Chronic Myeloid Leukaemia (CML)

A guide for patients, families and whānau

Leukaemia & Blood Foundation
Vision to Cure - Mission to Care

The Leukaemia & Blood Foundation gratefully acknowledges Novartis Oncology for their contribution to the production of this booklet.

CONTENTS

INTRODUCTION

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

If you or someone you care for has been diagnosed with CML, you may be feeling anxious or a little overwhelmed. This is normal. Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

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

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

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

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

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

Acknowledgements

The Leukaemia & Blood Foundation of New Zealand acknowledges the support of the Leukaemia Foundation of Australia for granting us permission to use material within this booklet.

The Leukaemia & Blood Foundation also gratefully acknowledges Dr Lucy Pemberton (Middlemore Hospital) for assistance with the revision of this booklet. We also acknowledge Dr Peter Browett (Auckland City Hospital) and Dr Humphrey Pullon (Waikato Hospital) for assistance with the development of the original edition of this booklet in 2008.

THE LEUKAEMIA & BLOOD FOUNDATION

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

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

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

VISION TO CURE - MISSION TO CARE

Within our vision to cure and mission to care the Leukaemia & Blood Foundation provides:

Patient Support

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

Research

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

Information

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

Awareness

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

Advocacy

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

Contacting us

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

Please call **0800 15 10 15** to speak to a local Support Services Coordinator or to find out more about the services offered by the Leukaemia & Blood Foundation. Alternatively, contact us via email by sending a message to info@leukaemia.org.nz or by visiting www.leukaemia.org.nz.

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

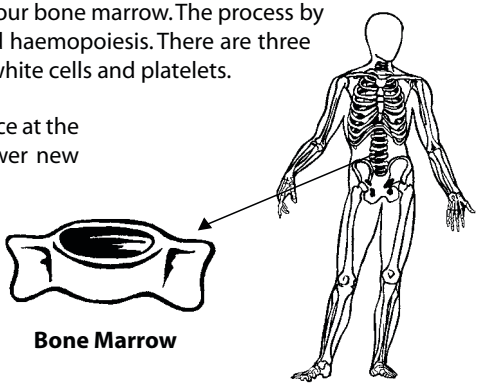
Leukaemia &
Blood Foundation
Vision to Cure - Mission to Care

BONE MARROW, STEM CELLS AND BLOOD CELL FORMATION

Bone marrow

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

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



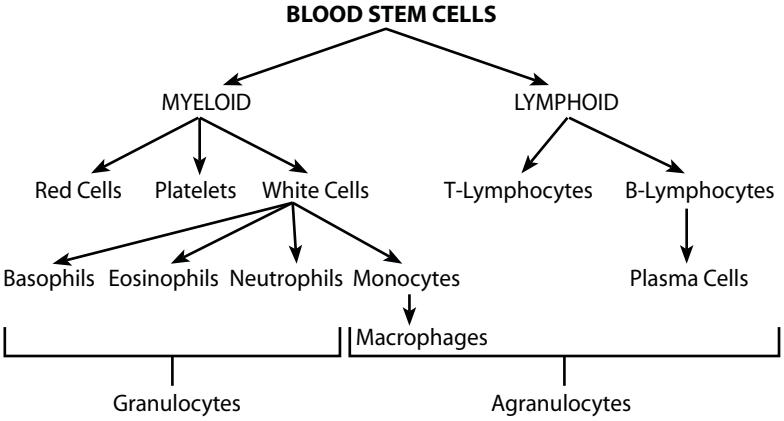
Bone Marrow

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

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

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

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



Growth factors and cytokines

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

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

Blood

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

Blood cells

RED CELLS AND HAEMOGLOBIN

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

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

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

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

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

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

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

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

WHITE CELLS

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

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

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

The normal adult white cell count is between 4.0 – 11.0 x 10^9/L

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1.0 (1.0 x10^9/L) you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections.

The normal adult neutrophil count is between 2.0 – 7.5 x 10^9/L

PLATELETS

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

The normal adult platelet count is between 150 - 400 x 10^9/L

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

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

WHAT IS LEUKAEMIA?

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

Types of leukaemia

There are several different types, and subtypes of leukaemia.

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

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

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

When leukaemia starts somewhere in the lymphoid cell line it is called lymphocytic (or lymphoblastic or lymphatic) leukaemia.

WHAT IS ACUTE LEUKAEMIA?

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

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

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

WHAT IS CHRONIC LEUKAEMIA?

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

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

There are 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)

There are separate booklets about the different types of leukaemia available from the Leukaemia & Blood Foundation.

Both adults and children can develop leukaemia but certain types are more common in different age groups.

Each year in New Zealand around 700 adults and 40 children are diagnosed with leukaemia.

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

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

WHAT IS CHRONIC MYELOID LEUKAEMIA (CML)?

Chronic myeloid leukaemia (CML) is a type of leukaemia that affects developing myeloid cells. Myeloid cells that mature become granulocytes (neutrophils, eosinophils and basophils), which are white blood cells that normally help the body to fight infection and disease. CML initially presents as a relatively slow-growing (indolent) disease where the bone marrow produces too many white cells. These cells spill out of the bone marrow, circulate around the body in the bloodstream and accumulate in various organs like the spleen and liver. Over time, CML progresses to a more aggressive type of disease where the bone marrow produces an excess number of immature granulocytes, known as blast cells or leukaemic blasts. These cells expand, rapidly crowding the bone marrow and preventing it from making adequate numbers of red cells, normal white cells and platelets. This makes people with CML more susceptible to anaemia, recurrent infections and to bruising and bleeding easily.

Chronic myeloid leukaemia is also known as chronic myelogenous leukaemia or chronic granulocytic leukaemia.

HOW COMMON IS CML AND WHO GETS IT?

Each year in New Zealand around 70 people are diagnosed with CML. CML can occur at any age but it is more common in adults over the age of 40 years, who account for nearly 70 per cent of all cases. CML is rare in children, and is slightly more common in men than women.

WHAT CAUSES CML?

Many people who are diagnosed with CML ask the question "why me?" Naturally, they want to know what has happened or what they might have done to cause their leukaemia. The truth is that no one knows exactly what causes CML. We do know that it is not contagious; you cannot 'catch' CML by being in contact with someone who has it. We also know that CML is not inherited i.e. passed down from parent to child.

Like other types of leukaemia, CML is thought to arise from an acquired mutation (or change) in one or more of the genes that normally control the growth and development of blood cells. This change or changes will result in abnormal growth. The original mutation is preserved when the affected stem cell divides and produces a 'clone', that is a group of identical cells all with the same defect arising from the same stem cell. As such CML is regarded as a clonal blood stem cell disorder.

