

CHRONIC MYELOID LEUKAEMIA (CML)

A guide for patients,
families & whānau



Vision to Cure. Mission to Care.

INTRODUCTION

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

If you or someone you know 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 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 health care team.

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

Interpreter service

New Zealand's Code of Health and Disability states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family/whānau member or friend may assist. The hospital can organise a trained interpreter if needed, either in person or through a telephone interpreter service. NZ Sign Language interpreters are also available.

Informed consent

If you are supporting a family/whānau member who needs language support at appointments, your doctor may ask an interpreter to join meetings where informed consent is required. Interpreters are specially trained to explain medical information clearly.

HOW TO USE THIS BOOKLET



Detailed information



Key points



Important information



More information available online

There are many resources available at leukaemia.org.nz such as fact sheets, booklets and more. Most resources available on the Leukaemia & Blood Cancer New Zealand (LBC) website can be obtained in a printed version. Ask your LBC Support Services Coordinator if you would like information posted to you.

Space for your questions

There is space at the end of this booklet to write questions that you can ask next time you see a doctor, nurse or LBC Support Services Coordinator. They will be happy to answer your questions or explain something in more detail.

Glossary

On page 43 there is a glossary (word list).

In this booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases. A Dictionary of Terms booklet is also available from LBC.

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WHAT IS LEUKAEMIA?

Leukaemia is a type of blood cancer. Blood is made up of red blood cells, white blood cells and platelets. These are made in the bone marrow, which is the spongy tissue found in the centre of some bones in the body.

Leukaemia is a cancer of the white blood cells. White blood cells are an important part of the immune system and help fight infection. Normally baby (immature) white blood cells divide and then mature (go from immature cells to adult cells) in a controlled way. It is the mature white blood cells which fight infection.

When someone has leukaemia, the immature white blood cells divide too quickly in the bone marrow, and do not mature. This means the bone marrow is overcrowded with immature white cells that are not able to fight infection.

Types of leukaemia

Leukaemias can be acute or chronic. Acute leukaemias typically develop very quickly and treatment must start right away. Chronic leukaemias usually develop slowly and may not need treatment right away, if at all. In medical terms, the word 'chronic' means persisting for a long time – it does not mean 'severe'.

The names of the main types of leukaemias are:

Acute

Acute myeloid leukaemia (AML)

Acute lymphoblastic leukaemia (ALL)

Chronic

Chronic myeloid leukaemia (CML)

Chronic lymphocytic leukaemia (CLL)

Both adults and children can develop leukaemias, but certain types are more common in different age groups. Each year in New Zealand around 680 adults and 50 children are diagnosed with leukaemias.



Key points

- Leukaemia is a type of blood cancer of the white blood cells.
- Leukaemia can be acute (develops fast) or chronic (develops slowly).

WHAT IS CHRONIC MYELOID LEUKAEMIA?

Chronic myeloid leukaemia (CML) is a type of leukaemia that affects developing myeloid cells. CML usually develops slowly during the early stages of disease. The phases of CML are discussed further on page 6.

To fully understand CML it is helpful to learn about the cells in your body and bone marrow.

BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 01).

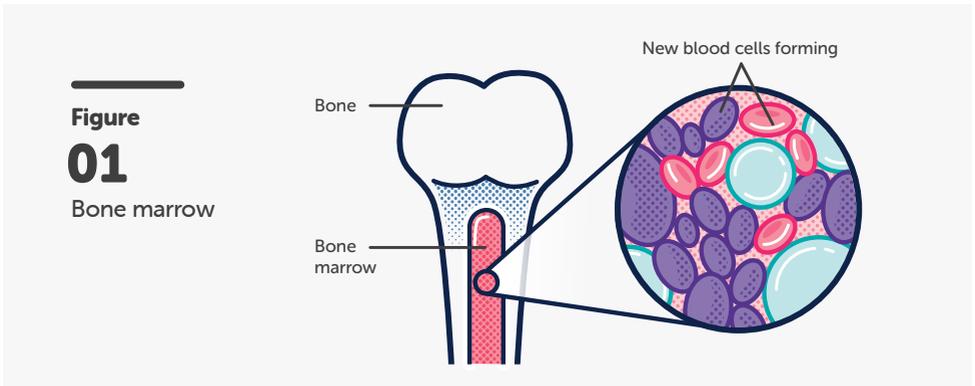


Figure 01
Bone marrow

In your bone marrow there are cells called blood stem cells. Blood stem cells create the new blood cells in your body.

The two main functions of blood stem cells are to:

- Make exact copies of themselves.
- Divide and make two different cell groups: myeloid (my-ill-oid) stem cells and lymphoid (lim-foid) stem cells.

Myeloid and lymphoid stem cells create the blood cells for your body including white blood cells, red blood cells and platelets.

In Figure 02 (on next page) you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create.

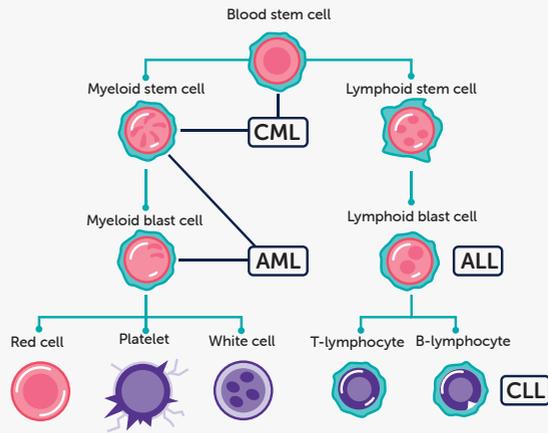
Leukaemia can start in either the myeloid cell line or the lymphoid cell line. This determines what type of leukaemia it is (either CLL or

CML). As you can see in Figure 02, CML affects myeloid stem cells, which will be explained further on page 6.

Figure

02

The cells created from blood stem cells



This indicates the different cells where abnormalities occur, causing the different leukaemias.



Detailed information

- The medical term for blood stem cells is haematopoietic (he-ma-to-po-ee-tick) stem cells. When a blood stem cell matures into a blood cell, this is called haematopoiesis (he-ma-to-po-ee-sis). In adults, haematopoiesis occurs in the bone marrow of large bones such as the breastbone (sternum), thigh bone (femur) and the hip bone (iliac crest).



Key points

- Blood stem cells in your bone marrow make exact copies of themselves, as well as divide to create myeloid and lymphoid stem cells. These cells create all the blood cells for your body, e.g. red blood cells, white blood cells and platelets.
- Leukaemias can develop from either myeloid cells or lymphoid cells.

YOUR BLOOD

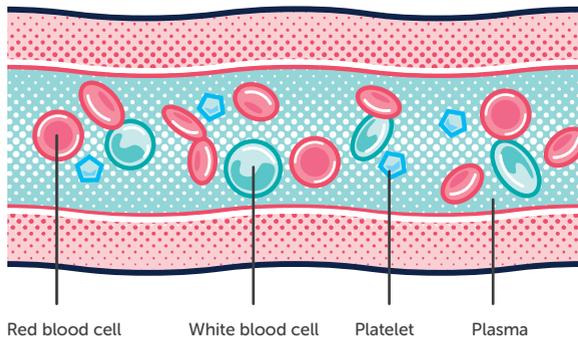
The red blood cells, platelets and white blood cells, created in your bone marrow, are released into your bloodstream so they can function around the body.

Blood is made up of blood cells and plasma. A blood test measures the amount of each type of blood cell in your blood. Figure 03 shows the three main types of blood cells in the plasma. The role of plasma and each type of blood cell is discussed in the next section.

Figure

03

Blood vessel and cells in your blood



Red blood cells

Red blood cells transport oxygen from the lungs to all cells in the body. A protein called haemoglobin (heem-a-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin in your body is called anaemia (a-nee-me-a).

White blood cells

White blood cells, also called leukocytes (loo-kar-sites), fight infection. For example, if bacteria entered your bloodstream through a cut, the white blood cells would attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

Neutrophils (nutra-fils) are the most common type of white blood cell. A low amount of neutrophils in your body is called neutropenia (nutra-pee-nee-a).

Platelets

Platelets help your blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding. A low level of platelets in your body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a).

Plasma

Plasma is a light-yellow coloured liquid in which blood cells travel around your body.



Detailed information

There are many different types of white blood cells, all with specific jobs to do.

Below is a list with the names of different types of white blood cells and what they do.

- **Neutrophils (nutra-fils)**
Kill bacteria and fungi.
- **Eosinophils (ee-o-sin-o-phils)**
Kill parasites.
- **Basophils (bay so-phils)**
Work with neutrophils to fight infection.
- **T-lymphocytes (T-lim-fo-sites) (T-cells)**
Kill viruses, parasites and cancer cells.
- **B-lymphocytes (B-cells)**
Make antibodies which can target harmful microorganisms (germs).
- **Monocytes (mono-sites)**
Work with neutrophils and lymphocytes to fight infection. They also help act as scavengers (cleaners) to remove dead tissue.
- **Macrophages (mac-row-fages)**
Monocytes are known as macrophages when they move to body tissue to help fight infection there.



Key points

- There are three main types of blood cells (red blood cells, white blood cells and platelets), each with an important role.
- Blood cells travel around your bloodstream in a light-yellow coloured liquid called plasma.

CHRONIC MYELOID LEUKAEMIA

Chronic myeloid leukaemia (CML) is not a very common type of cancer, but approximately 50 people are diagnosed each year in New Zealand. CML can occur at any age but it is more common in adults over the age of 40 years old.

