Chronic Myeloid Leukaemia (CML)

A guide for people with CML and their support people

Leukaemia Foundation

Leukaemia Foundation®

This booklet has been written to help you and your support people understand more about chronic myeloid leukaemia, commonly called CML.

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with CML. Maybe you are discussing different treatment options with your treatment team, or maybe you have started treatment. Whatever point you are at, this booklet will answer some of your questions and it may raise others, which you can jot down and discuss with your haematologist or nurse.

If you don't feel like reading this booklet from cover to cover, look at the Contents list and choose which parts to read now. You can come back to read other parts later. You may need more information, so towards the back of the booklet there is a list of useful resources. Your doctor or nurse might also give you some further reading. You can always call our Blood Cancer Support Coordinators to find out how we can help you.

You will meet many different types of healthcare professionals who work as a team to provide you with the best treatment available. The people you will see most often will be haematologists and haematology nurses, and you'll need a regular GP, but you'll also meet pathologists and allied health professionals, like dietitians. In this booklet, when we refer to 'your treatment team' we usually mean your haematologist and haematology nurses.

You will come across quite a few medical terms in this booklet. They are words that your treatment team will probably use and that you may not have heard before. Your treatment team will be happy to explain any terms you don't understand, so never be afraid to ask. Many of these words are defined in the text or in the Glossary at the end of this booklet.

Although we provide some information about treatments, this booklet does not recommend any particular form of treatment and you must discuss your circumstances and best treatment options with your haematologist.

We hope you find this information useful. We'd love to hear any feedback so we can make sure we best meet your information needs.

The Leukaemia Foundation acknowledges the traditional owners of country throughout Australia and recognises their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

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CML in brief

About CML

Chronic myeloid leukaemia (CML) is cancer that starts in the bone marrow, where blood cells are made.

Normally, the bone marrow makes red cells to carry oxygen around the body, platelets to stop bleeding from cuts and wounds, and white cells to defend the body against infections. There are different types of white cells which fight bacteria, viruses, and fungi. The normal healthy bone marrow makes just enough of each type of cell for normal body function. More cells are made in response to stress and infection.

In CML, the bone marrow makes an abnormally high number of cells. A chromosome switch referred to as the Philadelphia chromosome leads to a mutated gene, called *BCR-ABL*, which makes a defective enzyme, called *tyrosine kinase*. Tyrosine kinases are switches that control cell growth and division. Normally, tyrosine kinases switch cell growth on or off depending on the body's needs. The *BCR-ABL* tyrosine kinase is defective, in that it cannot be switched off. This leads to inappropriate cell growth.

Neutrophils are a type of white cell that are almost always overproduced in CML, however, the cells produced generally function normally. This situation is called chronic phase disease. Most patients are diagnosed in chronic phase, at which point the disease generally responds well to therapy with oral tablets.

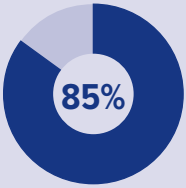
If left untreated, the disease progresses to accelerated phase, then to blastic phase disease. In accelerated and blastic phases, the disease is more advanced.

Symptoms of CML include tiredness, weakness, weight loss, fever, night sweats, infections, easily bruising, and/or looking pale.

CML is diagnosed using blood tests and a bone marrow biopsy.

Who gets CML?

317
Australians diagnosed each year



85% of people diagnosed aged 40+

59.8
average age of diagnosis

Risk of diagnosis 75YO

1 in 1254 1 in 983

Risk of diagnosis 85YO

1 in 902 1 in 669

What's the prognosis?

A prognosis is an estimate your haematologist will make of the likely course and outcome of your disease. Your haematologist will consider many factors when considering your prognosis. Some of these are the phase of your CML, your risk score if you are in the chronic phase, your age, your overall health, and how you respond to treatment. Your prognosis might change during or after you have treatment.

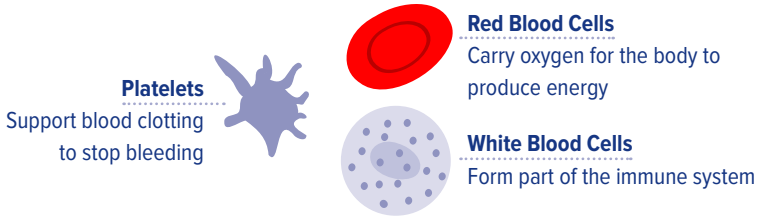
Scan to learn more about how the Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

All about blood

What is blood?

Blood travels to all parts of your body, carrying oxygen, nutrients, and waste products. Blood is made up of cells and plasma. Plasma is the straw-coloured liquid part of the blood that carries blood cells and other substances around your body.

The main types of blood cells are red and white. Platelets are talked about like blood cells, but they are *fragments* of blood cells.



Red blood cells

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives the blood its red colour and carries oxygen from the lungs to all parts of the body.

Most blood cells in your total blood volume (40-45%) are red blood cells.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs.

Although they make up only a small part (1%) of the blood, white blood cells protect us against and fight off infection. While all of them are important, you will hear the most about neutrophils and lymphocytes. Neutrophils fight bacteria and are especially important in recovering from chemotherapy.

Platelets

Platelets, also known as thrombocytes, are small pieces of bone marrow. They stick together to help your blood clot, a process called *coagulation*. They help stop bleeding when you have an injury.

Where and how is blood made?

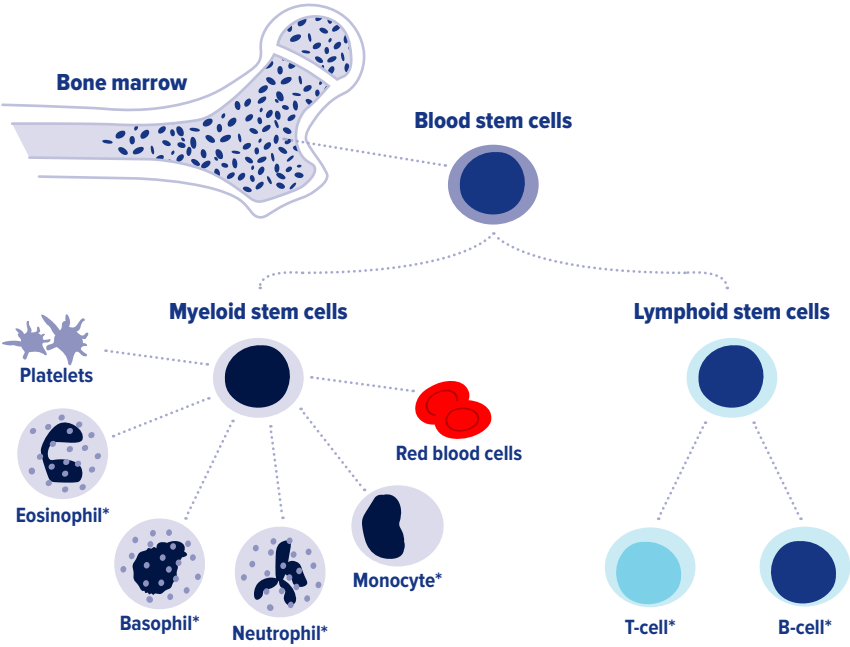
Bone marrow

Bone marrow is spongy tissue in the middle of certain bones. Most blood cells are made in your bone marrow. This process is called *haemopoiesis*.