Acquired mutations in genes are gained during a person's lifetime and are not passed from one generation to the next (inherited).

Why these mutations occur in the first place remains unknown but there are likely to be a number of factors involved. In CML, the only known environmental risk factor is exposure to very high doses of radiation, either accidentally (nuclear accident) or therapeutically (to treat other cancers). However in most cases there is no evidence of a high exposure to radiation and the cause is unknown.

Most people with CML have a distinctive genetic abnormality in their leukaemic cells known as the **Philadelphia (Ph) chromosome.** This abnormal chromosome is formed when part of chromosome 9 (the ABL gene) breaks off and attaches itself to part of chromosome 22 (the BCR gene) in a process known as translocation. This translocation t(9;22) produces the new fusion gene BCR-ABL which in turn increases the activity of a substance called tyrosine kinase. This abnormal tyrosine kinase continually signals to the bone marrow to make too many white blood cells, a classic feature of CML. This chromosomal change is only found in blood cells and bone marrow cells. It is not passed down from parent to child (inherited). Instead, it is acquired over time.

WHAT ARE THE SYMPTOMS OF CML?

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

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

Symptoms caused by a lack of normal white cells and normal antibodies:

- Frequent or repeated infections

Symptoms of anaemia, due to a lack of normal red cells:

- Persistent tiredness and fatigue
- Weakness
- Shortness of breath with minimal exercise
- Looking pale

Symptoms caused by a lack of normal platelets:

- Bleeding or bruising more easily for no apparent reason
- Frequent or severe nose bleeds or bleeding gums
- The appearance of red or purple flat pinhead sized purple spots on the skin, especially on the legs initially. These are due to small superficial capillary bleeds known as petechiae ('pe-tee-key-eye') and may have greater clinical importance than bruises.

Other symptoms of CML may include lethargy, fevers, excessive sweating at night and unintentional weight loss.

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

WHICH DOCTOR?

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

HOW IS CML DIAGNOSED?

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

Full blood count

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

Most people with CML have an abnormally high white cell count (leucocytosis) when they are first diagnosed. Blast cells are occasionally seen. A proportion of 10 per cent or higher blast cells usually indicates a more advanced phase of disease. Anaemia is a common finding. This is usually mild in the chronic phase becoming progressively more severe as the disease progresses. Some people with CML will also have a higher than normal number of platelets (thrombocytosis). These platelets may not function properly, increasing the risk of easy bruising and bleeding.

Your full blood count will be checked regularly both during and after treatment to see how you are responding.

Bone marrow examination

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

A bone marrow examination, or biopsy, involves taking a sample of bone marrow, usually from the back of the iliac crest (hip bone) or from the sternum (breast bone) and sending it to the laboratory for examination under the microscope.

A diagnosis of CML is confirmed by the detection of the Philadelphia (Ph) chromosome or the BCR-ABL gene in the bone marrow cells. Other findings may include a very active marrow filled with large numbers of mature and immature white cells and platelets. In healthy adults the bone marrow contains less than 5 per cent of blast cells. This is frequently higher in people with CML, particularly in more advanced stages of disease.

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

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

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

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

Cytogenetic, immunophenotyping and molecular genetic tests

Once a diagnosis of CML is made, blood and bone marrow cells are examined further using special laboratory tests. These include immunophenotyping, cytogenetic and molecular tests. These tests provide more information about the exact type of disease, the likely course of the disease and the best way to treat it.

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. Chromosomes are the structures that carry genes. Genes are collections of DNA, our body's blueprint for life. Standard cytogenetic tests involve examining the chromosomes under the microscope. These are used to detect the presence of the Ph chromosome at diagnosis, and at regular intervals during and after treatment to check the status of your CML.

Molecular genetic tests (for example polymerase chain reaction or PCR tests and fluorescent in situ hybridization or FISH tests) are more sophisticated genetic tests that may be used to assess how well your disease has responded to treatment. These tests are capable of measuring minute traces of left over (residual) leukaemic cells not normally visible under the microscope, which gives the doctor some indication of the likelihood of future relapse (return of the original disease). Using this highly sensitive technology, subtle changes in your disease can be detected earlier and when necessary treated earlier.

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

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

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

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

Molecular tests

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

Other tests

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

OTHER BLOOD TESTS

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

IMAGING TESTS

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

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

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

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 clinical and laboratory features of your disease at diagnosis and, more importantly, how well your disease responds to treatment.

The Sokal scoring or staging system for CML provides an initial estimate of the severity of your disease at the time of its diagnosis, in other words how quickly your disease is likely to progress once you have been diagnosed with CML.

This system takes different prognostic factors into account including your age, spleen size, platelet and peripheral blood blast cell count at diagnosis. These factors are given individual scores, which are then tallied to give your overall score. Depending on your score, you are regarded as being in either the low, intermediate or high-risk group. The likelihood of achieving the desired response to treatment (a complete cytogenetic response) has been closely correlated to the Sokal score. In other words more people in the low risk group (with a low score) are expected to achieve a complete cytogenetic response to treatment than those in the high-risk group.

However, a more important factor in determining your overall prognosis is how well your disease is responding to treatment. These days, standard disease monitoring techniques (regular full blood counts, cytogenetic tests, FISH and PCR testing), with desired response parameters, are used to assess your disease on a regular basis. If it is not responding as well as expected, your doctor may adjust your treatment. This is to ensure that you are receiving the best possible treatment at all times for your particular situation.

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

PHASES OF CML

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

Chronic phase

Most people (more than 90 per cent) are diagnosed in the early chronic phase of CML, during which time the disease progresses slowly. Blood counts remain relatively stable and the proportion of blast cells in the bone marrow and blood is low (5 per cent or less). Most people are generally well at this stage and have few if any troubling symptoms of their disease.

Many people have an enlarged spleen (splenomegaly) and a raised white cell count when they are first diagnosed with CML, but these are usually easily controlled with treatment.

Before tyrosine kinase inhibitors became standard therapy for CML, the chronic phase usually lasted between three to five years. With the development of newer treatments, the duration of this phase is often substantially longer than 5 years, and may exceed 15 years.

While you are in the chronic phase of CML regular blood tests are used to monitor your health and to see how well your disease is responding to treatment.

Accelerated phase

After some time and despite treatment, CML can change from a relatively stable disease into a more rapidly progressing one. This is known as the accelerated phase of CML. During this time your blood counts become increasingly abnormal and the proportion of blast cells may start to increase in your bone marrow and circulating blood. These signs that your disease is progressing are usually picked up during a routine blood test. Some people start to notice symptoms of their disease including night sweats, increasing tiredness and fatigue or symptoms caused by an enlarging spleen (see below).