CML is a type of leukaemia that affects the myeloid blood cells that are made in the bone marrow. In people with CML, the bone marrow produces too many white blood cells called granulocytes (gran-u-loe-sites). These granulocytes and their immature precursors divide more (proliferate) in the bone marrow and spill out into the bloodstream, which circulates blood around the body. They can also expand in the spleen, causing the spleen (and sometimes the liver) to increase in size.

CML has three important phases:

- Chronic phase
- Accelerated phase
- Blast (crisis) phase.

Chronic phase

Most people are diagnosed when they are in the chronic phase and may have no or few symptoms. The number of normal blood cells are still relatively stable and the proportion of blast cells in the bone marrow

and bloodstream is low (5% or less). With the development of newer treatments, most people in the chronic phase of CML can remain stable for many years, and can expect to have a near-normal life expectancy.

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. With modern treatments, progression to the accelerated phase of CML is now very uncommon.

During this time the blood counts become increasingly abnormal and the proportion of blast cells may start to increase in the bone marrow and bloodstream. These signs that the disease is progressing are usually picked up during routine blood tests. Some people may notice symptoms of their disease, which are listed on page 9 in the section 'What are the signs and symptoms of CML?'



Key points

- Approximately 50 people are diagnosed with CML each year in New Zealand.
- There are three different phases of CML:
 - Chronic phase
 - Accelerated phase
 - Blast (crisis) phase.
- Progression to the accelerated or blast phases is very rare because of modern treatments.

Blast phase

CML can transform into a rapidly progressive disease resembling acute leukaemia. This is known as the blast phase or blast crisis. As with the accelerated phase, modern treatments mean that progression to the blast (crisis) phase of CML is now very uncommon.

It is characterised by a dramatic increase in the number of blast cells in the bone marrow and bloodstream (usually 20% or more). Normal blood cell production cannot take place, which leads to increased chances of bleeding, infection and anaemia. Blast cells may accumulate in various parts of the body including the spleen, lymph nodes, skin and central nervous system (brain and spinal cord).

Approximately two thirds of people with CML in the blast phase transform into a disease resembling acute myeloid leukaemia (AML), the remaining one third resemble acute lymphoblastic leukaemia (ALL). The blast transformation either involves immature blood cells from the myeloid or lymphoid cell line. Figure 02 on page 3 shows the different types of leukaemia and what cell line they are part of.

What causes CML?

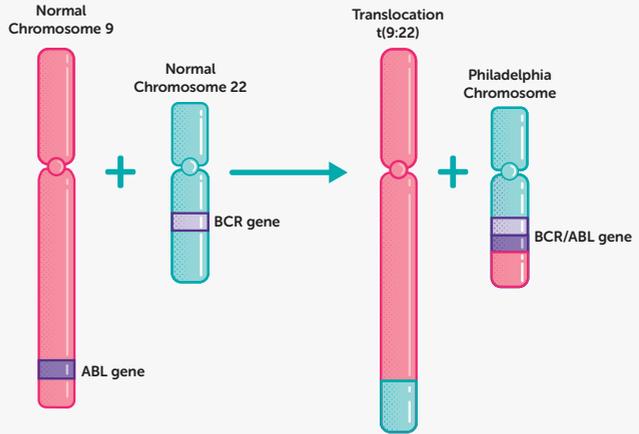
The cause of CML is not known. We do know that you cannot catch CML from someone else and most people with CML do not have a family/whānau history of CML.

People with CML have a genetic abnormality in their blood cells called the Philadelphia (Ph) chromosome. The Philadelphia 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 called translocation. This translocation t(9;22) produces a new fusion gene called BCR-ABL. See Figure 04 on page 8, which shows the translocation of the chromosomes. This BCR-ABL gene increases the activity of an enzyme called a tyrosine kinase. This abnormal tyrosine kinase continually signals 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.

There is ongoing research into what the possible causes of this damage might be and what may increase your risk. Exposure to very high doses of radiation, industrial chemicals (like benzene) and certain types of chemotherapy may increase your risk of developing CML. Why these mutations occur in the first place remains unknown but there are likely to be a number of factors involved.

Figure 04

Philadelphia chromosome translocation



Key points

- CML is not inherited or contagious.
- The cause of CML is not known but risk factors have been identified such as high doses of radiation and exposure to the chemical benzene.
- People with CML have an abnormal chromosome called the Philadelphia (Ph) chromosome that produces an enzyme called tyrosine kinase, which signals the bone marrow to make too many white blood cells.

WHAT ARE THE SIGNS AND SYMPTOMS OF CML?

Most people are diagnosed during the chronic phase of CML and have no or very few symptoms.

Your CML may have been picked up through a routine blood test and you may not have any symptoms. Initial symptoms may be vague and non-specific, but may become worse over time.

These vague symptoms may include:

- Fatigue
- Weight loss
- Increased sweating
- Abdominal discomfort due to enlarged spleen (splenomegaly).

If your symptoms are getting worse this may indicate that you are in the accelerated phase of CML.

In the accelerated phase, the number of CML cells grow faster and cause these vague symptoms to get worse. If left untreated, accelerated phase CML will eventually transform into blast phase CML.

Signs and symptoms of blast (crisis) phase CML

As mentioned earlier on page 6, it is very uncommon to have accelerated or blast (crisis) phase CML. The symptoms listed below are related to the blast (crisis) phase of CML as a result of low amounts of normal blood cells in the body.

Anaemia

Having a low haemoglobin level (because of a low number of red blood cells) causes anaemia.

The symptoms of anaemia include:

- Lack of energy (lethargy)
- Feeling very tired all the time (fatigue)
- Shortness of breath, especially when exercising
- Dizziness
- Pale skin (pallor).

Bleeding and bruising

Having a low platelet count (thrombocytopenia) can mean it's harder for your blood to form clots to stop bleeding.

The symptoms of thrombocytopenia include:

- Bruising easily
- Minor cuts or injuries that take a long time to stop bleeding
- Frequent or severe nosebleeds or bleeding gums
- Unusually heavy periods in women
- Red or purple pinhead-sized spots on your skin called petechiae (pe-tee-kee-i).

Infections

Neutrophils are the most common type of white blood cell, and having a low number of neutrophils in your blood is called neutropenia. If you have neutropenia, you are at higher risk of getting infections.

Common signs and symptoms of infection include:

- Fever (high temperature of 38°C or above)
- Shivering or rigours
- Coughing up yellow or green phlegm
- Fatigue or extreme tiredness.



Key points

- Most people are diagnosed during the chronic phase of CML and have few, if any, symptoms.
- You may experience symptoms if you are in the blast (crisis) phase which are a result of low amounts of normal blood cells in the body.

WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

You may meet a range of health professionals who are part of your health care team.

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will aim to give you and your family/whānau the best treatment and support so that you can live as well as possible following a diagnosis of CML. You may not meet all the health professionals listed below.

Your primary (main) doctor who specialises in CML and its treatment is a haematologist. A haematologist specialises in the treatment of blood cancers or blood conditions. They will be in charge of overseeing your treatment and follow-up.

Some of the health professionals you may meet are, in alphabetical order:

- **Charge nurse** – A senior nurse in charge of an outpatient department, day unit or hospital ward.
- **Clinical nurse specialist (CNS)** – A nurse with advanced skills in a specific area of clinical care. This person works closely with you and members of your health care team to coordinate treatment, and help you manage the symptoms of CML and the side effects of treatment.
- **Dietitian** – A dietitian may advise you on what to eat and drink to minimise symptoms or side effects from CML or your treatment. They may also prescribe supplements to make sure you are getting the calories and nutrients you need.
- **General practitioner (GP)** – A family and community doctor. They will work together with other health professionals to support you at home and in the community.
- **Occupational therapist** – Helps you manage everyday activities and achieve activities you want or need to do.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in clinic.
- **Pathologist** – A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.
- **Pharmacist** – Prepares and checks your drugs/medications. Pharmacists can advise you on how to take your medicine, possible side effects and interactions with other medications.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility.
- **Psychologist** – Specialises in helping you manage the emotional challenges such as stress, anxiety and depression.
- **Registrar** – A doctor who is in training. You may see a registrar in clinics, day units and wards. Registrars work closely with senior specialists (haematologists).

- **Social worker** – Helps you manage the practical and emotional impact of the condition and its treatment, such as advice about managing at home, employment or school.
- **Ward nurse** – A nurse who looks after you during a stay in hospital.

Other people you might hear about or meet are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of CML, helping improve quality of life and supporting people at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.

- **Non-governmental organisation (NGO)** – Gives emotional and practical support for those affected by cancer, e.g. Leukaemia & Blood Cancer New Zealand (LBC).
- **LBC Support Services Coordinator** – A professional who provides education as well as practical and emotional support. They can be contacted by calling 0800 15 10 15.

Meeting so many people can sometimes be confusing and overwhelming. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit in to your health care team.

TESTS AND INVESTIGATIONS

To find out if you have CML, your doctor will ask you to have some tests which will help make a diagnosis.

There are two main tests for diagnosing CML: a blood test and a bone marrow biopsy.

Blood test

The main blood test used to diagnose CML is called a full blood count (FBC) or complete blood count (CBC). Blood is taken from a vein in your arm and sent to a lab (laboratory) where it is looked at under a microscope.

If you have CML, the FBC is likely to show the following:

- A high number of leukocytes (white blood cells).
- Some blast cells might be present, but usually very low numbers.
- A lower amount of red blood cells.
- The platelet count may be normal, mildly reduced or in some cases raised.