In children, haemopoiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae) and hips, ribs, skull, and breastbone (sternum). You may have a bone marrow biopsy taken at the back of your hip (the iliac crest).

Think of blood production as a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

There are two types of progenitor cells that split the family tree: lymphoid cells and myeloid cells. At the bottom of the family tree are red blood cells, white blood cells*, and platelets.



Growth factors

All normal blood cells live a short time: red blood cells 80-100 days, neutrophils 8-14 days, and platelets 4-5 days. They then die off and are replaced by new cells from the bone marrow. This means that your bone marrow remains very busy throughout your life.

Chemicals in your blood called *growth factors* control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

Some growth factors can be made in the laboratory (synthesised) and given to people to help treat blood disorders.

All about leukaemia

Leukaemia is a group of cancers that usually develops in the bone marrow. Leukaemia starts in developing blood cells which have had a malignant change. They multiply in an uncontrolled way and don't mature how they are supposed to. Because they have not matured properly, these cells can't function normally.

Types of leukaemia

There are several different types and subtypes of leukaemia.

Leukaemia can be either *acute* or *chronic*. The terms 'acute' and 'chronic' refer to how quickly the disease develops and progresses. Acute diseases tend to develop and progress very quickly, whereas chronic diseases develop and progress over a long time. Chronic myeloid leukaemia is a chronic type.

What is chronic leukaemia?

In people with chronic leukaemia, the bone marrow makes too many mature white blood cells over time. These over-produced cells are called *leukaemic* cells.

The leukaemic cells build up in the bone marrow. They often spill out into the bloodstream. Sometimes leukaemia spreads from the blood to other organs like the spleen or liver.

All about CML

What is CML?

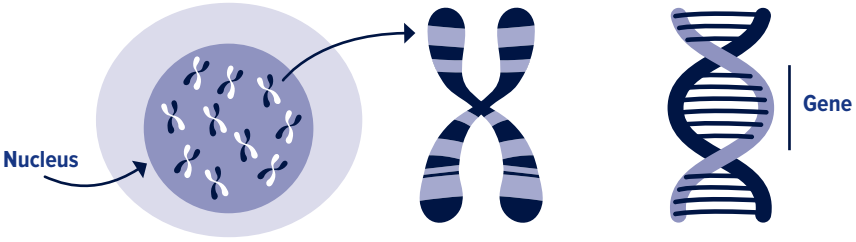
Chronic myeloid leukaemia (CML) is a slow-growing leukaemia. It starts in young (immature) white blood stem cells in the bone marrow. They mature into blast cells, then into white blood cells called *granulocytes*. There are three types of granulocytes: neutrophils, basophils, and eosinophils. People with CML have too many granulocytes.

There are three phases of CML: the chronic phase (by far the most common), the accelerated phase, and the blast phase (also called blast crisis). Your haematologist will work out which phase you are in after you have had all the tests you'll need for diagnosis. These phases are explained in more detail on page 20 of this booklet.

How does CML develop?

CML affects how normal blood cells are made in your bone marrow. Normally, myeloid stem cells make blast cells that become healthy blood cells.

Inside cells there are coded instructions that control how the cell should act. Chromosomes inside cells are long strands of DNA (deoxyribonucleic acid). Each section of DNA that holds the cell's instructions is called a *gene*.



Cell
The nucleus controls the processes of the cell

Chromosome
Chromosomes are thread-like structures made up of DNA tightly coiled many times around proteins called histones

DNA
Deoxyribonucleic acid is a self-replicating material present in nearly all living organisms as the main part of chromosomes. It is the carrier of genetic information

In CML, the DNA in stem cells in the bone marrow is altered. The DNA alteration is called an *acquired mutation*. Each altered stem cell divides and creates a clone. A clone is a group of identical cells all with the same mutation. This is why CML is sometimes called *clonal*.

In CML, for reasons that we don't understand, two chromosomes (9 and 22) swap genetic material to create a new 'hybrid' chromosome called the *Philadelphia chromosome*. The region where chromosome 9 joins chromosome 22 creates a new gene, called *BCR-ABL*. This gene codes for an enzyme called tyrosine kinase.

As a result of this overactive tyrosine kinase, the bone marrow makes too many granulocytes. They eventually build up and crowd the bone marrow (these are called *blast cells*). Because the bone marrow can't function properly, it can't make enough normal red blood cells, white blood cells, and platelets.

This means that people with CML can have very active bone marrow, producing many cells, but a low number of healthy blood cells are circulating in the bloodstream. Low numbers of blood cells are called *cytopenias*. One type of cytopenia is *anaemia*, which is where someone has low red blood cells.

Is CML cancer?

CML is a form of blood cancer. It is slow-growing and patients may not be unwell initially. If untreated, it will progress to more aggressive forms over months to years. Rarely, patients are already in the more aggressive accelerated phase or blastic phase when they come to medical attention.

Causes of CML?

Gene mutations in cells happen all the time. Healthy cells have clever ways of stopping them from causing problems in the body. But the longer we live, the more chance we have of getting mutations that can escape these safeguards. That's why CML is more often diagnosed in older people. Why a particular person at a particular time gets CML is not really known. But some things (*risk factors*) give some people a higher risk of developing CML.

Nearly everyone (95%) with CML has a chromosomal abnormality called the Philadelphia chromosome and the *BCR-ABL* fusion gene. Normal blood cells don't contain the *BCR-ABL* gene. It's found in CML blood and bone marrow cells.

Known risk factors

- **Ageing** because the risk of developing genetic mutations increases with age.
- Previous **radiation therapy**, or accidental exposure to high levels of environmental irradiation.

Symptoms of CML

Many people with CML have no symptoms at all. It may be just picked up during a routine blood test. Some visit their general practitioner (GP) because they have troubling symptoms.

You may have general symptoms, such as:

- fatigue (extreme tiredness not relieved by rest)
- loss of appetite/feeling full after eating a small amount
- weight loss without trying
- fever
- night sweats
- bone pain where there is a build-up of leukaemic cells
- a swollen (enlarged) spleen.

Low blood counts

Many symptoms of CML are because of low normal blood cell counts. Your bone marrow can't make enough healthy cells. You may have lower-than-normal numbers of red blood cells, white blood cells or platelets, or a combination of these.

Anaemia is caused by low red blood cells. Red blood cells carry oxygen around your body.

Neutropenia is a low number of a type of white blood cells (neutrophils). White blood cells support your immunity.

Thrombocytopenia is low platelet count. Platelets help control bleeding and help wounds to heal.

You may have symptoms from each of these groups because all your blood cell types can be low due to CML (which is called *pancytopenia*).