Blast phase

Eventually, CML transforms into a rapidly progressive disease resembling acute leukaemia. This is known as the blast phase or blast crisis. It is characterised by a dramatic increase in the number of blast cells in the bone marrow and blood (usually 20 per cent or more) and by the development of more severe symptoms of your disease. 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 markedly enlarged), the lymph nodes, skin and central nervous system (brain and spinal cord). This may also cause bone pain.

For many people CML remains stable for a long time causing few symptoms. Unfortunately for others, it can progress rapidly, transforming from a relatively stable disease into a rapidly progressive one. In some cases, CML may progress suddenly from the chronic to the blast phase of disease without moving through the accelerated phase.

In about two thirds of cases, blast transformation involves immature blood cells from the myeloid cell line, as the CML transforms into a disease resembling acute myeloid leukaemia (AML). In the remainder it involves immature blood cells from the lymphoid cell line, with the CML transforming into a disease resembling acute lymphoblastic leukaemia (ALL). In a 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 the accelerated and blast phases of disease is usually more intensive and is aimed at re-establishing the chronic phase and treating any symptoms of your disease.

Commonly used terms

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

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

Complete Haematological Response or CHR - This means that the treatment has successfully made the full blood count normal again.

Complete Cytogenetic Response or CCR - This means that the treatment has successfully reduced the number of CML cells, to the point that cytogenetic or FISH testing cannot find any CML cells in the bone marrow.

Major Molecular Response or MMR - This means that the treatment has reduced the CML cells even more than a Complete Cytogenetic Response. The very sensitive BCR-ABL PCR test is used to look for a Major Molecular Response or MMR. A MMR means that the treatment has successfully reduced the number of CML cells by over 1,000 times, compared to the number of CML cells seen at diagnosis. A BCR-ABL PCR test result of less than 0.1% is usually considered to indicate that a MMR has been reached.

Relapse - The leukaemia has reappeared or recurred.

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

TREATING CML

The treatment chosen for your CML largely depends on the phase of your disease, your age and general health. Current options include tyrosine kinase inhibitor (TKI) therapy, chemotherapy and stem cell transplant (dependant on the availability of a suitable stem cell donor).

Information gathered from hundreds of other people around the world who have had the same disease helps to guide the doctor in recommending the best treatment for you. 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 New Zealand and other parts of the world. Your doctor will be able to discuss with you all of the treatment options suitable for you.

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

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

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

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

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

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

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

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

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

Initial treatment at diagnosis

When you are first diagnosed with CML you may be given chemotherapy in tablet form to reduce the number of white cells in your circulating blood. In many cases a drug called hydroxyurea is used. During this time you may also be given a drug called allopurinol. This is not a chemotherapy drug, but is used to help prevent a build-up of breakdown products from the destroyed leukaemic cells and to help your kidneys excrete them safely. It also helps to prevent you developing acute gout.

Some people with CML are diagnosed with an extremely high white cell count. These cells need to be quickly removed from the bloodstream as they can otherwise accumulate and slow down the rate of blood supply to various organs and tissues. This can cause symptoms including difficulty breathing, blurred vision and confusion. Excess white cells are removed using a process known as leucopheresis. During this procedure a set amount of your blood is drawn from a cannula (plastic needle) placed in a vein in one arm, this blood is then passed through a special machine called a cell separator. This machine spins the blood very quickly and removes the excess white cells. Once the white cells have been removed the remaining blood is returned back to you through the cannula. This cycle of draw and return is repeated several times throughout the procedure. It is a painless procedure that usually takes about two to four hours to complete. If your veins are not suitable for this procedure, a special wide bore central venous catheter might be used instead. This line allows blood to be drawn from one of the bigger veins in your body.

Chronic phase

While you are in the chronic phase, treatment is given to control your CML by prolonging this phase and delaying the onset of symptoms and complications of your disease for as long as possible. During this phase you will be treated with tyrosine kinase inhibitors.

Advanced phase

In an advanced phase of CML the main aims of treatment are to try to re-establish where possible another or second chronic phase of disease, and to alleviate symptoms. There are several treatment options which may be used depending on your particular circumstances. These include more intensive chemotherapy using a combination of drugs similar to those used to treat acute leukaemia, a stem cell transplant, or another tyrosine kinase inhibitor. Some patients may benefit by participating in a clinical trial.

Supportive treatment to reduce symptoms of CML may include blood transfusions, antibiotics and other drugs to help keep you as well and comfortable as possible during this time.

Tyrosine kinase inhibitors (TKIs)

Most people with CML will be treated with a drug called imatinib mesylate (Glivec®). Imatinib belongs to a class of drugs known as tyrosine kinase inhibitors. They work by blocking the activity of the BCR-ABL tyrosine kinase, (produced as a consequence of the Philadelphia chromosome), thereby preventing the growth and development of leukaemic cells.

Imatinib produces a rapid and complete haematological response (controlling the blood count) in virtually all patients with Philadelphia chromosome positive (Ph+) CML in chronic phase. It also produces a high rate of complete cytogenetic remissions, causing the bone marrow stem cells to convert from Philadelphia chromosome positive (Ph+) to Philadelphia chromosome negative (Ph-). As such, imatinib prolongs the chronic phase, while reducing the rate of blast transformation for the majority of people diagnosed with CML.

Imatinib has proven more effective than other forms of treatment in producing effective long-term responses, and is recommended as standard of care for adult patients with newly diagnosed CML. While these drugs are usually very effective at controlling the disease, they do not cure it. Although TKIs can reduce the number of leukaemia cells to very low levels, they usually grow back if the drug is stopped. For this reason, treatment is usually continued for life.

Because TKIs are a relatively new therapy, very few patients have received imatinib for longer than 10 years. We don't yet know the stability of the response to this drug beyond this period, although the current information suggests the responses are stable and durable.

A small number of patients do not respond to imatinib, or have evidence of disease progression after an initial response. This is more common in those people who do not fully clear the Philadelphia chromosome from the bone marrow. Treatment options for this group of patients might include consideration of a stem cell transplant, or treatment with new drugs which are termed second generation tyrosine kinase inhibitors.

OTHER TYROSINE KINASE INHIBITORS

In recent years several new drugs that are similar to imatinib have been developed. These include dasatinib and nilotinib. It is likely that other new tyrosine kinase inhibitors will become available in the next few years. Nilotinib or dasatinib are usually given to the small number of CML patients who are either becoming resistant to imatinib or who experience very severe side effects. Both drugs seem to be similarly effective.