Someone with CML may have a high number of white blood cells and sometimes a high number of platelets as well. These blood cells may not function properly, causing symptoms explained on page 9.

You will continue to have regular blood tests to see how well you are responding to treatment and to monitor your blood counts before and after treatment.

Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a lab to be looked at

under a microscope. The doctor examining the bone marrow sample will be able to look at what type of cells are present, the amount of cells being formed, and confirm if there is a Philadelphia (Ph) chromosome or BCR-ABL gene in the bone marrow cells.

A sample of bone marrow is usually taken from the back of your hip bone (the iliac crest).

A bone marrow biopsy can be done when you are staying overnight in hospital or as an outpatient (you visit the hospital for this purpose).

The doctor might give you a drug that makes you feel relaxed and sleepy (a sedative) before the biopsy starts. You might also be given pain relief. The doctor will give you a local anaesthetic. This is a small injection that is put into your skin where the biopsy is going to be done, to make the area numb.

To do a bone marrow biopsy the doctor puts a long needle through your numbed skin into the bone and then into the bone marrow. Bone marrow has liquid and solid parts. A small sample of your bone marrow liquid is taken out. This is called bone marrow aspirate. A sample of the solid part of the bone marrow is also taken. This is called a bone marrow trephine (tre-fine). See Figure 05 (on next page).

Some people who have had a bone marrow biopsy say that it was painful and

other people describe it as uncomfortable. Everybody is different. We recommend that you bring a support person with you when you have a bone marrow biopsy. If you have a sedative, you will still feel a bit drowsy afterwards. Your support person can make sure you get home safely.

After the biopsy, your doctor or nurse will put a plaster or small dressing over the biopsy site. You may need paracetamol to help ease some discomfort in the area afterwards. Your doctor or nurse will talk to you about this.

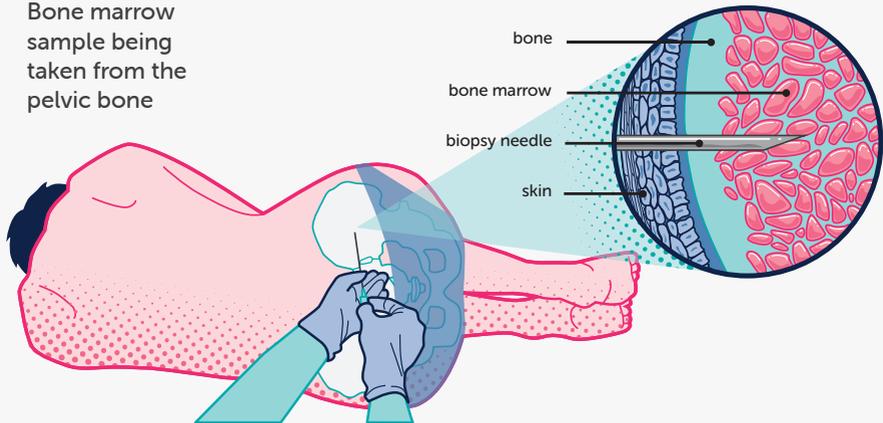
The bone marrow aspirate and trephine samples are sent to a lab and examined under a microscope. You will then have an appointment with your haematologist to talk about the findings of your bone marrow biopsy.

You may also have a bone marrow biopsy or biopsies after you have started treatment for CML to see how well you are responding to your treatment, although with modern treatment, monitoring can be done on peripheral blood samples in most patients.

Figure

05

Bone marrow sample being taken from the pelvic bone





Detailed information

Further tests are done on your bone marrow or blood sample. The results of these tests will show what subtype of CML is present and what the best type of treatment will be.

These tests are called:

- Cytogenetic (cy-toe-gen-et-ik) tests
- Immunophenotyping (imm-you-no-feen-o-tie-ping)
- Molecular genetic tests.

Cytogenetic tests provide information about the genetic make-up of the leukaemia cells like the number, structure and abnormalities of the chromosomes present. Changes to the chromosomes provide information about the subtype of CML and the best way to treat it.

Immunophenotyping checks if special markers, called antigens, are found on or in white blood cells. This is to determine the exact subtype of CML you have. Immunophenotyping is not required to diagnose CML in the chronic or accelerated phases. It can be helpful in the blast (crisis) phase to determine what cells are affected.

Molecular genetic tests are more specific and sensitive than cytogenetic tests. They can detect certain gene mutations seen in some subtypes of CML and can help predict response to treatment. These tests are capable of measuring minute traces of leftover (residual) leukaemia cells that may give some indication of future relapse.

Two common types of molecular tests used in diagnosing CML are:

- **Polymerase chain reaction (PCR) tests**
PCR is a technique that can trace amounts of DNA so further studies can be done to identify malignant (abnormal) cells based on genetic abnormalities, such as mutations or chromosomal changes. PCR testing is an important part of monitoring. It is explained further on page 25.
- **Fluorescent in situ hybridisation (FISH) tests**
FISH tests can detect DNA changes in genes. A doctor attaches a dye and ultraviolet (UV) light to your blood or bone marrow sample to find and count the gene changes.

Other tests

There are other tests that provide your health care team with information about your general health. These may include tests like X-ray, CT scan or echocardiogram (ECHO). Your health care team will let you know if you need to have these tests and what they are for.

Preparing for tests

Before you go for a test, ask your health care team how long the test will take, what the test involves and how you will feel afterwards.

Things that you can do to help prepare for going to the test are:

- Plan your journey so that you arrive on time and do not have to rush.
- Find out about parking. Your LBC Support Services Coordinator can help.

- Ask a support person to come with you.
- Ask for an interpreter if needed. Your health care team can help facilitate this.
- Take your favourite music on a device with headphones.
- Take something to read.

Normal blood test results

Table 01 gives you information about normal blood test results for adults. You may find this useful when you are having regular blood tests and want to compare your results with the normal range.

Please note that there may be small variations compared with the data used at your hospital or clinic.

Table 01: Normal range for adults (local laboratory ranges may differ slightly)

	Adult men	Adult women
Haemoglobin (Hb)	130–175 (g/L)	115–155 (g/L)
Neutrophils	2.0–7.5 ($\times 10^9/L$)	2.0–7.5 ($\times 10^9/L$)
Platelets	150–400 ($\times 10^9/L$)	150–400 ($\times 10^9/L$)



Key points

The two main tests for diagnosing CML are:

- Blood test (a full blood count - FBC)
- Bone marrow biopsy.

We recommend that you bring a support person when you have a bone marrow biopsy.

INFORMED CONSENT FOR TREATMENT AND PROCEDURES

You will be asked to give your informed consent for all treatments or procedures suggested by a health professional in your health care team.

Consent means that you agree. Informed consent means that you understand the information and accept the possible risks and benefits of the treatment or procedure. Informed consent also means that you have had other treatment or procedure options explained to you.

If you have any doubts or questions or need more information about a procedure or treatment, it is important that you speak to your doctor or nurse again. You may need to sign a consent form (written consent) or you may just say you agree to a treatment or procedure (verbal consent).

If someone is not able to give informed consent, a legal guardian, welfare guardian or person with enduring power of attorney (EPOA) can give consent on behalf of the patient.

Generally, a person over the age of 16 can give informed consent if the doctor feels they are able to do so.

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 18.



Key points

- Informed consent means that you understand the information around treatment or a procedure.
- Speak to your health care team if you have any doubts or need more information about treatment or a procedure.

MAKING TREATMENT DECISIONS

The main aim of CML treatment is to destroy the leukaemia cells in the body and allow the bone marrow and blood to function normally again.

No two people are the same. To help you make the best treatment decision, your doctor will consider all the information available.

Many people feel overwhelmed when they are diagnosed with CML. Waiting for test results and discussing treatment options can be very stressful.

Your doctor will spend time with you and your family/whānau discussing what they feel is the best option for you. Ask as many questions as you need to, at any stage. You should feel that you have enough information to make the important decisions you are facing.

Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist about your diagnosis and/or treatment. You can ask any member of your health care team, including your current haematologist, about getting a second opinion.

Questions to ask your health care team

Before going to see your GP or haematologist, or another member of your health care team, make a list of the questions you would like to ask.

In Appendix A on page 48 there are some examples of questions you could ask your

GP or haematologist. You could write your questions and answers at the back of this booklet or in the LBC Haematology Patient Diary available from your LBC Support Services Coordinator. There is also a list of questions that you might like to ask your doctor.

Bring a support person

We recommend that you bring a support person along to your appointments. Your support person can write down the answers to your questions, remind you of questions you want to ask and help you remember information.

Prognosis

Prognosis means the likely course of a disease, i.e. how likely it is to be cured or controlled. Your prognosis will depend on many things. Your haematologist is the best person to give you a prognosis and tell you how well your leukaemia is likely to respond to treatment.

There are prognostic scoring systems (e.g. Sokal scoring system) that your doctor may use to help guide with treatment choices.

When doctors and the other members of the health care team talk about prognosis, they might use the terms: deep molecular response, stable disease, refractory disease, relapse or treatment-free remission.

Here is what these terms mean:

- **Stable disease** – The CML has not improved or worsened with treatment.
- **Relapse** – The CML has come back again. Some people's CML may never relapse while others may have a higher chance of relapse.
- **Refractory disease** – The leukaemia is not responding to treatment (it is 'resistant' to treatment).
- **Deep molecular response (DMR)** – Molecular response is measured through a PCR test. A DMR is defined by the amount of BCR-ABL gene in your blood which has majorly reduced with treatment.
- **Treatment-free remission (TFR)** – This term is used in CML when there is DMR without the need for ongoing tyrosine kinase inhibitor (TKI) treatment. This is discussed in more detail on page 25.

if a new treatment or different ways of giving treatment are better than treatments that are already available. Participation in a clinical trial can provide an opportunity to access these latest treatments, or to use existing treatments for CML in a new way.