Condition	Cause	You might notice
Anaemia	Low RBCs or Hb	Tiredness, weakness, pale skin, shortness of breath, heavy legs, difficulty concentrating, feeling lightheaded, rapid or irregular heartbeat.
Neutropenia	Low WBCs (neutrophils)	More frequent or severe infections e.g. chest or skin, fevers, shivering, chills, low blood pressure, mouth ulcers.
Thrombocytopenia	Low platelets	Easy bruising and bleeding e.g. nosebleeds, cuts that keep bleeding, coughing up blood, petechiae (see image below) – tiny, unraised red blood spots under the skin often starting on the legs.
Pancytopenia	All three blood cell types are low	A mix of symptoms from all three conditions.

Petechiae

Enlarged spleen

Your spleen is an organ that is in the top left of your abdomen, near your rib cage. It acts like a sponge for blood cells. It stores blood cells but can also make them. If your spleen starts making blood cells it may swell up. When the spleen is swollen (enlarged), it is called *splenomegaly*. Up to half of people with CML will have an enlarged spleen.

If you have splenomegaly you may feel fullness, discomfort, or pain in the upper left side of your abdomen and you may feel rapidly full after eating or drinking. Your liver can act in the same way, although this is rarer in CML. When the liver swells up, it's called *hepatomegaly*. It will feel like splenomegaly, but in the top right of your belly.

Symptoms caused by high numbers of leukaemic cells

Some people in the blast phase of CML may have a condition called *leukostasis*. Blasts are bigger than normal white blood cells. It can be hard for them to get through small blood vessels. With high blast counts, blood vessels can clog up. This means red blood cells can't get to the tissues. This is a medical emergency. Symptoms include:

- headache
- confusion
- slurring speech
- weakness on one side of the body
- sleepiness.

These symptoms are similar to a stroke. It's important to go straight to emergency if you have them.

How is CML diagnosed?

Your haematologist will diagnose CML by talking with you about how you are feeling, and looking at samples of your blood and bone marrow. Some symptoms of CML, like feeling tired, and low or abnormal blood counts, are part of many conditions as well as side effects of some medications. Over recent years, the diagnosis and stage of CML has become increasingly important to provide clinicians with all the information they need to make the best treatment decisions for each patient. It is important for the clinician to understand the exact subtype classification (if applicable) and stage for treatment and prognostic decisions. You may need a few types of tests before the CML and your phase is diagnosed.

Medical history and physical exam

First, your treatment team will take a full medical history. They'll ask you to talk about past and present illnesses, health problems, infections, and bleeding. They'll also need details of any old and new medicines you're taking, including prescribed and any over-the-counter medicines you take regularly.

Blood tests

Blood tests can identify a range of issues in your body that will help your doctor diagnose any conditions you may (or may not) have. They are a key diagnostic, observation, and maintenance tool for people living with blood cancer.

Full blood count

You'll be asked to have a simple blood test called a full blood count (FBC). This test measures the number of red cells, white cells, and platelets in circulation. Your treatment team will give you a referral and tell you where to go to have it done. They will also tell you if you need to fast (not eat or drink) for a certain amount of time before you have the blood test.

Blood chemistry tests

Blood chemistry tests measure the levels of different chemicals in your body. These blood tests will often be taken at the same time as your FBC.

Some substances that may be tested include:

Substance tested	What it indicates
creatinine	Kidney function
electrolytes	Kidney function
blood urea nitrogen (BUN)	Kidney function
Liver function tests (LFT)	Liver function
uric acid	Cell breakdown
lactate dehydrogenase (LDH)	Blood cell damage

Bone marrow biopsy

If your treatment team thinks you may have CML, based on your blood test results, the next step is a bone marrow test. This test is more complex than a blood test, but it won't involve a hospital stay. It will be done in your haematologist's rooms or in a day procedure clinic, or outpatient ward in a hospital. You should bring a support person with you to keep you company while you wait and to help you home, as you may not be able to drive.

What does a bone marrow biopsy involve?

A bone marrow biopsy involves using a needle to enter the bone marrow, most commonly in the hip bone towards the lower end of the back. This is an area where the bone is usually quite close to the skin and an area that can be easily accessed by the bone marrow needle.

Is a bone marrow biopsy painful?

Having a bone marrow biopsy is sometimes painful. With the use of local anaesthetic before the bone marrow needle is inserted this pain is usually well tolerated. Often, you will be given a form of pain preventer that you breathe in, or a small dose of sedative (under appropriate hospital conditions) to assist in the management of the discomfort.

What to expect afterwards

You should try to rest for the day. If you have had sedation then you must not drive a car or work for 24 hours, so you will need someone to take you home. You may not have any pain but if you do, take a paracetamol tablet. You can take off the dressing and shower 24 hours after the test, or as advised by your treatment team.

Molecular genetic tests

Molecular genetic tests, such as polymerase chain reaction (PCR), look directly at the genetic sequence/code and help your haematologist work out the best course of treatment for your CML. It may take a few weeks for these test results to come through.

PCR

Polymerase chain reaction (PCR), sometimes called *quantitative reverse transcriptase PCR* or *QPCR*, uses DNA to look for specific gene mutations. This test can find one CML cell in more than 100,000 normal cells. It is often done at the same time as cytogenetics/FISH and also checks for the *BCR-ABL* gene. This test also is used regularly after treatment starts to monitor your response.

Cytogenetic tests

Cytogenetic tests using the bone marrow are one type of genetic test. Their results give your treatment team information about

the genetic make-up of your cells. They look at the structure of chromosomes in bone marrow cells to see if there is any gain, loss, or switching of genetic material between chromosomes. Your haematologist will use the results to plan your treatment. This test will show if you have the Philadelphia chromosome.

FISH

Fluorescent in-situ hybridisation (or FISH) is a type of cytogenetic test your treatment team might mention. It can be done on either a blood or a bone marrow sample. The pathologist uses dyes to highlight parts of chromosomes to check if they are abnormal. This will check for the *BCR-ABL* gene.

HLA testing

HLA testing tests for human leukocyte antigen. The test is also called tissue typing or histocompatibility testing. It tests which HLA genes someone has inherited. People who are eligible for stem cell transplants and their donors will be HLA tested to see if they are suitable matches. You can read more about stem cell transplants later in this booklet and in our booklet, *Understanding Allogeneic Stem Cell Transplants.*

Heart tests

Some medicines for CML can cause heart problems. Before you start treatment you might have an echocardiogram. This test takes pictures of your heart to check how well it pumps blood. You may also have an electrocardiogram (ECG) to check your heart's rhythm.

Other tests

You might need more blood tests and imaging tests when you are diagnosed and throughout your treatment. Ultrasound and CT scans look for signs of leukaemia in other parts of your body, like your spleen.

What happens next?

After diagnosis

When all your test results have been reviewed, you'll meet with your haematologist to discuss your CML. You'll learn which phase you're in and discuss treatment goals and options. It's natural to feel scared, confused, or sad. You'll hear a lot of information and it can be overwhelming.

Don't be afraid to ask your haematologist to repeat things and for some written information. It's helpful to bring someone along to the appointment as second pair of ears and to take notes.