Nilotinib (Tasigna®) has a similar mode of action to imatinib, but is effective in some people who have become resistant to imatinib.

Dasatinib (Sprycel®) has a slightly different mode of action to imatinib and nilotinib.

Both nilotinib and dasatinib can cause an abnormal heart rhythm called QT prolongation in a small number of people. This risk is increased by 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.

Some people taking dasatinib develop fluid in the space around the lungs, called a pleural effusion. If identified early, pleural effusion may be well managed. This may require treatment with a steroid medicine, dose reduction, temporarily stopping dasatinib, or occasionally a procedure to drain the fluid.

TKIs can be taken in tablet or capsule form at home and are well tolerated by the majority of patients.

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

SIDE EFFECTS

Side effects are usually mild, and can vary from person to person depending on the dose given and how an individual responds to it. There is no doubt that side effects can be very unpleasant at times but it's good to remember that most of them are temporary and reversible. It is important that you report any side effects you are experiencing because many of them can be treated successfully, reducing any unnecessary discomfort for you.

Your nurse and doctor will tell you about the side effects you might experience and how they can be best managed.

Potential side effects of TKIs

- nausea and vomiting
- diarrhoea or constipation
- fluid retention and swelling
- muscle cramps
- skin problems
- abnormal heart rhythm
- fatigue
- low blood counts

To reduce the nausea and vomiting sometimes associated with TKIs it is important to take your medications in the middle of a substantial meal, with a large glass of water. They should not be taken on an empty stomach.

These medications interact with many other drugs. Drug interactions may interfere with the effectiveness of other drugs, by increasing or decreasing their concentration in your blood. Because drug interactions may be harmful to you, it is important that you speak to your doctor before taking any other drugs. These include prescription drugs, over-the-counter drugs, and herbal remedies.

Your bone marrow's ability to produce adequate numbers of blood cells can also be affected, resulting in a temporary reduction in the number of white cells, platelets and red cells circulating in your blood. This can cause symptoms of anaemia, make you more susceptible to infections, and result in bruising and bleeding more easily.

PREGNANCY

It is strongly recommended that you or your partner do not become pregnant whilst taking any tyrosine kinase inhibitor as it may harm the developing baby. As such, you need to ensure that you or your partner use a suitable form of contraception if either of you are having this treatment. Mothers are advised not to breast feed, if also taking a TKI.

ADHERENCE TO TREATMENT

Adherence, also commonly called compliance, to treatment regimes for CML is very important for the drugs to work effectively. If there is not enough drug in the body, the CML cells may mutate, potentially making treatment much more difficult in the future. Some mutations cannot be treated with TKIs and therefore your options for treating your CML are more limited. It is important not to make any changes in your treatment regime without discussing it first with your haematologist. Your doctor will be able to give you the best advice for your particular situation.

It is important that you don't stop taking your medication unless you are instructed to do so by your doctor. To be effective it needs to be taken every day.

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 may involve 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 blood cell count. The dose of the drug should be adjusted to the response of the white cells and also the response of other blood cells such as red cells and platelets. For example, sometimes a balance has to be made between the effect on lowering the white count and the increase in anaemia and thrombocytopenia caused by the drug; this is why blood counts may need to be monitored more frequently in this situation. Hydroxyurea is usually very well-tolerated and does not usually cause significant nausea or major hair loss, although it can cause dry skin.

People in accelerated or blast phase CML may benefit from more intensive anti-leukaemia therapy. This commonly involves the use of a combination of chemotherapy drugs given intravenously (into a vein), frequently in conjunction with a TKI, if appropriate. The drugs chosen are tailored to treat the type of leukaemic transformation which has occurred (acute myeloid leukaemia or acute lymphoid leukaemia). 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, and other more suitable treatment options will be considered.

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

Potential side effects of chemotherapy

- nausea and vomiting
- fatigue
- hair loss and thinning
- mouth problems
- diarrhoea or constipation
- skin problems
- low blood counts
- fertility problems

Stem cell transplant (peripheral blood stem cell or bone marrow transplant)

An allogeneic (donor) stem cell transplant, using donated bone marrow or peripheral blood stem cells, is currently the only option for curing CML. This treatment carries significant risks however and is generally only considered for a minority of patients, including those for whom a suitably matched donor can be found.

This 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).

Donor transplants carry significant risks and are only suitable as a second or third line of therapy in those uncommon cases where TKI therapy has failed. Best results are achieved when the transplant is carried out during the chronic phase of CML. Although this form of treatment may be offered to some patients with advanced disease, the risk of relapse is much higher during this time.

An alternative transplant approach involves using lower and therefore less toxic doses of chemotherapy and radiotherapy. This may be suitable for selected older patients and those with certain health problems who would benefit from, but might not be able to tolerate a conventional donor transplant. Using this approach less intensive doses of chemotherapy are used to treat disease in the bone marrow and suppress the patient's immune system sufficiently for it to accept the new, donated healthy stem cells. Meanwhile it is hoped that the donor's immune system will attack and destroy any left over CML. This is called a reduced intensity conditioning (RIC), non-myeloablative, or mini-allogeneic (mini-allo) stem cell transplant. Again, this is usually only undertaken in people whose CML is progressing despite imatinib and other tyrosine kinase inhibitors, or who have developed accelerated phase or blast crisis.

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

There are separate booklets about stem cell transplants available from the Leukaemia & Blood Foundation.

HOW DO I KNOW IF 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 1-2 weeks. This is to make sure that the high number of white blood cells that were found at diagnosis are returning to normal. It also makes sure that your platelets and red cells are alright. After this time blood tests are needed less frequently, usually every six weeks.

Once your white cell count returns to normal, your doctor uses a more sensitive blood test to detect how much leukaemia is still present. This is referred to as BCR-ABL PCR. This is a complicated test which often takes 10 days or more to complete. It can detect tiny amounts of leukaemic cells which would not be detected by simply looking at your blood or bone marrow under the microscope. The results of the BCR-ABL PCR will give your doctor the best indication of how well the treatment is working. This test also allows your doctor to detect the disease early if it is coming back. A blood test for BCR-ABL PCR is usually done every 3 to 6 months.

If your BCR-ABL PCR level is increasing significantly your doctor may arrange another blood test called a mutation analysis. This is because sometimes the leukaemic cells undergo slight changes called mutations which can effect how well the treatment works. The results of the mutation analysis can help your doctor decide whether a different tyrosine kinase inhibitor may be better for you.

A bone marrow biopsy is usually done at 6 and 12 months after starting treatment. This is used for cytogenetic tests and also BCR-ABL PCR.