Taking part in a clinical trial is voluntary, which means that you do not have to take part in the trial if you do not want to. If you do not want to be part of the trial, your decision will be respected. You do not have to give a reason why you don't want to be part of the trial and there will be no change in the way you are treated by the hospital or health care team.

Make sure you understand the reasons for the trial and what is involved. You need to give informed consent for a clinical trial. Take time to talk through the trial with your haematologist and other members of the health care team before signing the consent form.

Being in a clinical trial

Your doctor might ask you to take part in a clinical trial. Clinical trials are also called research studies. Clinical trials help find out



More information available online



Key points

- Your doctor will recommend a course of treatment to you, and will give you the opportunity to discuss your treatment and ask questions.
- You will be given information so that you can understand the risks and benefits of treatments and procedures. You will be asked to give your written or verbal consent for treatments and procedures.
- We recommend you bring a support person to your appointments if possible.
- Clinical trials (research studies) help find new treatments or aim to improve current treatments. Clinical trials are voluntary.

TREATMENT FOR CML

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

The main goals of CML therapy is to have:

- A normal life expectancy
- Good quality of life
- Potential to avoid lifelong treatment.

Most people with CML will be treated with drugs called tyrosine kinase inhibitors (TKIs) or TKI therapy.

If you have a high white blood cell count when diagnosed with CML then you may be given a short course of chemotherapy tablets called hydroxyurea before commencing TKI therapy.

If you do not respond well to TKI therapy and your CML is progressing (getting worse) then different treatment will be considered. Some people may benefit from having a stem cell transplant.

These different treatment options are explained in more detail below.

Tyrosine kinase inhibitor (TKI) therapies

TKI therapies are a type of targeted therapy. Targeted therapy works by identifying and

attacking specific types of cancer cells while causing less damage to normal cells. In CML, TKIs target the abnormal BCR-ABL1 protein by blocking its function, which stops the growth and reproduction of the leukaemia cells. TKI drugs are taken orally (tablets that you swallow) and they usually have to be taken each day for life to keep your disease under control. Some people might be able to stop taking the drugs after a period of time, and treatment-free remission is now a goal of therapy in CML.

Adherence, also commonly called compliance, to TKI treatment is very important for the drugs to work effectively. This means that it is very important to continue taking your prescribed tablets each day and not miss any doses. If there is not enough drug in your body (due to skipped doses), it is possible that the CML cells may become resistant and stop working effectively. See page 25 for ways to help you remember to take your drugs as prescribed.



Important information

- If you have accidentally missed a dose then take the missed dose as soon as you remember, then continue with your normal schedule. If you have any questions, contact your haematology nurse or doctor.

There are three different TKI drugs currently used and funded in New Zealand:

- Imatinib
- Dasatinib
- Nilotinib.

There are other TKI drugs being developed and used around the world (e.g. bosutinib and ponatinib). Most TKI drug names end in 'tinib'. Your haematologist will be able to give you the latest information about available treatment options.

Side effects of TKI therapy

All drugs can have side effects, sometimes they are serious but most of the time they are not. Generally, TKI drugs are very well tolerated so you may not experience any, or many side effects.

Here is a list of the most common side effects of TKI therapy – in alphabetical order:

- Changes in appetite and weight
- Constipation
- Diarrhoea
- Difficulty sleeping
- Dizziness or light-headedness
- Dry mouth
- Fatigue and tiredness
- Feeling anxious or depressed
- Headache
- Indigestion or feeling bloated
- Muscle cramps
- Nausea (feeling sick) or vomiting
- Puffiness around the eyes
- Shortness of breath and/or cough.

These side effects, and what you can do if you have them, are discussed in the section called 'Living with CML' on page 27.



Important information

- It is important to let your haematologist know if you start taking any other medications while on TKI therapy. Some drugs (including paracetamol) may interfere with it.
- Avoid having grapefruit and grapefruit juice while taking TKI drugs as they may interact.



Key points

- Tyrosine kinase inhibitors (TKIs) are the main form of treatment for CML. There are different kinds of TKI drugs.
- Imatinib is the most common TKI drug currently used and is a tablet that needs to be taken each day, often for life.

Chemotherapy

Chemotherapy, often called chemo, is the name given to anti-cancer drugs (also called cytotoxic drugs) that work by stopping cancer cells dividing. Each drug affects the cancer cells in different ways.

Most chemotherapy drugs travel around the body in the bloodstream, which means they can reach cancer cells anywhere in the body. Sometimes the chemotherapy drugs also kill healthy cells, which leads to side effects.

Chemotherapy can be given (administered) in different ways, e.g. into a vein or as a tablet.

Chemotherapy is not always used when treating CML. Sometimes a chemo tablet called hydroxyurea is given if you have a high white blood cell count before starting TKI therapy. Chemotherapy can also be given in combination with TKI drugs and may be more effective if someone is in accelerated or blast phase. Chemotherapy is also given before having a stem cell transplant. Further information about stem cell transplants is discussed on page 23.

Intensive chemotherapy

Intensive chemotherapy is a treatment that involves being given a full dose of chemotherapy in hospital, with the aim of managing CML. If your CML has transformed into an acute leukaemia (either AML or ALL) you will need a combination of intensive chemotherapy and TKI therapy. There are separate booklets on AML and ALL if you want further information about these types of leukaemia.



**More information
available online**

If you have intensive chemotherapy, you may spend long periods of time in hospital, often several weeks. Some intensive treatments can only be given in a main centre hospital so you may have to travel to another city for this. On page 36 there is more information about spending time in hospital and moving to a hospital in a main centre.

Hydroxyurea

Hydroxyurea is classed as a chemotherapy drug because it causes cell death. It is given orally (as a tablet that you swallow). Hydroxyurea is generally well tolerated but can have some side effects. It works by suppressing the function of your bone marrow and controlling blood cell production. It interferes with the DNA of blood cells so instead of growing and maturing normally, they die.

Side effects of hydroxyurea

You may experience some side effects from taking hydroxyurea. Most people do not experience all of the side effects. Side effects are almost always reversible and will go away after treatment stops. Let your health care team know if you have any unusual symptoms.

Common side effects of hydroxyurea may include:

- Nausea and/or vomiting
- Diarrhoea
- Mouth sores
- Poor appetite
- Nail thickening and discolouration of nails or skin
- Weakness
- Fatigue
- Hair thinning.

Other chemotherapy drugs and their side effects are discussed in more detail on the LBC website.



More information available online



Important information

If you are receiving hydroxyurea or other chemotherapy drugs, you may be at risk of a very low white blood cell count (neutropenia), increasing your risk of infection. If this is the case, your health care team will tell you what to do if you develop a fever or other symptoms of infection. Infections during chemotherapy can be very serious, and even fatal, if you do not seek medical advice quickly for an assessment and antibiotics.

Important things to consider are:

- Make sure you have a thermometer at home and you know how to check your temperature correctly. If you have been told you are at risk of infection, you should contact your hospital if you have a temperature of 38°C or higher. Do not wait to see if your temperature goes away as you could deteriorate very quickly.
- You should promptly see your GP or an emergency doctor if you develop a fever or other symptoms of infection. Infections can get worse if left untreated.
- Be cautious about using aspirin or ibuprofen in any form. These drugs can increase your risk of bleeding if your platelet count is low. Always check with a doctor or nurse first.
- Ask a member of your health care team for the phone numbers of the hospital.



Key points

- Chemotherapy drugs work by stopping cancer cells dividing. There are many different types of chemotherapy and it is given in a variety of ways, e.g. via a drip (IV) or a tablet.
- Chemotherapy is not always used when treating CML. A chemo tablet called hydroxyurea is sometimes used to treat people with CML who have a high white blood cell count.

Stem cell transplant

Stem cell transplant (bone marrow transplant) is not indicated for most people with CML. If your specialist thinks a stem cell transplant is necessary or an option for you, they will discuss it with you in detail.

Stem cell transplants allow you to have much higher doses of chemotherapy. This may be necessary for some people if their CML is not well managed on other treatment, e.g. if you are in the blast crisis phase.

LBC has separate booklets on stem cell transplants, ask your health care team or LBC Support Services Coordinator if you would like more information.



**More information
available online**

Supportive care

Supportive care is important to help people cope with their diagnosis of CML, symptoms of CML and the impact of treatment. Supportive care ensures that you have the best quality of life.

Examples of supportive care include:

- Being prescribed medicines to help manage side effects or symptoms, e.g. pain relief or antiemetic drugs (drugs to stop you feeling sick).
- Being given vaccines, antibiotics or immunoglobulin to help prevent or manage infections.
- Support from a dietitian, psychologist or chaplain.
- Practical support at home.
- Support for families/whānau who have to relocate for treatment.

- Being given blood products via a drip (a transfusion) to help with symptoms of low red blood count or platelets.

Palliative care

The palliative care team is made up of doctors, nurses and other health care professionals who specialise in managing symptoms of diseases, including CML. They aim to improve quality of life through support and services as you face a life-limiting illness. The palliative care team may be involved in providing you with supportive care.

Many people associate the word 'palliative' with end-of-life care. Palliative care does include end-of-life care, but the palliative care team also supports people with symptoms and side effects of their disease or treatment.

