserted central venous catheter (PICC)

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

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## Philadelphia chromosome

The abnormal chromosome present in nearly all cases of chronic myeloid leukaemia and some cases of acute lymphoblastic leukaemia (ALL). The Philadelphia chromosome (also called bcr-abl) 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.

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## Platelets

Tiny disc-like fragments that circulate in the blood and play an important role in clot formation.

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## Prognosis

An estimate of the likely course of a disease.

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## Purpura

Purple spots on the skin, often accompanied by bleeding from the gums. It is caused by a shortage of platelets as well as fragile skin.

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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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## 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 in the body. Note it is difficult to classify a patient with a complete molecular response as being in “remission” as the current testing equipment does not definitively rule out the presence of leukaemia cells below this detection threshold.

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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 or splenomegaly.

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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 cells that can give rise to more than one cell type. There are many different types of stem cell in the body. Bone marrow 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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### **Translocation**

A chromosomal abnormality in which part of the one chromosome is transferred to another.

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### **T-cell**

A type of white cell involved in controlling immune reactions.

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### **Tumour**

An abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

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### **Ultrasound**

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

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### **White blood cells (white cells)**

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

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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 charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life. It exists only because of the generous and ongoing support of the Australian community.

## How can I give?



**ONLINE** [leukaemia.org.au](http://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

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I enclose my gift of (please tick box)

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

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

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

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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
- Workplace Giving
- Monthly giving program
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-  **PHONE** 1800 620 420 **EMAIL** [info@leukaemia.org.au](mailto:info@leukaemia.org.au)
-  **FURTHER INFORMATION ONLINE** [leukaemia.org.au](http://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 by contacting us.

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

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## CONTACT US



1800 620 420



GPO Box 9954, IN YOUR CAPITAL CITY



info@leukaemia.org.au



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