Treatment for relapsed and resistant CML

Finding out that your CML has come back (relapsed) or is resistant to standard treatment can be devastating. It is important to remember however that there are still several options for treating the disease and getting it back under control. These may include the use of second generation tyrosine kinase inhibitors, a stem cell transplant or combinations of chemotherapy with TKIs.

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 New Zealand and other parts of the world. Your doctor will be able to discuss with you all of the treatment options suitable for you.

Palliative care

If a decision is made not to continue with anti-cancer treatment (chemotherapy, radiation, TKIs) for your CML, there are still many other options which can be used to support your quality of life and comfort for some time. Palliative care is aimed at relieving symptoms or pain you might be experiencing as a result of your disease or its treatment, rather than trying to cure or control it.

COMMON SIDE EFFECTS

Treatment with anti-cancer therapy such as TKIs, chemotherapy, radiotherapy and stem cell transplant may have unintended effects, known as side effects. Everyone is different and the side effects you experience may be different from the commonly experienced ones listed here. Before you start treatment your doctor or nurse will discuss the side effects associated with your particular course of treatment with you. You may also be given other medication before and during treatment to prevent or minimise known side effects. If you experience any side effect from treatment, even if not listed, please talk to your treatment team.

Nausea and vomiting

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

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

Changes in taste and smell

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

Mucositis

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

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

Infections

Infections can occur more commonly in CML. Don't hesitate to contact your doctor or treatment centre if you develop any of the following signs of infection so that you can be treated appropriately, with antibiotics and other drugs if necessary.

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

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

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

Bowel changes

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

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

Hair loss

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

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

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

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

Transfusions

If symptoms of anaemia are interfering with your normal daily activities, your doctor may recommend that you have a red blood cell transfusion. Platelet transfusions are sometimes given to prevent or treat bleeding (for example a persistent nose bleed). You do not need to be admitted to hospital for a red blood cell or platelet transfusion and they are usually given in the outpatient department.

Transfusions these days are relatively safe and they don't usually cause any serious complications. Nevertheless you will be carefully monitored throughout the transfusion. In the meantime, remember to call the nurse if you are feeling hot, cold, and shivery or in any way unwell, as this might indicate that you are having a reaction to the transfusion. Steps can be taken to minimise these effects and ensure that they don't happen again.

Fatigue

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

REPRODUCTIVE HEALTH

Fertility

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

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

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

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

Protecting your fertility - Men

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

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

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

Protecting your fertility - Women

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

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

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

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

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

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

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

Early menopause

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

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

It is important that you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you or refer you to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

Menstruation

Cancer treatment can also affect your periods; you may find your periods stop or become irregular. You may be prescribed a birth control pill to stop your periods. This prevents heavy bleeding and blood loss when your platelets are low. If you are having chemotherapy, it is best to use pads instead of tampons if you are menstruating as this will reduce the risk of infections. Always let your doctor know if you are having your period.

BODY IMAGE, SEXUALITY AND SEXUAL ACTIVITY

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

During treatment you may experience a decrease in libido, which is your body's sexual urge or desire, sometimes without there being any obvious reason. It may take some time for things to return to 'normal'. It is perfectly reasonable and safe to have sex while you are having treatment or shortly afterwards, but there are some precautions you need to take. It is usually recommended that you or your partner do not become pregnant as some of the treatments given might harm the developing baby. As such, you need to ensure that you or your partner uses a suitable form of contraception. Condoms (with a spermicidal gel) offer good contraceptive protection as well as protection against infection or irritation. Your partner may be worried that sex might in some way harm you. This is not likely as long as your partner is free from any infections and the sex is relatively gentle. Finally, if you are experiencing vaginal dryness, a lubricant can be helpful. This will help prevent irritation. Using a condom is also important to protect your partner from chemotherapy drugs that can be excreted in body fluids in the first few days after they are administered.

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

SUPPORTIVE CARE

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 side effects that arise from your disease or treatment. Blood transfusions, antibiotics, and for some people, complementary therapies, are all important elements of supportive care.

Complementary therapies

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

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

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

Nutrition

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

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

MAKING TREATMENT DECISIONS

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

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

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

Your doctor will spend time with you and your family discussing what he or she feels is the best option for you. Feel free to ask as many questions as you need to, at any stage. You are involved in making important decisions regarding your wellbeing. You should feel that you have enough information to do this and that the decisions made are in your best interests. Remember, you can always request a second opinion if you feel this is necessary.

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

Interpreting services

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

There are resources available from the Leukaemia & Blood Foundation in languages other than English.

INFORMATION AND SUPPORT

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

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

In some areas there may be patient group meetings, and there is also an online support and information forum run by the Leukaemia & Blood Foundation – LifeBloodLIVE. This is available at www.lifebloodlive.org.nz.

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

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

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

USEFUL INTERNET ADDRESSES

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

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

Leukaemia & Blood Foundation of New Zealand

www.leukaemia.org.nz

www.lifebloodlive.org.nz

Cancer Society of New Zealand

www.cancernz.org.nz

Leukaemia Foundation of Australia

www.leukaemia.org.au

American Cancer Society

www.cancer.org

MacMillan Cancer Support (A UK cancer information site)

www.macmillan.org.uk

Leukemia & Lymphoma Society of America

www.leukemia-lymphoma.org

Leukaemia & Lymphoma Research (UK)

www.llresearch.org.uk

National Cancer Institute (USA)

www.cancer.gov/cancerinfo

GLOSSARY OF TERMS

Acute leukaemia
Rapidly progressing cancer of the blood. Usually of sudden onset and characterised by the uncontrolled growth of immature blood cells which take over the bone marrow and spill into the bloodstream. If left untreated, it may be fatal within a few weeks or months.

Allogeneic stem cell or bone marrow transplant
Transplant using stem cells or marrow collected from a matched healthy donor, usually a brother or sister.

Alopecia
Loss of hair. Usually temporary when due to chemotherapy or radiotherapy treatment.

Anaemia
Deficiency of red blood cells which results in a reduced level of the oxygen carrying pigment haemoglobin in the blood. Causes pale skin, tiredness and other symptoms such as shortness of breath.

Antibiotics
Drugs that kill or stop the growth of bacteria, for example, penicillin.

Antibodies
Naturally produced proteins in the blood that destroy or neutralise specific toxins or infections such as viruses. They are produced by white blood cells known as lymphocytes when the body is exposed to these agents. They form an important part of the body's defence system against infection. Auto-antibodies or antibodies that attack the patients own tissues are produced in auto-immune disorders such as ITP.