Complementary therapies

Many people find complementary therapies, or a combination of these, help them to feel better physically and emotionally.

Examples of complementary therapies are:

- Relaxation
- Yoga
- Mindfulness techniques
- Massage
- Reiki
- Acupuncture
- Aromatherapy
- Homeopathy
- Reflexology
- Meditation
- Art therapy
- Music therapy
- Visualisation
- Tai chi.

If you are not sure what some of these therapies are, ask a member of your health care team. If you plan to use complementary therapies, including any supplements, make sure they are a safe option for you by asking your haematology health care team first. Some supplements or natural therapies can interfere with some drugs, which is why it is important to let your doctor know if you are taking anything else.



Key points

- Supportive care helps people cope with their diagnosis of CML, the impact of symptoms and the side effects of treatment.
- Palliative and end-of-life care provide people with support and services as they face a life-limiting illness.
- There are a range of complementary therapies that can have physical and emotional benefits.

MONITORING RESPONSE TO TREATMENT

Careful, ongoing monitoring is essential to make sure your CML is controlled well. Treatment goals for CML are to normalise your blood counts and reduce or eliminate the Philadelphia (Ph) chromosome and the BCR-ABL gene.

Ongoing monitoring for people with CML is important to ensure treatment is working effectively and to identify quickly if it is not.

The best way to monitor this is through regular blood tests. After you have a blood test, the doctor will analyse your sample using a method called polymerase chain reaction (PCR) testing. PCR testing is an accurate tool that can monitor the BCR-ABL gene, which is a marker of CML.

In general, if the amount of BCR-ABL1 in your blood decreases over time, then you are responding to treatment. If the BCR-ABL1 level rises, then this indicates that your disease is getting worse. It may indicate a resistance to the treatment you are on, or if you are not having any treatment, that your CML is progressing.

It is important that you know how often you should be having a blood test and how often you should see your haematologist. This will vary from person to person so check with your health care team. You may find it useful to add these dates into your calendar, phone or diary.

Adherence to monitoring and treatment

Taking your drugs as prescribed is very important and can impact how well you

respond to treatment. The responsibility for taking your daily oral drugs (like imatinib) falls on you as the patient. It is very important to make a habit of taking your TKI therapy at the same time every day. If you are struggling to remember to take your drugs each day, it is important to talk to your health care team. They are there to help you and may have helpful suggestions. It can be easy to forget to continue taking drugs when you start feeling well again so make a plan of ways to remember.

Examples may include:

- Set a daily alarm or reminder on your phone that goes off at the same time each day.
- Take your drugs at the same time you eat breakfast, lunch or dinner.
- Keep your drugs in a safe and obvious place that you will see each day (e.g. by your toothbrush or on your desk).
- If you don't spend much time at home, keep your drugs in your purse, bag or car.

Treatment-free remission

Treatment-free remission (TFR) is now a treatment goal for people with CML who have achieved a stable and deep response to treatment. TFR is achieved when you remain in a deep molecular response (DMR) when TKI therapy has been discontinued.

Not everyone with CML will be eligible to discontinue their TKI therapy. If you have chronic phase CML and have had a DMR for several years, your haematologist might consider stopping your treatment. The guidelines for stopping treatment may vary slightly between hospitals.

The potential benefits of TFR may include:

- Reducing or eliminating side effects of TKI drugs
- Cost of ongoing treatment (usually publically funded in NZ)
- Adherence to daily medications
- Wish to become pregnant.

Close monitoring is essential and you will be required to have regular PCR monitoring through blood tests. Life-long monitoring is important, even if you have stopped treatment. If a molecular relapse does occur (usually in the first six months of stopping treatment) then treatment will be restarted. Response to restarting treatment after a molecular relapse is very successful.



Detailed information

TKI withdrawal syndrome

TKI withdrawal syndrome can occur, and affects about 30% of people who have stopped their TKI treatment. The most common symptom is musculoskeletal pain (usually joint stiffness and pain, particularly in the hips and shoulders). It occurs four to six weeks after stopping treatment and can last several months. Pain relief is often needed to manage symptoms. It is important to let your haematologist know of any pain you experience after stopping your TKI therapy.

LIVING WITH CML

Each person's diagnosis of CML will be different. There are a variety of challenges you may face.

Being told you have a chronic condition like CML can be overwhelming and it is common to experience a range of feelings like anger, confusion, worry or sadness. There are people to support you through your diagnosis and help you navigate the areas of your life that are challenging.

This section helps you manage the more common side effects of CML treatments and are listed in alphabetical order.

Remember to report any side effects to your doctor or nurse. Each person will experience different side effects and it will also be dependent on what treatment you are on. If you are having chemotherapy or a stem cell transplant, see the LBC website for more information on side effects. Your LBC Support Services Coordinator can give you support or more information.

Cardiovascular risk

There is cardiovascular risk if taking the TKI drug nilotinib. It is recommended that you avoid smoking and consider having a regular check-up with your GP (e.g. to check blood pressure, cholesterol and diabetes), to ensure there are no other factors putting you at excess risk of heart disease.

Talk to your health care team if you're taking nilotinib and have any concerns about your cardiovascular risk.

Constipation

Constipation means that you cannot pass a bowel motion easily, usually because your bowel motions are hard. Tell your nurse or doctor if you are constipated or sore.

Hard bowel motions can damage the lining of your bowel and cause bleeding or infection.

Things you can do to help:

- Drink plenty of water.
- Eat more fibre such as cereals, raw fruit and vegetables. See page 33 for recommendations on food safety.
- Do some gentle exercise.
- Tell your doctor or nurse, as they can give you something to soften your bowel motions.
- Talk to a dietitian.

Diarrhoea

Sometimes treatment (e.g. chemotherapy) damages the lining of your bowel wall. This might cause diarrhoea (die-a-rea) (loose bowel movements) and other symptoms such as:

- Cramping (pains in the lower abdomen or gut)
- Abdominal swelling (swollen tummy/lower gut).

If you have diarrhoea, the health care team will do a test to see if you have an infection.

Things you can do to help:

- Take the drugs that your doctor or nurse give you to stop the diarrhoea.
- Wipe your bottom with soft toilet paper or flushable wipes.
- Apply a barrier cream around your bottom to protect and soothe the skin.
- Drink plenty of fluids.
- If you are unable to drink fluids, tell your doctor or nurse as you may need to have a drip (IV).
- Eat less fibre, such as cereals, raw fruits and vegetables.



Important information

Call the hospital if you have more than four episodes of diarrhoea in a day.

Difficulty concentrating or remembering (chemo brain)

Chemo brain is also called mild cognitive impairment (MCI). It can also affect people with cancer who have not had chemotherapy. The exact cause of chemo brain is not known.

The symptoms of chemo brain are:

- Difficulty concentrating
- Feeling very tired
- Difficulty remembering things, including finding the right word.

Chemo brain can be frustrating and it can make everyday life difficult. Things you can do to help:

- Keep a diary of your symptoms.
- Make lists, take notes, and use sticky pads or your phone for reminders.
- Keep a calendar or diary.
- Do mental exercises such as crosswords and puzzles.
- Try to keep calm.
- Do some regular exercise.
- Get plenty of rest and sleep.
- Read short articles rather than books and watch episodes of programmes rather than films.



More information available online

Dizziness and headaches

You may experience dizziness and/or headaches after starting treatment like imatinib. Let your doctor know as they can assess you properly and give you pain relief medications.

It is important to get enough sleep, eat well and reduce stress when possible as this may help reduce headaches or dizziness. Some people find complementary therapies useful to prevent or relieve headaches.

These are listed on page 23. Talk with your health care team about whether you may benefit from complementary therapies for your headaches.

Dry or sore mouth

A dry mouth can be an uncomfortable side effect of TKI therapy.

Things you can do to help:

- Keep your mouth moist by drinking water, sucking on ice chips or sugar-free hard candy.
- Ask your doctor if a saliva substitute would be appropriate.
- Avoid smoking tobacco as this irritates the mouth. Ask your health care team if you do smoke and need help to quit.

Some CML treatments (in particular chemotherapy drugs) can cause a sore mouth. A sore mouth occurs when there is damage to the cells in the lining of your mouth and digestive system, usually when your white blood cell count is low. The medical name for this side effect is mucositis (mew-co-site-is). Mucositis is a rare side effect from TKI therapy.

The symptoms of mucositis can include any of the following:

- Mild soreness of the mouth especially the inside of your cheeks, the sides and underneath of your tongue and the back of your throat
- Taste changes
- White rough-feeling patches on the inside of your mouth
- Red and inflamed patches on the inside of your mouth
- Painful ulcers (sores) on the inside of your mouth
- Difficulty or pain eating, drinking and taking tablets
- Thick saliva (spit)
- Sore throat and/or cracked lips.

Regular mouth care is important for comfort and to prevent infection, especially from mouth ulcers.

If you do have mouth pain or a dry mouth, it is important to let your health care team know as they can advise you on how to manage it. Your health care team can also advise you about when and how to do mouth care properly.

Effects on the eyes

TKI therapy can cause eye pain, dry or watery eyes, or changes in vision. You may experience puffiness/swelling around the eyes, which is caused by fluid retention. If your eyes are affected, tell your doctor. You should be careful when driving or operating machinery if your vision has changed.

Fatigue (extreme tiredness)

Fatigue is very common for people with CML or if you are having CML treatment. Extreme tiredness can be caused by:

- CML itself
- Chemotherapy and targeted therapies
- Emotional stress
- Poor sleep
- Low blood counts (especially anaemia caused by low red blood cells)
- Muscle loss
- Loss of appetite or dehydration.