Phases of CML

There are three phases of CML: the chronic, accelerated, and blast phases. Which phase you are in depends on the number of immature leukaemic blast cells (abnormal white blood cells) you have in your blood or bone marrow. There are a few other factors the World Health Organization (WHO) has suggested that help haematologists diagnose the phase you are in.

Chronic phase

Most people (more than 90%) diagnosed with CML are in the chronic phase. In the chronic phase, CML progresses (gets worse) very slowly. For most patients receiving current treatment, an excellent response is achieved. This is termed a major molecular remission (MMR). Patients who achieve an MMR have a normal life expectancy.

If untreated, chronic phase CML will eventually progress to accelerated and/or blast phase.

Accelerated phase

Uncommonly, people may present in the first instance, with more advanced and rapidly growing CML, which is called accelerated phase. In about 5% of patients, CML *progresses* from a relatively stable disease into a more rapidly progressing accelerated phase of CML. During this time the proportion of blast cells may start to increase in your bone marrow and circulating blood.

During the accelerated phase of disease your treatment team will look at changing to a more effective treatment option.

If untreated, accelerated phase CML will eventually transform to blast phase CML.

Blast phase

The blast phase is also called a *blast crisis* and it is very serious. Overall, for patients with CML, there is generally a less than 5% risk their disease will transform into a rapidly progressing disease resembling acute leukaemia. This risk is less than 1% in those who have an excellent response to current drug therapy.

This phase is characterised by a dramatic increase in the number of blast cells in the bone marrow and blood (usually 30% or more) and by the development of more severe symptoms of your disease.

In *blast crisis*, about two-thirds of CML cases transform into a disease resembling *acute myeloid leukaemia (AML)*. The remainder transform into a disease resembling *acute lymphoblastic leukaemia (ALL)*. Occasionally, the blast cells are said to be undifferentiated (all look the same) or mixed.

Treatments and side effects

Your haematologist will recommend treatment based on:

- the phase of your CML
- your age
- your general health
- your wishes.

There are several kinds of treatment for CML:

1. Targeted therapy drugs, called *tyrosine kinase inhibitors (TKIs)* – this is the most common treatment for people with CML.
2. Chemotherapy – very few people may have chemo and only in advanced phase disease.
3. Supportive care controls symptoms of CML, like blood transfusion for anaemia – you will have this if you need it.
4. Stem cell transplantation replaces bone marrow cells with new, healthy cells – for very few patients.

Your treatment team will explain the treatments, their benefits and possible side effects. They might ask you to sign a consent form to agree to the treatment after you have thought about the options.

Apheresis

People with extremely high white blood cell counts at diagnosis (called *hyperleukocytosis*) may need a procedure called *apheresis*. It removes abnormal white blood cells from your blood and is done in an outpatient ward. Apheresis lowers your white blood cells right away.

Treatment goals

There are a few treatment goals for CML:

- Kill the cells that contain the *BCR-ABL* gene
- Normalise blood cell counts
- Reduce the risk of progression to another phase.

If you're in the accelerated or blast phases, one goal will be to get you back into the chronic phase. The main treatment goal is to achieve a major molecular response (MMR) and long-term control of the disease.

Treatment responses

During and after treatment, your treatment team will order bone marrow and blood tests to check how you are going.

There are three types of treatment responses:

1. Haematologic response – checks your blood cell counts are responding to treatment.
2. Cytogenetic response – checks the number of cells you still have with the Philadelphia chromosome.
3. Molecular response – checks the number of cells you still have with the *BCR-ABL* gene. This result may be expressed as a ratio. For instance, a ratio of 0.01 means only 1 in 10,000 cells has the *BCR-ABL* gene.

These responses are typically assessed by doing regular blood tests. Most patients do NOT need further bone marrow tests after they are diagnosed.

Targeted therapies for CML

Targeted therapies target leukaemic cells but don't harm normal cells. They can act by switching genes on or off, or by sending substances straight to the leukaemic cells to kill them or stop them growing.

Tyrosine kinase inhibitors (TKIs)

Nearly all people diagnosed with CML will be given a type of targeted therapy called a tyrosine kinase inhibitor (TKI). There are several different TKIs. They all work slightly differently. You may switch to another type of TKI depending on your treatment response.

TKIs don't cure CML, but they control it long-term for most people.

Your haematologist will recommend a TKI depending on:

- your phase of CML
- your risk score if you are in the chronic phase
- your overall health and other conditions you have
- potential side effects from the different TKIs.

TKIs are all in tablet form and need to be taken once or twice every day long-term. It's important you don't miss any doses. Usually, within 3-6 months you'll know if your TKI is working. If your first TKI doesn't work well enough or has major side effects, you'll be switched to another.

There are some foods and drugs that you should avoid if you're taking a TKI. They can interact with the drug or how your body absorbs it. You should not eat grapefruit, Seville oranges, pomegranate, star fruit, or licorice. You should not take excessive paracetamol or the herb St John's Wort.

TKI side effects

Although they share some potential side effects, each TKI also has different ones. Everyone gets different side effects with TKIs. You may have no side effects, or one or more of them, and they may change over time.

Which side effects you have and how severe they are depends on:

- your TKI
- your overall health and wellbeing
- any other conditions you have.

TKI side effects are usually milder than chemotherapy side effects. Smoking may increase the risk of some TKI side effects. It is important to attempt to stop smoking after you are diagnosed with CML.

Chemotherapy

Chemotherapy medications (also called chemo) sometimes also called *cytotoxic* (which means 'cell killing') medications, make cancer cells stop growing. They either kill the cells or stop them from dividing, replicating, and reproducing. They also damage normal cells, but these cells can repair and recover. In CML, strong chemo is only given for resistant or aggressive disease (like blastic phase disease).

Intravenous chemo is given in cycles of treatment days. This means that you will have treatment for a certain number of days, followed by a set number of rest days. Chemo cycle times, the number of treatment days, and the number of cycles depend on the drug.

Unlike supportive care, which treats symptoms, chemo treats the actual disease. Because of this, it's often called *disease modifying* treatment.

Chemo can be given as tablets, injections, or infusions via a drip (IV). The type of chemo given depends on the type of cancer. It's common to be on more than one chemo drug at a time. You can take some tablet chemo at home and may have injections or IV.

Chemotherapy side effects

Chemotherapy kills cells that multiply quickly, like leukaemia cells. It also damages fast-growing normal cells. These include hair cells and cells that make up the tissues in your mouth, gut, and bone marrow. You get chemo side effects because of the damage to the normal cells.

Everyone gets different side effects with chemo. You may have no side effects, or one or more of them, and they may change over time.

Which side effects you have and how severe they are depend on:

- your type of CML
- the type of chemotherapy you are given
- your overall health and wellbeing.

Changes in blood counts

Chemo affects your bone marrow's ability to produce enough blood cells. Your red blood cells, white blood cells, and platelets will usually drop within a week of treatment. They should then increase before your next cycle of chemo.