Anti-emetic
A drug to prevent or alleviate nausea and vomiting that can sometimes be a side effect of chemotherapy. Drugs of this type include metoclopramide (Maxolon) and ondansetron (Zofran).

Autologous stem cell or bone marrow transplant
Transplant using stem cells or bone marrow collected from the patient's own blood or bone marrow that has been collected and stored after remission-inducing treatment. Because there are no problems with tissue matching this type of procedure has less risk than an allogeneic transplant and may be offered to all ages, including patients in their sixties and sometimes seventies.

Bacteria
Microscopic organisms which cause many infections, for example pneumonia. The reduced ability of patients to fight infections following chemotherapy or a transplant. Sometimes results in serious illness caused by normally harmless bacteria on the skin or in the mouth.

BCR-ABL gene
See Philadelphia (Ph) chromosome.

Blast cells
Immature marrow cells that normally represent up to five percent of cells in the bone marrow. They mature to replenish and produce the normal cells in the bone marrow and eventually the blood. Blast cells are not normally found in healthy peripheral blood.

Blast crisis
The phase of a chronic condition which has transformed into an acute condition. For example, when chronic myeloid leukaemia progresses to acute leukaemia. This can result in a very high number of immature, abnormal white blood cells (blasts) in the bone marrow and blood.

Blood cells
There are three main types of cells in the bloodstream – the red blood cell which carries oxygen, the white blood cell which fights infection, and the platelet which helps prevent bleeding.

Blood count
A routine blood test that measures the number and type of cells circulating in the blood. Also known as a Full Blood Count (FBC) or a Complete Blood Count (CBC).

Blood disease
This is a misleading term, because although diseases are often found in the blood, they usually originate from the bone marrow, where the blood cells are produced. Diseases are classified by their cell of origin. For example, lymphoma, from the lymphatic system.

Bone marrow
The tissue that is found within the hollow cavities of most of the bones of the body. In children these include the arms and the legs, but the red marrow regresses centrally from the limbs in adult life and is replaced by non-functional fatty marrow. Red bone marrow contains stem cells from which all blood cells originate.

Bone marrow biopsy
A procedure to collect a sample of the bone marrow. This is usually from the back of the hip bone, or occasionally from the breastbone (sternum). This procedure is often done under local anaesthetic with or without light sedation and incorporates either or both of the following:

Aspirate - A procedure that involves removing (or aspirating) a small sample of bone marrow fluid for examination in the laboratory.

Trephine - A procedure that involves removing a small core of bone and bone marrow for examination in the laboratory.

Bone marrow transplant (BMT)
Type of transplant, also called a stem cell transplant, used in the treatment of a variety of bone marrow disorders including leukaemia, lymphoma and myeloma. The patient receives very high does of chemotherapy and/or radiotherapy to treat the disease. This destroys the bone marrow and makes the blood count fall. Replacement stem cells are taken from the bone marrow of a matched donor under anaesthetic (allogeneic stem cell transplant) and returned to the patient through a vein (or central venous line) in a similar way to a blood transfusion. See also stem cell transplant.

Cancer
Disease due to abnormal cells growing in an uncontrolled fashion, creating a tumour, invading nearby tissues and/or spreading through the blood and lymph systems. Also called malignant disease or neoplasia. Cancer causes problems from the release of chemicals from the cells, direct pressure or infiltration of organs such as the lungs, or loss of normal cellular functions such as the production of blood cells.

Cannula
A plastic tube which can be inserted into a vein, usually in the hand or arm, to allow fluid to enter the blood circulation, such as an intravenous (IV) infusion.

Central venous line
A narrow plastic tube inserted through the skin into a major blood vessel in the chest or neck. It is used for patients undergoing intensive therapy and provides a route for taking blood samples and administering drugs and other treatments without repeated needle punctures into the patient's arm. It may have one or multiple tubes (called lumens). Different manufacturing companies produce these devices - examples include the Groshong catheter, Hickman catheter, Apheresis catheter and the Portacath.

Chemotherapy
Treatment using anti-cancer drugs. These may be used on their own or in combination to kill or prevent the growth and division of cells. Although aimed at the cancer cells, chemotherapy often affects rapidly dividing normal cells such as those in the scalp and gut, causing hair loss and nausea in some instances. These side effects are usually temporary, reversible and can be minimised by other means such as using anti-nausea drugs. Some newer drugs are more specific to cancer cells and therefore less toxic to other cells in the body. An example is rituximab (Mabthera) used to treat non-Hodgkin lymphoma (NHL).

Chemotherapy cycle
Chemotherapy is usually given in cycles, with chemotherapy drugs given for a predetermined number of days, followed by a recovery period. The purpose of the recovery period between cycles of chemotherapy drugs is to allow the recovery of the normal cells in the bone marrow, i.e. the red blood cells, white blood cells and platelets before giving further chemotherapy to eradicate remaining cancer cells.

Chromosomes
Chromosomes contain the genetic code compactly packaged, and are visible under the microscope when a cell divides. Chromosomes carry the 100,000 genes that provide the inherited blueprint of each individual. In humans there are normally 23 pairs contained in the nucleus of each cell. Alterations in the number or organisation of the chromosomes may play a key role in the development of cancer.

Chronic leukaemia
A persistent cancer of the blood, usually of gradual onset and generally of slow progression. May be diagnosed by chance following a routine blood test and before clinical symptoms appear. In chronic leukaemia, the cells are more mature than acute leukaemia cells.

Clinical trial
A controlled and carefully monitored assessment of new forms of treatment subject to ethical approval. Trials can vary in design and size from small-scale trials of experimental treatments to large international trials that compare subtle variations in current therapies. Patients will be informed and will always be given the option to join or not, without detriment to their usual treatment if they decline to participate. Likewise, patients can opt out of a clinical trial at any time.

Complete remission
Anti-cancer treatment has been successful in that so much of the disease has been destroyed that it can no longer be detected. In people with leukaemia this means the proportion of blast cells present in the circulating blood has vastly decreased and the blood count has returned to normal.

Cure
This means that there is no evidence of disease and no sign of the disease reappearing. In practical terms the absence of symptoms (being cancer free) for five years after treatment is considered a cure for many different types of blood cancers.

Cytogenetics
The study of the structure of chromosomes. Cytogenetic tests are carried out on samples of blood and bone marrow taken from leukaemia patients to detect chromosomal abnormalities associated with the disease. These tests help in the diagnosis and selection of optimal treatment.

Deoxyribonucleic acid (DNA)
Molecules found in the nucleus 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.

Diagnosis
The identification and naming of a person's condition.

Disease progression
Disease advancement, or worsening, despite treatment.