Extreme tiredness can have a huge impact on your life. If you have chemotherapy, it can sometimes be several months before you feel your energy levels are back to normal. Some people feel tired for a year or more afterwards.

Things you can do to help:

- Have a regular night sleep routine.

- Have regular rest periods throughout the day.
- Don't try to do too many things in a day, just do the important things.
- Note the times in the day when you have the most energy and set goals to do your main activities at these times.
- Do some light exercise each day. This will help your body condition and make you feel good.
- Keep a diary so you can look back and see your improvements in energy levels over time.

In hospital your sleep can be very interrupted. Speak with your health care team if you are finding this is making you very tired during the day. Also speak with the team about emotional support if you are having trouble coping due to fatigue.



More information available online

Low mood, anxiety, depression or difficulty coping

After finding out you have CML or during treatment, it can be common to have a low mood, feel anxious or depressed, or find it difficult to cope.

There can be a lot of things that cause these feelings.

- Being unable to work, study or do the things you usually do (may be short term or long term).
- Symptoms and side effects, such as fatigue or risk of infection, can make it hard to be with other people or attend social events.

- A lack of support from family/whānau or friends who may not know what to say or do.
- Financial difficulties can make it hard to maintain social activities or visit family/whānau and friends.

Things you can do to help:

- Talk about how you feel with someone you feel comfortable with e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger longer-term goals.
- Make a list of things that make you feel better such as your favourite TV show, talking to someone on the phone or doing a hobby.
- Try to maintain your social circle by keeping in touch with friends and family/whānau.
- Try to spend time each day relaxing, e.g. meditation, listening to music.
- Exercise regularly.
- Try to keep a regular sleep pattern.
- Keep a diary. This can help you express how you feel without needing to talk to anyone.
- Try complementary therapies such as massage, aromatherapy or reflexology. Information on complementary therapies can be found on page 23.

It is important to tell a member of your health care team if you continue to have feelings of low mood, anxiety, depression or difficulty coping. They can make sure you get the support you need.

Feeling isolated can have an impact on your physical and mental well-being. It is important to speak to your doctor, nurse, social worker or LBC Support Services Coordinator if you feel isolated or alone.

Muscle cramps

Muscle cramps can be a side effect of TKI therapy. It may cause pain, weakness or stiffness and most often occurs in the arms or legs.

Things you can do to help:

- Gentle massage of limbs to encourage blood flow.
- Taking a warm bath or shower might help relieve symptoms for a short period of time.

Talk to your health care team if you are experiencing muscle cramps. Some people may benefit from taking a supplement.

Nausea, vomiting and dehydration

Some chemotherapy can make you feel sick (nausea) or be sick (vomiting). Feeling anxious can also cause nausea and vomiting.

There are drugs called antiemetics which can help treat nausea and vomiting. Different antiemetic drugs work in different ways and you may have one or more types to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch.

Tell your doctor or nurse if you still feel sick because they might be able to try a different antiemetic or give it to you in a different way.

Controlling your nausea and vomiting is important so you can keep up your food

and drink intake. If you have bad nausea and vomiting and are unable to drink or keep fluid down, it is important you speak with your doctor or nurse to ensure you don't become dehydrated.

Things you can do to help:

- Eat smaller meals or snacks, more frequently throughout the day.
- Don't eat foods with a strong smell or taste.
- Don't eat hot or fatty foods.
- Try fizzy drinks.
- Try ginger tea or ginger ale.

Complementary therapies such as relaxation, aromatherapy or massage might help some people.



Important information

Some CML treatments can cause inflammation of the pancreas (pancreatitis). If you develop severe tummy pain, possibly with vomiting, you should seek urgent medical attention, as you may need tests to rule out pancreatitis or other serious causes.

Pain

Some people may experience pain as a result of treatment.

It is important to tell your health care team if you have pain. Your health care team will ask you about the pain, for example:

- What is the pain like, e.g. dull, sharp, burning?

- How bad is the pain on a scale of 0–10? (0 being no pain, 10 being the worst pain you've ever felt)
- What makes the pain worse and what makes it better?

Pain can be caused, or made worse, by your emotions or how you are coping with your diagnosis and treatment. This is called 'total pain'. Total pain can be psychological, social and/or spiritual. Examples of things that might cause total pain are anxiety, worries about your family/whānau or a crisis of faith. It is important total pain is managed as well as physical pain. Ask your health care team for the support you need.

Poor appetite and taste changes

You may not feel like eating and have taste changes. This may be because of the TKI therapy, chemotherapy, the worry of having CML or doing less physical activity.

Poor appetite

Having a poor appetite can be disappointing for people who usually enjoy eating. It is important to keep eating to help maintain your weight and energy levels. It is also important to drink plenty of fluids, especially if you are not eating very much.

It can be common for people to really feel like eating certain foods but then by the time it has been made, they cannot eat it. Choose meals that can be made quickly and are easy to eat.

If you are finding it difficult to eat, or are worried about your weight, ask to speak with a dietitian who will be able to advise you.

Things you can do to help:

- Eat small amounts of food as often as possible.
- Keep snacks handy such as nuts and dried fruit.
- Add extra energy and protein to your diet by using full-fat products or prescribed supplements.
- Eat what you feel like, you can return to your normal diet when your appetite returns.

Taste changes

You may find that your sense of taste changes or that the texture of food seems different. This may mean that you no longer enjoy food, that all food tastes the same, or food has a metallic taste. Your sense of smell can also be affected.

Things you can do to help:

- Eat food cold as it often tastes better and smells less.
- Suck boiled sweets or drink fruit juice as they leave a pleasant taste in the mouth.
- Try different seasonings such as herbs and spices on your food.

If you are in hospital and don't feel like eating the hospital food, ask your charge nurse about suitable foods that family/whānau or friends can bring in for you.

LBC has an 'Eating well' fact sheet available on the LBC website or from an LBC Support Services Coordinator.



**More information
available online**

Risk of infection

The risk of infection has been reported to be modestly increased in people taking TKI drugs for CML.

We recommend you keep your vaccinations up-to-date (including an annual influenza vaccination).

You should maintain a low threshold for seeking medical advice if you develop symptoms of an infection, such as:

- Fever
- Cough
- Spreading skin redness and tenderness
- Stinging when you pass urine.

Some chronic infections can reactivate during treatment with TKIs. One chronic infection that has particular risk is reactivation of hepatitis B if you have previously been exposed to it, but reactivation of other infections, including the virus that causes shingles (herpes zoster) and of tuberculosis, have no greater risk of reactivation.

If you become unwell while taking a TKI drug, make sure the doctor assessing you knows that you have CML, and what treatment you are receiving.

There are a number of things you can do to reduce your chance of getting an infection.

Food

You need to be careful when preparing and cooking food. Be sure to:

- Always wash your hands before preparing or eating food.
- Tell your family/whānau to wash their hands before preparing food.

- Prepare food in a clean place.
- Prepare raw chicken on a separate chopping board from other foods.
- Wash fresh fruit and vegetables well.
- Cook food well and makes sure it is very hot.
- Make sure reheated food is very hot.
- Eat food before its best before/use-by date.
- Do not reheat food more than once.

Pets

When you have a low white blood cell count, you may get an infection from pets. You need to:

- Always wash your hands after touching pets.
- Do not let a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Keep pets away from areas where food is prepared.
- Don't touch the litter tray or dog poo.

Talk to your health care team if you would like more information.

Gardening

Garden soil can cause infections in people with a low white blood cell count. You need to:

- Wear gloves, as soil or potting mix can have harmful germs in it.
- Wash any cuts from gardening very thoroughly.
- Check cuts for signs of infection.
- Wear a mask when working with manure or soil to avoid breathing in particles.

Sex and fertility issues

Fertility means a person's ability to get pregnant or father a child. Infertility means that you may not be able to become pregnant or father a child. Some chemotherapy may cause infertility.

It is important that you discuss any questions or concerns you might have about your fertility with your doctor and nurse as soon as possible. There may be some things you can do before you start treatment that mean you might be able to have a baby, or father a child, in the future.

For some people, the possibility of losing their fertility can be very upsetting. There is practical and emotional support available. Talk to a member of your health care team. They will help you get the support you need.

LBC has fact sheets on fertility for both men and women available on the LBC website or ask an LBC Support Services Coordinator for a copy.



More information available online

TKI therapy and chemotherapy can affect the development of a foetus, so use a condom when you have sex in the months before, during and after treatment to avoid a pregnancy.

More information on contraception, sex and relationships can be found on pages 37-40.

Shortness of breath

If you develop unusual shortness of breath while taking a TKI, you should seek medical advice as you may need a blood test and/or a chest X-ray.

TKIs can sometimes cause anaemia, and some TKIs can cause fluid build-up around the lung which are called pleural effusions.

Skin and nail changes

Some CML treatments can affect your skin and nails.

Your skin may become dry or oily. Your skin can also become red, sore, itchy and more sensitive. Some TKI drugs can cause a rash, which may be itchy.

Nails may become brittle and flaky. Ridges or lines may appear on your nails and they can also become painful or swollen.

Things you can do to help:

- Don't use soap and perfumed products or products that contain alcohol.
- Moisturise dry skin once a day, or more if needed.
- Use lip balm regularly.
- Don't scratch.
- Don't shave with razor blades.
- Use oil-free moisturiser on oily skin.
- Use hand cream regularly.
- Use nail-strengthening cream.
- Wear gloves when doing chores.