Low circulating red blood cells cause anaemia. You may feel tired, short of breath, and look pale. Take it easy and contact your treatment team. You might need a blood transfusion to help your levels recover.

If your platelets are low, you can bruise and bleed more easily. If you notice these signs please let your treating team know.

When your white blood cell count (neutrophils) is too low, this puts you at a higher risk of developing an infection.

Managing chemo side effects

Potential side effects	What might help
Feeling sick – nausea and vomiting	• eat smaller meals more often during the day • try cool or cold food like, jelly • let someone else cook for you • drink ginger ale or soda water • avoid strong smells • you'll be given medicine to help
Change to taste	• add a little more sugar to sweet foods • add a bit more salt to savoury foods • if you have a metallic taste, try rinsing your mouth out
Mouth problems – mucositis	• use a soft toothbrush and mild toothpaste • brush every time you eat • use salty water, sodium bicarbonate in water or alcohol-free mouthwash • continue to floss but stop if your gums bleed
Bowel changes	• drink plenty of fluids • get some diet advice from your treatment team • if you're constipated, don't strain • if you have haemorrhoids don't push on them, tell your treatment team, you'll be given medicine to help
Fatigue	• see page 33 in this booklet for more info • rest or nap when needed • take regular gentle exercise

Chemo brain	• keep a notebook handy to write things down • ask your pharmacist to Webster pack your medications • take regular gentle exercise • socialise – tell your loved ones what's going on
Hair loss and thinning	• prepare your family and friends • use a soft hairbrush and a mild baby shampoo • pat your hair dry gently with a towel • cut your hair shorter or have it shaved when you start chemo • use an electric shaver • avoid using heat or chemicals – don't dye or blow dry your hair • use sunscreen on your scalp
Sun sensitivity	• cover up with long sleeves and long pants • wear sunglasses and a hat or a beanie to protect your scalp • talk to your nurse about which sunscreens are best to use • avoid sun exposure at high UV times of the day

Supportive care

Supportive care prevents and treats symptoms and side effects. It includes emotional and social support too. The goal is to improve symptoms of your CML, but it doesn't treat the disease itself.

Blood transfusions

If you notice symptoms of anaemia, tell your treatment team. You may need a blood transfusion or instead, an effective alternative to transfusion (for example replacement therapy for iron deficiency).

Blood transfusions are slow infusions of blood into a vein (*intravenously*, or *IV*). The nurse will use your CVAD (a device that gives access through a central vein in your chest) or will insert a 'drip' (a *cannula*), a plastic tube, into a vein in your arm. The cannula connects to a bag of blood (called *packed red blood cells*). Each bag of blood will take 60-120 minutes to transfuse.

Platelet transfusions

If you have symptoms of low platelets (*thrombocytopenia*), you may need a platelet transfusion. This is like a red blood cell transfusion, but you will be given a bag of platelets.

Growth factors

Growth factors are chemicals in your blood that help the bone marrow produce different types of blood cells. Some growth factors can be made in the laboratory. They are used to boost low blood counts.

In Australia, white blood cell growth factors are given. Neutrophils are white blood cells that help fight infections. A growth factor called *granulocyte colony stimulating factor* (usually called G-CSF) makes the bone marrow produce more neutrophils. Low neutrophils can be a side effect of some TKIs.

Growth factors don't usually cause any major side effects, but some people may have chills, headaches, and bone pain after an injection.

Antibiotics

When your white blood cell count is low you have a higher risk of getting infections. If you do, it's important to be treated as soon as possible. If you develop signs or symptoms of infection, your treatment team will probably prescribe antibiotics; either in tablet form or given via a 'drip' straight into your bloodstream (IV).

Vaccines

Vaccines are important for people with CML because you may have a higher risk of infection. Vaccines help prevent infections. Only some vaccines are safe, and these are called *inactivated* vaccines. You will need to check with your treatment team when to have them. You should not have any *live* vaccines so, before getting a vaccine, always ensure that it is not live.

Stem cell transplantation

Stem cell transplants are also called *bone marrow transplants (BMT)*, or a *hemopoietic cell transplants* (*HCT*). They are very rarely needed in CML and are generally reserved for patients who don't respond to TKIs or have blastic phase disease. This treatment has very serious side effects. Your haematologist will work out if you need and can have a stem cell transplant.

Stem cell transplantation involves having very high doses of chemotherapy. The aim is to completely destroy the abnormal stem cells in your bone marrow. These cells are then replaced with healthy stem cells.

Allogeneic (donor) stem cell transplant

The healthy stem cells are donated from a matched donor. Your siblings may have tests to see if they are a match to you. If they are, they are called *HLA matched donors*. This procedure is called an *allogeneic* (donor) stem cell transplant. The stem cells can also come from someone who is not related but is a match.

The goal of a stem cell transplant is twofold. First, is to create an immune response called a *graft-versus-leukaemia* (GVL) effect. The donated stem cells make their own immune cells and these create a new immune system. These immune cells kill any cancer cells that are left after you've had the high-dose chemotherapy.

Second, is to restore normal blood cell growth with healthy donated stem cells after 'conditioning' chemo destroys your abnormal cancerous stem cells.

Stem cell transplant side effects include:

- low blood counts
- similar side effects to chemo, but more severe
- graft-versus-host disease.

These side effects can go on for years after the stem cell transplant.

You can find out more about stem cell transplants in our booklet *Allogeneic Stem Cell Transplants* and on our website.

Clinical trials

Clinical trials (also called *research studies*) test new treatments. They are compared against current treatments to see if the new treatment works better. They also check for the new treatment's side effects. Many clinical trials are randomised, which means some patients receive the new treatment and others receive the current standard of care treatment.

Clinical trials provide important information about how treatments can be improved. Sometimes people on clinical trials (called 'participants') have access to expensive new treatments that aren't on Australia's Pharmaceutical Benefits Scheme (PBS).

Your haematologist may suggest you join a clinical trial. Before you can start, you will need to give informed consent. This shows that you understand the risks and benefits of the trial treatment.

Clinical trials are run through hospitals and clinics, just like other treatments. You will have a clinical trial nurse as part of your treatment team.

Clinical trial participation is purely voluntary. If you are offered a clinical trial, make sure you understand how that treatment will be different compared to what is generally given (standard of care treatments). Be sure to ask any questions you have before deciding whether to participate.

You can search current clinical trials at:

Australian Cancer Trials: *australiancancertrials.gov.au*

ANZ Clinical Trials Registry: *anzctr.org.au and*

ClinTrial: *clintrial.org.au*

Second opinion

If you feel unsure about your diagnosis or treatment, you are entitled to seek a second opinion from an independent doctor. This may be at the same hospital or clinic, or at a different location. If you feel overwhelmed, then you might benefit from speaking with someone at the Leukaemia Foundation, your GP, or a counsellor for advice.

Complementary therapies

Complementary and alternative medicines (CAM), also known as integrated therapies, are not standard medical treatments. However, some people find that they help with side effects.

These therapies should 'complement' or be done alongside medical treatment, after consultation with your treatment team.