Febrile
Having a fever or a high temperature above the normal baseline (37^{0}C).

Generic drug
This is the chemical or scientific name for a particular drug, such as aspirin or allopurinol. Each drug company will also add a trade name to the drug, such as Cartia or Solprin (examples of aspirin) or Zyloprim or Progout (two brands of allopurinol). There may be differences in the costs and pharmaceutical benefits of different brands. Any changes in the type of drug that you are dispensed should be discussed with the pharmacist or your doctor.

Genes
Collection of DNA on a chromosome, present in the nucleus of the cell. Genes which direct the cell activity and functions, are responsible for the inherited characteristics that distinguish one individual from another. Each person has an estimated 100,000 separate genes.

Granulocyte
A type of white blood cell containing granules in its cytoplasm. The three subtypes, neutrophils, eosinophils and basophils, protect the body against infection by seeking out and killing micro-organisms. Mature neutrophils known as segmented neutrophils are the body's most important protection from bacteria.

Haematologist
A specialist doctor who diagnoses and treats diseases of the blood and bone marrow. These diseases may be malignant such as leukaemia and lymphoma, or non-malignant such as inherited blood disorders like haemophilia and thalassemia.

Haemopoiesis or haematopoiesis
Term used to describe the growth of cells maturing from very primitive (stem) cells through to fully developed and functional blood cells.

Haemorrhage
Technical name for bleeding, can occur inside the body (internal), as well as outside the body (external).

Hickman catheter
A type of central venous line.

Human leucocyte antigens (HLA)
A complex family of genetically inherited proteins which are found on the surface of cells throughout the body. HLA antigens must be matched between patient and potential donor(s) in transplantation. HLA factors are inherited from both parents, and the chance of having the same HLA type between brothers and sisters is one in four. HLA types are inherited differently from red blood cell types.

Immunocompromised
Lowered immune function, can be due to disease or treatment side effects.

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

Immunosuppression
A reduction in the body's defence mechanisms. Deliberate immunosuppression is a necessary part of the transplant procedure to allow engraftment and to prevent graft versus host disease. Immunosuppression is also used to treat other diseases such as rheumatoid arthritis and ITP.

Indolent
Slow growing.

Informed consent
A form that a person signs to indicate that they understand the information they have been given about the treatment or trial and agree to take part.

Intravenous (IV)
Into a vein; this route is used to inject antibiotics, chemotherapy and other drugs, blood products and fluids quickly as a bolus, or slowly as an infusion.

Leukaemia
Cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and/or immature blood cells. These cells crowd the bone marrow and spill out into the bloodstream.

Low grade
Slow growing.

Malignancy
A term applied to tumours characterised by uncontrolled proliferation of cells. See cancer.

Mucositis
Inflammation of the lining of the mouth, throat or gut which often occurs after high dose chemotherapy.

Mutation
A minute change to the DNA code, caused (for example) by exposure to hazardous chemicals or copying errors during cell division. Some mutations can affect normal cell function leading to disease development and can be inherited by the next generation.

Neutropenia
Reduction in the blood neutrophil count. This may be caused by bone marrow disease, infection, auto-immune disorders, vitamin B12 or folate deficiency, or by high dose chemotherapy. The normal adult range is $>2.0 \times 10^9$/L, less than this is considered neutropenic and if $<0.5 \times 10^9$/L, the patient is considered severely neutropenic and is at high risk of infection.

Oncologist
A specialist doctor who diagnoses and treats cancers, usually those other than diseases of the bone marrow, such as breast, lung, prostate.

Palliative care
Treatment aimed at relieving symptoms, pain and improving quality of life, if possible. This type of treatment is given to all patients, often in addition to other treatment aimed at reducing the cancer size or disease activity. Patients with advanced disease receive palliative care to relieve pain and other symptoms, even when curative treatment is no longer an option.

Partial remission
The disease has responded to treatment but remains detectable.

Peripheral blood stem cells
Stem cells which have spilled over from the bone marrow to the blood stream and are circulating in the blood throughout the body.

Peripherally inserted central catheter (PICC line)
A form of a central intravenous long line, which is a narrow plastic tube inserted into and threaded up a vein of the arm. This is used in patients undergoing intensive therapy for the administration of drugs, transfusions and other treatment and may also be used for taking blood samples.

Petechiae
Small red or purple pinhead spots in the skin or mucous membrane (such as the lining of the mouth). These are small bleeds and usually occur when the platelet count is very low. Smaller in size than purpura.

Phenotype
An individual's anatomical structure, physiology and behaviour under a particular set of environmental factors, regardless of the actual genotype or inherited genes. For example, in haemochromatosis, patients with the same gene mutation can have varying degrees of iron overload and organ damage; or the differences that can occur in identical twins. Also used to describe the characteristics of a cell or tissue.

Philadelphia (Ph) chromosome
An abnormal chromosome that is present in almost all cases of chronic myeloid leukaemia and some cases of acute lymphoblastic leukaemia. It is formed when part of chromosome 9 (the ABL gene) is translocated to chromosome 22 (the BCR gene). This translocation t(9;22) produces a new gene BCR-ABL and can be measured with PCR testing. Named Philadelphia after the city in which it was first described.

Plasma
The yellow fluid component of the blood in which the cells are suspended. This contains soluble substances such as glucose, fats, hormones, clotting factors, for distribution around the body.

Platelets
Type of blood cells produced in the bone marrow, which circulate in the blood playing an important role in the prevention and immediate control of bleeding.

Polymerase Chain Reaction (PCR)
Type of cytogenetic blood test looking at molecular changes in a cells DNA. Used in the diagnosis and monitoring of conditions such as BCR-ABL levels in chronic myeloid leukaemia.

Prognosis
An assessment of the likely progression of disease, particularly concerning the chances of cure, complete recovery or likely years of survival.

Purpura
A small bleed (up to about 1 cm in diameter) in the skin or a mucous membrane (such as the lining of the mouth), which may be caused by a shortage of platelets, clotting factors or because of trauma.

Quality of life
A measure of how your disease and its treatment is affecting you and your ability to carry out your normal daily activities.

Radiation therapy
Also known as radiotherapy. High-energy rays are used to damage cancer cells and stop them from growing and dividing. This can be very effective, particularly in lymphoma and myeloma. Side effects vary according to the dose and site of treatment and are discussed with the patient when such treatment is being planned. Radiation can be administered by an external beam (the usual type), by an internally placed tube (brachytherapy), or by an implant (a small container of radioactive material) placed directly into or near the tumour.