If you are having problems with your skin or nails and none of the above suggestions are helping, get support and advice from a member of your health care team or your LBC Support Services Coordinator.

Sun protection

After chemotherapy, you might find that the sun burns your skin much quicker than it used to.

Things you can do to help:

- Wear sunscreen with a high SPF and reapply regularly.
- Don't go outdoors in the hottest part of the day.
- Cover exposed skin with clothing.

You should do this for the rest of your life.

Swelling

Swelling around your eyes, in your legs, feet or hands may occur if you are taking imatinib or dasatinib. This happens when your body retains (holds on to) extra fluid. It is important to let your health care team know if you have rapid weight gain or notice any swelling. There might be a role for additional drugs to reduce fluid overload, or for a change of your CML drug.

Things you can do to help:

- Elevate your feet when sitting.
- Avoid tight clothing and shoes that are too tight.
- Try not to stand or walk around too much at one time.



Important information

When to contact your doctor or the hospital for help.

Contact your doctor or the hospital straight away (night or day) if you are feeling unwell or have any of these symptoms:

- A temperature of 38°C or over and/or shivering.
- Bleeding or bruising, e.g. blood in your urine, bowel motion or sputum (spit), bleeding gums or a nosebleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or severe constipation.
- Coughing or shortness of breath.
- A new rash, reddening of the skin or itching.
- A headache that won't go away, confusion or blurry vision.
- A new pain or soreness anywhere.
- A serious cut or an injury.
- Pain, swelling, redness or pus anywhere on your body.

Contacting the hospital after-hours

Remember to ask your health care team for the hospital after-hours phone number.

If you are feeling unwell, ring the number and ask for advice, no matter what time it is. Your health care team and the hospital would rather that you rang to discuss how you feel than not ring and feel worse. If in doubt, make the call.

The emergency department at the closest hospital will always be open and their phone numbers can be found on page 53.

Moving to a main centre hospital for treatment

If your local hospital cannot provide the treatment you require, you may need to move to another hospital in a main centre.

A social worker can help you with information and practical support such as advice on how to get accommodation, transport and financial assistance.

Moving to another hospital for treatment can be stressful for you and your family/whānau.

Contact your LBC Support Services Coordinator to obtain a relocation booklet with practical information about moving to a main centre hospital.

RELATIONSHIPS

A diagnosis of CML can have both positive and negative impacts on relationships with family/whānau and friends.

Relationship with your partner

A diagnosis and the treatment of CML can put a lot of strain on a relationship but some couples grow closer as they go through this experience together. Good communication is essential to supporting your relationship, including sharing how you feel with your partner.

Other things you can do to help:

- Planning activities together such as meals out. If you are in hospital and feel well enough, you and your partner could eat together and you could ask your nurse if it would be possible to have some time when no one comes into your room.
- Tell your partner how they can support you.
- Get support from a counsellor or psychologist. Ask your health care team or LBC Support Services Coordinator for more information or a referral.

There are other practical things you might want to discuss with your partner, such as setting up your partner, or another trustworthy person, to be your 'power of attorney'. A power of attorney is where you give a person the authority to act on your behalf if you are not well enough to do so yourself.

You could complete an Advanced Care Plan (ACP) and discuss this with your partner. An ACP gives you the opportunity to say what is important for you. Your doctor, nurse or LBC

Support Services Coordinator can explain what an ACP is and how to get a copy of the booklet.



More information available online

If you are studying, contact your departmental Dean to discuss your situation.

Ask your social worker for advice and support about money worries.

Talking to your children

Helping children to understand CML and how this will affect them can help them to cope with the changes and challenges.

You can encourage younger children in your treatment journey to use an LBC sticker journal. Your children can record your treatments and write and share journal entries with you. Ask your LBC Support Services Coordinator for more information about the LBC sticker journal.

Counselling or psychological support is available if you are concerned about how your child or children are coping. Ask your health care team or LBC Support Services Coordinator for more information.

For pre-school or school-age children, it is a good idea to speak with their teachers to let them know about your diagnosis and how this is affecting family/whānau routines and relationships.

LBC has a 'Supporting a child through a loved one's cancer diagnosis' fact sheet available on the LBC website or from an LBC Support Services Coordinator.



More information available online

Talking to friends and colleagues

It can sometimes feel difficult to talk to friends and work colleagues about your CML diagnosis, and they may also find it difficult to discuss it with you.

Sometimes people, without realising it, make comments that can be hurtful or make suggestions that are unhelpful. Most people are very keen to offer support but just don't know how.

Here are some suggestions to help you build your own support team:

- Let people know what you need such as a regular phone call, text or visit.
- Share how you are feeling and any worries you have with a good listener.
- Encourage people to read this booklet or speak to your LBC Support Services Coordinator to learn more about CML.
- Either you or a friend could make a list of practical tasks others can do to help you. You might like to include things like cooking meals, picking a child up from school or cleaning the house.

You may not always feel well enough to take individual phone calls or respond to texts. Some people find it helpful to have one person who updates friends and colleagues on how you are doing. That person can set

up an email or social media group to share information.

Sexual relationships

You cannot give cancer to another person when you have sex with them.

People who receive a diagnosis of CML and have treatment can experience changes in their sex life. The reasons for this include:

- Extreme tiredness
- The side effects of treatment, e.g. nausea
- Changes in mood, e.g. anxiety
- Changes to body image, e.g. due to hair loss, weight change
- Changes to libido
- Vaginal dryness or difficulty getting an erection.

It is important to talk to your partner about sex and how your diagnosis and treatment are making you feel. If you are having problems with sex and it is affecting your relationship, or you are worried about starting a new relationship, speak with someone in your health care team. They can give you more information or refer you to someone who can help.

Contraception

Women are advised not to become pregnant while on some treatments for CML. This is because CML drugs may harm a developing baby (foetus). It is important to use contraception during treatment and for several months afterwards.

If you are having, or recently finished, treatment, always use a condom when having sex.

Even if you are beyond childbearing age or no longer need birth control, it is still important to use condoms until after your treatment has finished, for two main reasons:

1. To protect yourself from getting an infection (your low white blood cell count puts you at a higher risk).
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, bowel motions and sperm and vaginal secretions. The small amounts of chemotherapy that come out this way can cause irritation (a rash or itching) to your partner's skin.

Talk to your health care team if you have any questions about contraception or getting pregnant.

Sex when you have a low platelet count

Speak with your doctor or nurse about sex if your platelet count is low as you may need to be careful due to the risk of bleeding. It is often a good idea for women to use a lubricating jelly (lube) such as KY Jelly.

New relationships

Some people feel worried about starting a new relationship following a diagnosis of CML. It can be difficult to know what to say. Being open and honest about your experience will make it easier for you. Talk to your friends, family/whānau or your health care team if you have concerns about what to say.

Information for people supporting someone with CML

As the partner, parent or carer of someone with CML, it is quite common to experience feelings of stress, anger, fear, anxiety or depression. Speak with the health care team or LBC Support Services Coordinator if you are feeling this way. There is a lot of support available to you.

Other things you can do:

- Look after yourself by eating well, getting enough sleep, doing regular exercise and relaxing.
- Keep doing your normal social activities.
- Join a support group and/or see a counsellor.
- Write down a list of things that have helped you get through a tricky situation previously. Use these tips to assist you now. Some ideas might include talking to friends or writing a diary.

A diagnosis and the treatment of CML can put a lot of strain on a relationship. However, some people find that they feel closer as a result of what they go through together.

Because CML is a chronic type of leukaemia, it can be difficult for some friends and family to understand that you don't suddenly 'get better' or 'are cured'. Your journey with CML may look different to other types of cancer and other people with leukaemia. You also may have periods of time where you are quite unwell, or that your condition is well managed and you can continue to work and socialise as you normally would have before your diagnosis.

Some people find that after a year or so of having CML, others don't ask how they are doing or understand that they might still be having ongoing treatment and appointments for their CML. Try and find a support network that helps you feel validated and cared for. This might be a variety of people like close friends, family/whānau, colleagues, a counsellor/psychologist and/or LBC Support Services Coordinator.

Remember the health care team or LBC Support Services Coordinator are there to support you at any time throughout your diagnosis, treatment and beyond.

Financial worries

A diagnosis of CML can cause money worries, perhaps through a drop in income or extra expenses. If you are working, keep in touch with your boss to discuss sick leave and your plans for returning to work. Information about your employment rights while undergoing cancer treatment can be found on the LBC website or by asking your LBC Support Services Coordinator.

KEEPING IN GOOD HEALTH AFTER YOUR CML DIAGNOSIS

After a diagnosis of CML, it is important to look after your health. When you feel well enough, doing regular exercise is very important, as well as eating healthily.

The following health changes should be made immediately to reduce complications from your treatment or any long-term side effects:

- Stop smoking
- Protect your skin from the sun
- Stop drinking alcohol or cut down.

Your health care team can advise you on how to keep well.

The physiotherapist can advise you about the exercise that is right for you.

The dietitian can advise you about eating well, especially if your treatment is making you feel sick or you have taste changes.

Ask your doctor or nurse about support to help you stop smoking and reduce or stop drinking alcohol.

Contact your LBC Support Services Coordinator if you would like more information about exercise options in your area.

THE FUTURE

A diagnosis of CML can affect many areas of your life such as work, your emotions, relationships and finances.