No complementary or alternative treatment on its own can treat CML. They may help with some symptoms or side effects after consultation with your treatment team.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue. It can be hard to describe to people who haven't felt it. It's more than being tired, it's different to normal everyday tiredness, and is often not resolved with sleep or rest. You will feel tired but you may also feel weak and be sleepy, drowsy, impatient, or confused. It's hard when you have no get-up-and-go, however, for most people fatigue should improve after you finish treatment.

Tips for managing fatigue

Fatigue is a side effect of your blood cancer or treatment so managing fatigue is an important part of your overall treatment and care. Make sure you talk to your treating team about it; they may suggest referral to a psychologist who specialises in sleep management. It's very important to explain how you feel to your carers and support people, and to let them know your priorities and discuss how they can help.

A positive sleep routine, pre-sleep relaxation techniques, napping if tired during the day for an hour or less, regular moderate exercise or movement, eating well, drinking plenty of water, and avoiding use of electronic equipment such as computers late at night can be very helpful in improving sleep and reducing fatigue.

While you're managing your fatigue, you can jot down what time of day you have most energy and when you feel most tired. That will help you get into a routine and prioritise your energy. Play games, listen to or play music, read, catch up with friends and family; these things might seem difficult, but they will help distract you from the fatigue.

Fertility decisions

It may seem unusual to be reading about fertility here, given the average age of most CML patients. But some young people do get CML, while others have younger partners.

Some types of treatment may affect your fertility, which is your ability to conceive a baby. It is important to talk to your treatment team about future fertility *before* you start treatment. If you are planning on having a child, there are steps you can take.

Make sure you understand:

- the fertility preservation processes
- success rates
- the risks
- side effects of fertility treatments
- any costs.

For men

If you need chemo, it can stop or lower your sperm production. It can reduce your sperm's ability to move. This can be temporary or permanent. Chemo also affects the hormone testosterone. The effect of TKIs on sperm production is less certain, and many male CML patients have successfully fathered children after treatment with TKIs.

For women

Chemo can reduce your number of available eggs (ova) and can affect your hormones. Tell your treatment team right away if you are pregnant or think you may be. The effect of TKIs on ova production is less certain. There are three standard fertility preservation options for women. It is NOT recommended for women to fall pregnant while on TKIs, due to the risk of birth defects.

Fertility Society of Australia: *fertilitysociety.com.au*

Future Fertility: *futurefertility.com.au*

Practical matters

Navigating the health system

The Australian health system may seem large, complicated and stressful especially when you are also living with a blood cancer. Knowing a bit about how our health system works and who are key people in your care can make navigating the system much easier.

Key people in your health team

Haematologist - A specialist doctor trained in diseases of the blood including blood cancer who leads a team of doctors in your care.

Radiation oncologist - A doctor who specialises in treating cancer using radiotherapy.

Cancer care coordinator (CCC)/Cancer nurse consultant (CNC) - Specialist cancer nurses who coordinate patient care and provide referrals to allied health professionals if needed.

Cancer nurse - A nurse in an outpatient clinic or cancer ward who supports, educates and gives you your chemo treatment.

Palliative care physician - A doctor who specialises in controlling symptoms and improving quality of life in people with terminal illnesses and chronic health conditions.

Pharmacist - A health professional who prepares, dispenses medicines (drugs), and supports your understanding of how to manage your side effects with medication prescribed.

Accredited practising dietitian - A university-qualified professional with ongoing training and education who helps to support your recovery and manage challenges in your diet.

Social worker - A health professional who specialises in emotional support, counselling, and advice about practical and financial matters.

Physiotherapist/Exercise physiologist - A health professional who specialises in treating and rehabilitating patients through physical means.

Psychologist - A health professional who specialises in providing emotional support for difficulties such as anxiety, distress, and depression.

Record your important contact details here:

	Contact name	Phone	Comment
Emergency			
GP			
Haematologist			
CNC/CCC			
Chemo day unit			
Pharmacist			
Dietitian			
Social worker			
Psychologist			

Useful website: *patients.cancer.nsw.gov.au/diagnosis/navigating-the-health-system*

The new normal – what is it?

For many people, the start of treatment signals changes to life that includes the day-to-day managing of a multitude of new activities and changes around treating and monitoring of your blood cancer. Frequent appointments with your health care team and regular follow up can be tiring and stressful for all.

Life is not the same as it was before the blood cancer diagnosis. Everyday life changes for you and the people around you. Things that were once important may no longer be so, or things that weren't important before now take greater priority.

In essence, a 'new normal' is about living with your blood cancer, creating and maintaining your new normal to live as good a life as possible while facing changes such as and not limited to:

- Physical/mental/spiritual
- Emotional/relationships/identity/sexuality
- Financial, ability to work/return to productivity.

Seeking information, tools and support and accepting help to manage challenges that arise throughout a person's cancer experience is very important.

Having this support, enables individuals to have a high quality of life throughout their blood cancer journey. It is also important to remember that dealing with the diagnosis and treatment of blood cancer is a big life change and everyone handles it and is affected differently.

Diet and nutrition

During treatment, nutritional goals are to prevent or reverse malnutrition, avoiding weight loss (preserving lean body mass/ muscle) and minimise side effects such as decreased appetite, nausea, diarrhoea, dry mouth, and taste changes.

Being underweight or malnourished can have a negative effect on your overall quality of life. Poor appetite and weight loss are associated with symptoms such as weakness, fatigue, difficulty sleeping, and pain.

It is likely you will be encouraged to eat a high-energy diet to meet the changing metabolic demands of your body during this time. During chemo treatment you may experience complications that negatively affect your nutrition and hence your overall wellbeing such as mucositis (ulcers in the mouth/throat/stomach).

You may be given drugs, called *corticosteroids* or *steroids* for short, as part of your treatment. Steroids can cause weight gain through increased appetite stimulation and fluid retention (oedema) in your limbs, abdomen and face.

General nutrition recommendations for people receiving cancer treatment:

- **Maintain a healthy weight.** For many people, this means avoiding weight loss by getting enough calories every day. For people who are obese, this may mean losing weight. It's important to get advice from your health care team before you try to lose weight during treatment
- **Get essential nutrients.** These include protein, carbohydrates, fats, and water.

You can make an appointment to see a hospital dietitian as an outpatient or ask to see one if you are an inpatient. Your treating team may refer you to a dietitian. Community dietitians are also available, and your GP can arrange this through a care plan if you don't have private health insurance or insurance that covers dietitians.

Exercise/physical activity

With any blood cancer treatment it is common to experience deconditioning; a physical and/or psychological drop in function. Having cancer doesn't mean you can't be physically active.

People with blood cancer should attempt to avoid inactivity and sedentary behaviour as much as possible and return to normal daily activities as soon as possible following diagnosis.

What are the benefits of exercise/physical activity?

Strong evidence is available to show that exercise and physical activity improves outcomes for people with cancer across a range of dimensions including:

- cancer-related fatigue, pain, psychological distress, anxiety, depression
- bone health, cognitive and cardiovascular function
- health-related quality of life.