Randomised trial
A scientific study where patients are randomly allocated to specific treatment therapies to test effectiveness and toxicity. The type of treatment is sometimes blinded, meaning that the patient and their doctors do not know who is receiving which form of treatment. These trials are regularly reviewed by the investigators, coordinators and the ethics committees and if at any time one treatment option is found to be superior, future patients usually are likely to receive that therapy. Such studies are very important in patients with leukaemia and other blood conditions, as many diseases are relatively rare and the best type of treatment is unknown or is still to be identified.

Red blood cells
The cells of the blood containing haemoglobin which carries oxygen from the lungs to all the tissues of the body. Low haemoglobin is called anaemia.

Relapse
The recurrence of disease in the bone marrow or other organs after a remission has been achieved. In leukaemia this may be indicated by changes in the blood, bone marrow, CNS or testes, even before the patient experiences any symptoms.

Remission
Restoration of the blood, bone marrow and general health of the patient to normal. Usually induced by chemotherapy and/or radiotherapy.

Side effect
Unintended effects of a drug or treatment.

Spleen
An organ that is involved in the development of the immune system, which destroys red cells at the end of their lifespan and helps the body to fight certain infections. The spleen, situated high on the left side of the abdomen under the ribcage adjacent to the stomach, is often enlarged in leukaemia and some non-malignant blood conditions.

Standard therapy
The most effective and safest treatment currently being used.

Stem cells
The most primitive cells in the bone marrow from which all the various types of blood cell develop from.

Stem cell transplant (SCT)
General name given to bone marrow and peripheral blood stem cell transplants, used in the treatment of a variety of bone marrow disorders including leukaemia, lymphoma and myeloma. The patient receives very high doses of chemotherapy and/or radiotherapy to treat the disease. This destroys the bone marrow and makes the blood count fall. Stem cells are collected from the blood via apheresis, the bone marrow or placental (cord) blood of a matched donor. Stem cell transplants can be autologous (collected from the patient) or allogeneic (collected from another person). Replacement cells are returned to the patient through a vein (or central venous line) in a similar way to a blood transfusion. See also bone marrow transplant.

Supportive care
Treatment directed against the effects of the cancer, not against the cancer itself.

Transformation
A term to describe either the change of a normal cell into a cancerous cell, or the acceleration of disease. For example, in chronic myeloid leukaemia transformation from the chronic to a more acute phase (characterised by the production of large numbers of blast cells).

Translocation
A chromosome abnormality in which part of one chromosome has transferred to another.

White blood cells
Also known as leucocytes, these include several different types of cells within three main groups: granulocytes, lymphocytes and monocytes. White blood cells are formed in the bone marrow and their uncontrolled proliferation leads to leukaemia.

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

Leukaemia &
Blood Foundation
Vision to Cure - Mission to Care

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

- ❑ Dictionary of Terms
- ❑ Acute Myeloid Leukaemia
- ❑ Chronic Myeloid Leukaemia
- ❑ Non-Hodgkin Lymphoma
- ❑ Myeloproliferative Disorders
- ❑ Multiple Myeloma
- ❑ Autologous Stem Cell Transplants
- ❑ Haematology Patient Diary
- ❑ Acute Lymphoblastic Leukaemia
- ❑ Chronic Lymphocytic Leukaemia
- ❑ Hodgkin Lymphoma
- ❑ Myelodysplastic Syndromes
- ❑ Allogeneic Stem Cell Transplants
- ❑ Clinical Trials
- ❑ My guide to blood cancer - for adolescents and young adults

Or information on:

- ❑ The Leukaemia & Blood Foundation's Support Services
- ❑ How to make a bequest to the Leukaemia & Blood Foundation
- ❑ How to become a volunteer

Newsletters:

- ❑ LifeBlood
- ❑ Lymphoma Today
- ❑ Myeloma Today

Name: .....

Address: .....

Postcode: ..... Phone: .....

Email: .....

Send to: The Leukaemia & Blood Foundation

PO Box 99182 Newmarket, Auckland 1149

Phone: (09) 638 3556 or 0800 15 10 15

Email: info@leukaemia.org.nz

The Leukaemia & Blood Foundation will record your details to facilitate services and keep you informed about leukaemia and related blood disorders. We value your privacy and take all the necessary steps to protect it. You can access, change or delete this information by contacting us at info@leukaemia.org.nz

NOTES

Chronic Myeloid Leukaemia

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

1. Did you find this booklet helpful?

❑ Yes ❑ No

Comments: _____

_____

_____

2. Did you find the booklet easy to understand?

❑ Yes ❑ No

Comments: _____

_____

_____

3. Where did you get this booklet from?

_____

_____

_____

4. Did you have any questions that were not answered in the booklet?

❑ Yes ❑ No

If yes, what were they?

_____

_____

_____

5. What did you like most about this booklet?

6. What did you like least about this booklet?

7. Any other comments?

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

Please return to: Leukaemia & Blood Foundation
PO Box 99182
Newmarket
Auckland 1149

Leukaemia & Blood Foundation
Vision to Cure - Mission to Care

Contact details of Haematology Centres throughout NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road Whangarei	(09) 430 4100
North Shore Hospital	Shakespeare Road Takapuna	(09) 486 1491
Auckland Hospital	Park Road Grafton	(09) 379 7440
Starship Hospital	Park Road Grafton	(09) 379 7440
Middlemore Hospital	Hospital Road Otahuhu	(09) 276 0000
Waikato Hospital	Pembroke Street Hamilton	(09) 839 8899
Thames Hospital	Mackay Street Thames	(07) 868 6550
Tauranga Hospital	Cameron Road Tauranga	(07) 579 8000
Hastings Hospital	Omahu Road Hastings	(06) 878 8109
Rotorua Hospital	Pukeroa Street Rotorua	(07) 348 1199
Whakatane Hospital	Stewart Street Whakatane	(07) 306 0999
Palmerston North Hospital	Ruahine Street Palmerston North	(06) 356 9169
Wellington Hospital	Riddiford Street Newtown	(04) 385 5999
Christchurch Hospital	Riccarton Avenue Christchurch	(03) 364 0640
Dunedin Hospital	Great King Street Dunedin	(03) 474 0999
Invercargill Hospital	Kew Road Invercargill	(03) 218 1949

Leukaemia &
Blood Foundation
Vision to Cure - Mission to Care

Freephone 0800 15 10 15
Telephone (09) 638 3556
Facsimile (09) 638 3557
Email info@leukaemia.org.nz

National Office:
6 Claude Rd, Epsom 1023
PO Box 99182, Newmarket 1149
Auckland, New Zealand

www.leukaemia.org.nz

12/2010 V3
Charities Commission no. CC24498