For some people, a diagnosis of CML can mark a turning point in their lives. For others, a diagnosis means they feel their life has been put 'on hold'. The length of time it may take to recover emotionally and physically from a CML diagnosis or treatment is different for everyone. Getting back to your previous routine of work or childcare, for example, may be a goal, or it may not be what you want any more. You may need to make a few adjustments to your life.

Your health care team and LBC Support Services Coordinator can help you manage:

- Day-to-day practical problems including work, travel and travel insurance.
- Relationships and communication with family/whānau, friends and colleagues.
- Emotional effects of CML and treatment including fear of relapse and feeling uncertain about the future.

There is a lot of support available to help you and those around you cope.

Some people find it helpful to speak to someone else who has been diagnosed with CML, or their support person. Your nurse, specialist or LBC Support Services Coordinator may be able to put you in contact with someone you can talk to.

Travelling overseas

If you are thinking of travelling overseas, speak to your doctor before making any bookings to check if they have any concerns about you travelling.

It can sometimes be difficult to get travel insurance when you have been diagnosed with cancer. Speak with your LBC Support Services Coordinator, who will be able to help you.

GLOSSARY

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

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

Antiemetic – A drug which prevents or reduces feelings of sickness (anti-sickness).

Antigens – An antigen can stimulate white blood cells to get rid of the antigen or attack it directly. This is called an immune response. Also see immune system.

Anxiety – An ongoing worry or concern about something that doesn't go away. Feelings of worry that a person does not seem to be able to control or which seem greater than they should be for a situation.

Blast cells – Immature blood cells normally found in the bone marrow.

Blood count – Also called a full blood count (FBC) or complete blood count (CBC). A routine blood test that measures the number and types of cells circulating in the blood.

B-lymphocyte – A type of white blood cell normally involved in the production of antibodies to combat infection. Also called B-cells.

Bone marrow – The tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

Bowel – Also known as intestines or guts. After your stomach has finished with the food you eat it goes into your small bowel, which absorbs nutrients that the body needs. What is left after this moves into your large bowel and eventually moves out of your body as waste, known as a bowel motion or, as it is commonly known, poo.

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

Cannula – A plastic tube that is inserted into a vein (intravenously or IV) to allow fluid to enter the bloodstream.

Chemotherapy – Single drugs or combinations of drugs which may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some unwanted side effects. Most of the side effects of chemotherapy are usually temporary and reversible.

Chromosomes – Your body is made up of cells. Inside most cells are chromosomes which, under a microscope, look like threads. These threads contain hundreds to thousands of genes. Genes determine things like what colour your hair and eyes are and how your body develops. You have 23 pairs of chromosomes and you get half from your mother and the other half from your father.

Chronic – An illness or disease that persists for a long time or is constantly recurring.

Complementary therapies – Therapies used alongside your medical treatment that help you feel better or help you cope with your diagnosis and treatment, e.g. massage, yoga.

Compliance – Also called adherence to treatment. Following a regime of treatment and not stopping or changing it.

CT scan or CAT scan – A specialised X-ray or imaging technique that produces a series of detailed three-dimensional (3D) images of cross sections of the body.

Cure – This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Cytogenetic tests – Cytogenetic tests are commonly carried out on samples of blood and bone marrow to detect chromosomal abnormalities (things that are wrong with the chromosomes) associated with disease. This information helps in the diagnosis and selection of the best treatment.

Digestive system – The system in your body that deals with food. Starts at your mouth and ends at your bottom. Turns food and fluids into fuel for your body.

Disease progression – This means that the disease is getting worse despite treatment.

DNA (deoxyribonucleic acid) – The cell's hereditary material which contains instructions for development, growth and reproduction. DNA is located in nearly every cell of the human body. DNA is found in chromosomes.

Echocardiogram (ECHO) – A special ultrasound scan of the heart.

Enzymes – Molecules, usually proteins, which speed up chemical reactions that take place within cells. Some enzymes help break large molecules down to smaller pieces. Other enzymes help bind two molecules together to produce a new molecule.

Foetus – An unborn child.

Genes – Genes are made up of DNA. Each chromosome contains many genes. Every person has two copies of each gene, one inherited from each parent.

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

Haematopoiesis (or haemopoiesis) – The processes involved in blood cell formation.

High-dose therapy – The use of higher than normal doses of chemotherapy to kill off resistant and leftover cancer cells. Also called intensive treatment or chemotherapy.

Immature – Not fully developed, e.g. a cell that is immature is still at a baby stage. It will mature (or develop) over time to an adult stage.

Immune system – The body's defence system against infection and disease.

Immunocompromised – When the function of the immune system is reduced.

Immunoglobulin – See antibodies.

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

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

Leukaemic cells – Abnormal cells which multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the bloodstream and can accumulate in other organs.

Lymph nodes or glands – Structures found throughout the body, e.g. in the neck, groin, armpit, chest and abdomen, which contain both mature and immature lymphocytes. There are hundreds of lymph nodes throughout the body.

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

Lymphoid – Term used to describe a pathway of maturation of blood cells in the bone marrow. White blood cells (B-lymphocytes and T-lymphocytes) are derived from the lymphoid stem cell line.

Malignancy – See cancer.

Markers – A gene or DNA sequence with a known physical location, and where it has come from. In genetics, markers act as chromosomal landmarks. They are used to trace or identify a specific region of a gene or chromosome.

Menopause – The time in a woman's life when her period stops and she is no longer able to have children. Hormones produced by the ovaries decrease after menopause.

Mucositis – An inflammation of the lining of the mouth, throat or gut.

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

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

Neutrophils – Neutrophils are the most common type of white blood cell. They are needed to mount an effective fight against infection.

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

Petechiae – Tiny purple or red spots on the skin caused by bleeding into the skin. They commonly appear in clusters and may look like a rash. They are usually flat to the touch and don't lose their colour when you press on them.

Power of attorney – One person gives another person permission to act on their behalf, such as making decisions about their health or operating their bank account. You usually go to see a lawyer to arrange this.

Prognosis – An estimate of the likely course of a disease.

Psychological – Concerning your mental and emotional well-being.

Radiotherapy (radiation therapy) – The use of high-energy X-rays to kill cancer cells and shrink tumours.

Relapse – The return of the original disease.

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

Rigours – A chill (feeling cold), usually with shivering, at the onset of having a high fever (temperature).

Spleen – An organ that accumulates lymphocytes, acts as a reservoir for red blood cells for emergencies, and destroys red blood

cells, white blood cells and platelets at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It is often enlarged in diseases of the blood or bone marrow.

Splenomegaly – Enlargement of the spleen.

Stable disease – When a disease is stable, it is not getting any worse or any better with treatment.

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

Stem cell transplant (haemopoietic or blood stem cell transplant) – The general name given to bone marrow and peripheral blood stem cell transplants. These transplants are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of cancers including leukaemia, lymphoma, myeloma and other diseases.

Supplements – Tablets or liquids you take as well as the food you eat. Supplements include vitamins, minerals, herbs or other plants.

T-lymphocyte – A type of white blood cell involved in controlling immune reactions. Also called T-cells.

Translocation – When a chromosome or part of a chromosome migrates onto another chromosome.

Tyrosine kinase – Enzymes that help send growth signals in cells, so blocking them stops the cell growing and dividing.

Tyrosine kinase inhibitors (TKIs) – A group of drugs that inhibits tyrosine kinases.

Urinary tract infection – A urinary tract infection (UTI) is an infection in any of the parts of your body which make or store urine or take urine out of your body, e.g. bladder or kidneys.

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

APPENDIX A

The following are sample questions to ask your doctor when considering treatment options for CML.

Place a tick alongside the questions you would like to ask. You could add your own questions in the space provided. Record the answers to your chosen questions in your Haematology Patient Diary or on the 'Questions and notes' page that follows.

- What is the expected outcome of this treatment for me? For example, treatment-free remission, prolong remission, symptom management.
- What exactly does the treatment involve? How long will the entire treatment take? What are the alternatives to this treatment?
- How ill might I feel before, during and after treatment?
- What are the potential side effects, how long might they last and how serious are they? Why are you recommending this treatment for me?
- If the CML comes back (relapse) or gets worse, what are the options for me?
- Which doctor will be looking after me while I am having this treatment? How can I prepare myself for treatment?

ACKNOWLEDGEMENTS

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Leukaemia & Blood Cancer New Zealand

LBC is the leading organisation in New Zealand dedicated to supporting patients and their families/whānau 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.

LBC is committed to improving the quality of life for patients and their families/whānau living with these blood cancers and conditions by providing patient support services, investing in and supporting research, providing information, raising awareness and advocating on behalf of patients and their families/whānau.

HAEMATOLOGY CENTRES IN NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
North Shore Hospital	Shakespeare Road, Takapuna, Auckland	09 486 8900
Auckland City Hospital	Park Road, Grafton, Auckland	09 367 0000
Starship Hospital	Park Road, Grafton, Auckland	09 367 0000
Middlemore Hospital	Hospital Road, Otahuhu, Auckland	09 276 0044
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
Thames Hospital	Mackay Street, Thames	07 868 0040
Tauranga Hospital	Cameron Road, Tauranga	07 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	07 348 1199
Hastings Hospital	Omahu Road, Hastings	06 878 8109
Whakatane Hospital	Stewart Street, Whakatane	07 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	06 356 9169
Wellington Hospital	Riddiford Street, Newtown, Wellington	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
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

Contacting us

Leukaemia & Blood Cancer New Zealand 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, and our Support Services Coordinators are here to help.

Freephone 0800 15 10 15

Telephone 09 638 3556

Facsimile 09 638 3557

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