Exercise can be tailored to the individual and often around activities of daily living. Before you commence any exercise program, it is important to speak with your treatment team first to make sure it is safe to do so and to see who is best placed to help you.

Information on exercise in cancer can be found on the Clinical Oncology Society of Australia (COSA) website: *cosa.org.au*

Please see our website for more detailed information and videos that may be helpful: *leukaemia.org.au*

Specific information for older people on exercising with chronic illness and some advice about healthy eating is available from the Australian Government Choose Health: *Be Active A physical activity guide for older Australians at health.gov.au*

Mental health and emotions

Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings and it is not uncommon to feel low, depressed, or anxious.

Feeling sad is a normal response to a cancer diagnosis as is worrying about the future. Feelings can be challenging and may include anxiety, grief, guilt, uncertainty, anger, spiritual distress, fear, and feeling isolated or lonely. Worrying about treatment, its success and side effects or changes in your physical, lifestyle and family dynamics, can also impact your mental health.

Seeking help from your healthcare team is important. They and/or your GP can refer you to someone who can help, such as a psychologist who specialises in blood cancer. The Leukaemia Foundation Blood Cancer Support Coordinators and Grief Counsellors can also help you to work through what you are feeling and provide information on who might assist you in your local area.

Call us on 1800 620 420 or visit leukaemia.org.au

Relationships/carers/family and friends

Undergoing treatment for a blood cancer can affect your role as a parent, partner, friend, or work mate, to name a few. You and all the people in your life will cope differently. Be open with your communication and encourage family and friends to be open with you.

Communicating effectively with family, children, friends, and a carer is essential. Being clear with others about what you want and need allows them to be of greater support. Together you can work as a team to manage and solve problems as they arise.

There are many allied healthcare staff and not-for-profit organisations that can assist with support and information. The Leukaemia Foundation is one of them and can assist you, your carer or family in identifying who can help with different issues and how to contact them.

Carers Australia: *carersaustralia.com.au*

Carer Gateway (Australian Government): *carergateway.gov.au*

Canteen: *canteen.org.au*

Redkite: *redkite.org.au*

Work/finances/legal matters

Finances

People with blood cancer often report a negative impact on their financial situation during treatment. Monthly costs can increase and may be influenced by financial considerations such as travel, childcare, and taking time off work for appointments. Your household income may be reduced due to you or your carer having to stop work, or reduce hours permanently or temporarily, as a result of your diagnosis.

A financial stocktake

When you become aware that you may lose your income or suffer a reduced income, as a result of the ill health of you or an immediate family member, the first step should be to run a quick 'financial stocktake'.

First, assess what income you can expect or what financial resources you have available. **Possibilities may include:**

- Are you or your partner able to work part-time?
- Do you have sick leave or long service leave?
- Do you have income protection or trauma insurance, either as a stand-alone policy or part of a life policy?
- Do you have money in the bank or a line of credit against your mortgage which can be drawn against?

The second step involves checking on important expenses which need paying in the immediate future. Put together a brief budget if you don't have one.

Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources.

Your local Leukaemia Foundation Blood Cancer Support Coordinator can help point you in the right direction.

A few other options to consider are:

Centrelink

If you expect to lose all or most of your income or your partner's income, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you may receive some relief payments. If you have employment to return to, this will affect the basis of your benefit. Your partner may also be eligible for a Carer Payment or Carer Allowance, so be sure to enquire about this.

Centrelink online account *(sign in through myGov for instructions: my.gov.au): centrelink.gov.au*

Financial institutions

If you are unable to make your regular payments on your mortgage as a result of serious ill health, it is important that you let the relevant organisations know as soon as possible. Most banks and other financial organisations have special arrangements for customers in financial hardship as a result of ill health.

Other sources of help

Do not hesitate to discuss your financial circumstances with your treatment centre social worker or your private insurer. They may be able to assist with advice on deferring payments. Some of your household accounts may also have hardship support programs (including energy providers). It may be possible to access some money from your superannuation fund to help with emergency payments. Don't forget to check if your superannuation has income replacement insurance as one of its features. If you are not sure, give their helpline a call.

Moneysmart: *moneysmart.gov.au*

National Debt Helpline: *ndh.org.au or phone 1800 007 007*

Legal matters

This information applies equally to all members of the community, not just those who have a blood cancer or their carer. The best time to get your affairs in order is when you are in good health. Here we consider some of the most common legal documents you should have and where to get help.

Enduring Power of Attorney/Enduring Guardian

There may be circumstances when a person loses the capacity to make decisions for themself. You can sign a legal document which allows you to choose a trusted person to make decisions on your behalf.

An *Enduring Power of Attorney (EPOA)* is a document that allows your trusted person the power to sign documents on your behalf, make personal, administrative and, if you choose, financial decisions.

An *Enduring Guardian (EG)* is another document where your trusted person can make decisions on your behalf regarding your health matters such as medical treatment, care, and protection, even if this decision overrides your wishes.

Australian Guardianship and Administration council: *agac.org.au*

Wills

It is very important to have specialist legal advice when preparing your Will. There are many questions and options your legal adviser will discuss with you which may not be immediately apparent. This is particularly important when you have dependent family members, and you need to determine who will be responsible for them in the event of your death.

If you die without leaving a valid Will, you leave what is known as 'intestacy'. Although you may feel your affairs are very simple and your immediate family will receive your assets, this is not necessarily true. Should you die intestate, distribution of your estate will be determined by a formula set down in legislation. If you already have a Will, you need to consider if it is still current.

Advance Health Directive

This is a document you may complete to clearly indicate your wishes as to medical treatments you may or may not wish to receive in the event of a serious illness or accident. Although this is a lengthy document, it is simple to complete as it mainly consists of a series of optional questions. There are also sections where you make comments in your own words. While this form can be completed on your own, you may wish to discuss it with your family and you are also required to have a doctor sign the form to certify that you understand the contents of the document.

Advance Care Planning Australia: *advancecareplanning.org.au or phone 1300 208 582.*

Getting help

Help with legal matters is available from several sources including:

- Solicitors
- Trustee companies
- The Public Trustee in your state.

More information & help

Glossary

You can find any **bold** terms in the definitions also defined in this glossary.

accelerated/blastic phase	The second and third phases of CML, when the number of blast cells increase in the bone marrow.
active disease	Where the disease is still present during treatment, or where it has relapsed.
anaemia	A lower-than-normal number of **red blood cells** in the blood. It causes tiredness, paleness, and sometimes shortness of breath.
baseline	A first measurement of a condition taken early on, used to compare over time, to look for changes.
biotherapy	A type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.
basophils	A type of **white blood cell**. They help fight infection.
blast cells	Immature blood cells normally in the **bone marrow** in small numbers.
bone marrow	Soft, sponge-like tissue in the centre of most bones. It contains **stem cells** that make all blood cells.
bone marrow biopsy	Also called a **bone marrow aspirate** and trephine or BMAT. The removal of a small sample of **bone marrow**. This is sent to the lab for a pathologist to look at under a microscope.
biotherapy	A type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.
bone marrow aspirate	A procedure that takes a sample of bone marrow fluid.

bone marrow transplant	Also called a **stem cell transplant**. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).
bone marrow trephine	A sample of bone marrow tissue.
cancer	Diseases where some of the body's cells become faulty, begin to multiply out of control, can invade and damage the area around them, and can also spread to other parts of the body to cause further damage.
chemotherapy	The use of drugs to treat cancer.
chromosome	Part of a cell that contains genetic information.
chronic phase	The first phase of CML. **White blood cell** count is higher than normal but there may be no symptoms.
coagulation	Process of changing from a liquid blood to a solid. Also called *clotting*. **Platelets** help with coagulation.
complete cytogenic response	Where tests find no **Philadelphia chromosome** after you've had treatment.
cytogenetic tests	The study of the structure of **chromosomes**. These tests are carried out on samples of blood and **bone marrow**. The results help with diagnosis and getting the most appropriate treatment.
cytopenia	Where there is a lower-than-normal number of a type of blood cell in the blood.
dysplasia	Also called dysplastic cells. A change in size, shape and arrangement of normal cells seen under a microscope.
eosinophils	A type of **white blood cell**. They help fight infection.

erythrocytes	Also called **red blood cells**. A type of blood cell made in the bone marrow and found in the blood. **Haemoglobin** makes these cells red in colour.
full blood count	Also called FBC or complete blood count. A routine blood test that measures the number and type of cells, and the **haemoglobin** and **haematocrit** in the blood.
granulocytes	A kind of **white blood cell**. There are three types: **eosinophils**, **basophils**, and **neutrophils**. They help fight infection.
growth factors	Proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.
haematocrit	The amount of blood that is made up of **red blood cells**.
haematologist	A doctor who specialises in diagnosing and treating blood disorders.
haemoglobin	A protein inside **red blood cells** that carries oxygen around the body.
haemopoiesis	The formation of new blood cells.
immune system	The body's defence system against infection and disease.
immunotherapy	A type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.
leukaemia	Cancer that begins in blood-forming tissue, such as the **bone marrow**. It causes large numbers of abnormal blood cells to be made and to enter the bloodstream.
leukocytes	Also called **white blood cells** that are made in the **bone marrow** and found in the blood and lymph tissue. They help the body fight infection and are part of the **immune system**. Types: **granulocytes** (**neutrophils**, **eosinophils**, and **basophils**), monocytes, and **lymphocytes** (T-cells and B-cells).
lymphocytes	A type of **white blood cell** that plays a role in the **immune system**.

megakaryocytes	Very large bone marrow cells that break apart to form **platelets**.
molecular response	An improvement related to treatment where tests show fewer cells with the *BCR-ABL* gene.
mutation	A harmful change in 'normal' DNA (the building blocks of all cells).
neutropenia	A lower-than-normal number of **neutrophils** in the blood. It increases the risk of infection.
neutrophils	The most common type of **white blood cell**. They help fight infection.
pancytopenia	Where there are lower-than-normal numbers of a type of all blood cells and **platelets** in the blood.
pathology	The study of diseases to understand their nature and their cause. A specialist in this field is called a pathologist. In cancer, histopathology/histology involves examining tissue under a microscope. Haematopathology involves blood and lymph tissue.
petechiae	Tiny, unraised, round red spots under the skin caused by bleeding.
Philadelphia chromosome	An abnormal chromosome 22 formed when parts of chromosomes 9 and 22 switch. It contains the new fusion gene, *BCR-ABL*.
platelets	Also called **thrombocytes**. Tiny pieces of cells (**megakaryocytes**) found in the blood and spleen. They help form blood clots (**coagulation**) to slow or stop bleeding and to help wounds heal.
prognosis	An estimate of the likely course and outcome of a disease.
purpura	Bleeding and bruising under the skin.
radiotherapy (radiation therapy)	Uses high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells or injure them so they can't grow or multiply.

red blood cell	Also called an **erythrocyte** or RBC. A type of blood cell made in the bone marrow and found in the blood. **Haemoglobin** makes these cells red in colour.
resistant or refractory disease	Where the disease is not responding to treatment.
relapse	Return of the original disease after it has improved for a time.
rigor	Also called a chill. Feeling cold with shivering or shaking and looking pale, but with a high temperature. A symptom of infection.
spinal tap	Also called lumbar puncture. A procedure to take fluid from the spine in the lower back through a hollow needle, usually as part of diagnosis.
stem cells	Young (immature) blood cells that can develop into more than one type of cell. Bone marrow stem cells grow and produce **red blood cells**, **white blood cells** and **platelets**.
stem cell transplant	Also called a SCT or **bone marrow transplant**. A procedure where a patient is given healthy **stem cells** to replace their own damaged stem cells. The healthy stem cells may come from the **bone marrow** of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).
thrombocytes	Also called **platelets**. Tiny pieces of cells (**megakaryocytes**) found in the blood and spleen. They help form blood clots (**coagulation**) to slow or stop bleeding and to help wounds heal.
thrombocytopenia	A lower-than-normal number of **platelets** in the blood. It causes bruising and bleeding.
white blood cells	Also called **leukocytes** or WBCs. Blood cells made in the **bone marrow** and found in the blood and lymph tissue. They help the body fight infection and are part of the **immune system**. Types: **granulocytes** (**neutrophils**, **eosinophils**, and **basophils**), **monocytes**, and **lymphocytes** (T-cells and B-cells).

Useful websites

Leukaemia Foundation:	leukaemia.org.au
Australian Cancer Trials:	australiancancertrials.gov.au
Australian New Zealand Clinical Trials Registry:	anzctr.org.au
eviQ Cancer Treatments Online:	eviq.org.au
Australian Red Cross Blood Service:	mytransfusion.com.au
Pharmaceutical Benefits Scheme:	pbs.gov.au
ClinTrial Refer:	clintrial.org.au

Question builder

- ☐ Who will be my main contacts? How do I best contact you/them?
- ☐ What can I do to avoid infections?
- ☐ Can I have the flu shot and other vaccinations?
- ☐ Is it safe to take my supplements or vitamins?
- ☐ Can I eat normally, is there anything I need to avoid, or special diets that will help me?
- ☐ Can I exercise and what is the best frequency and type for me?
- ☐ Are there any clinical trials for my type of CML and am I eligible?
- ☐ Could this treatment affect my sex life? If so, how and for how long?
- ☐ Will my treatment send me into menopause?
- ☐ Where can I or my loved ones get any other support?

The Leukaemia Foundation gratefully acknowledges those who assisted in the development of this information: Leukaemia Foundation Blood Cancer Support Coordinators, nursing staff, clinical haematologists, and bone marrow transplant physicians representing the various states and territories of Australia.

The Leukaemia Foundation values feedback. If you would like to make suggestions or tell us about your experience in using this booklet, please contact us via email: **info@leukaemia.org.au** or phone us on **1800 620 420**.

Leukaemia Foundation®

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♻ The Leukaemia Foundation cares about our environment. Please recycle or dispose of thoughtfully.