Cancer Council

Understanding Chronic Leukaemia

A guide for people with cancer, their families and friends

Cancer information

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13 11 20

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council NSW excludes all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help beat cancer, visit cancercouncil.com.au or phone 1300 780 113.

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Introduction

This booklet has been prepared to help you understand more about the two main types of chronic leukaemia: chronic lymphocytic leukaemia (CLL) and chronic myeloid leukaemia (CML).

Many people feel shocked and upset when told they have chronic leukaemia. We hope this booklet will help you, your family and friends understand how CLL and CML are diagnosed and treated.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 50 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 51). You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by chronic leukaemia. It is based on clinical practice guidelines for chronic leukaemia.[1–3]

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit our website at **cancercouncil.com.au**.

Cancer Council 13 11 20

Contents

What is blood cancer?

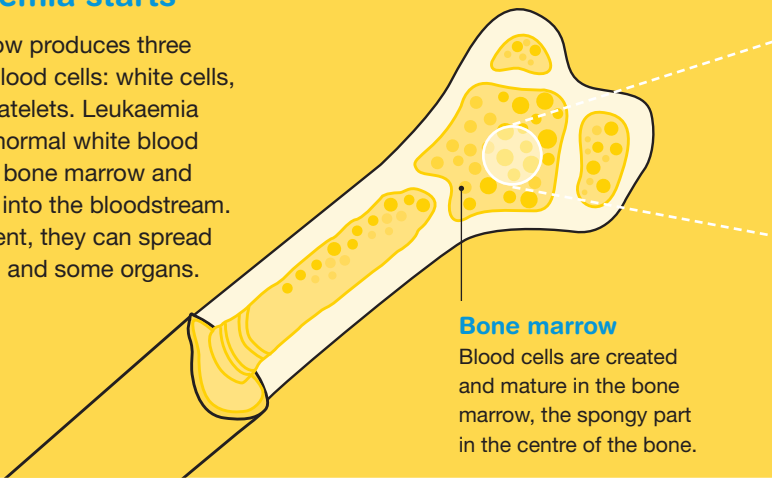
Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury. Normally cells grow and multiply in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause different kinds of cancer. Most cancers, such as breast cancer or bowel cancer, are solid cancers. In these, the abnormal cells form a lump called a tumour. Leukaemia, however, is a blood cancer. It begins in the bone marrow, the spongy part in the centre of the bone where blood cells are produced.

In leukaemia, white blood cells grow abnormally and multiply in such a way that they crowd the bone marrow. This can reduce the bone

How leukaemia starts

The bone marrow produces three main types of blood cells: white cells, red cells and platelets. Leukaemia starts when abnormal white blood cells crowd the bone marrow and are pushed out into the bloodstream. Without treatment, they can spread to lymph nodes and some organs.

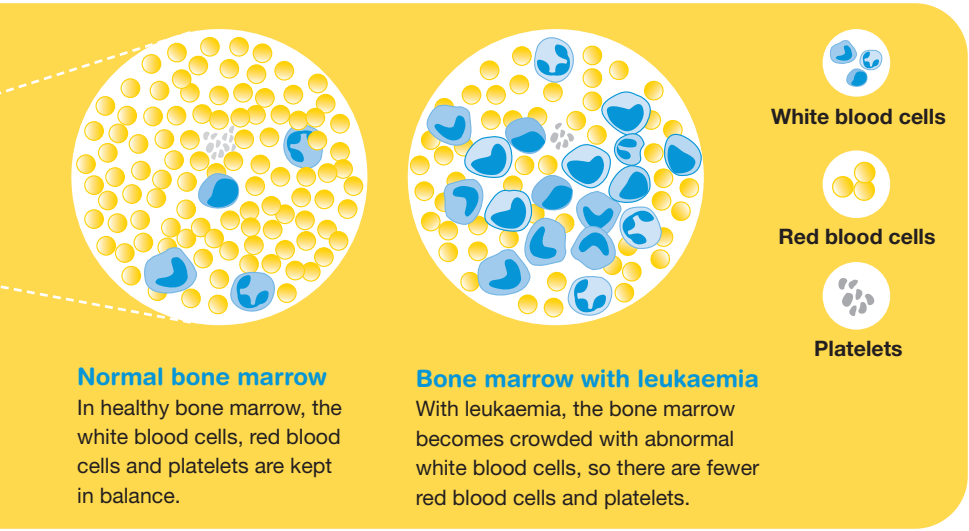


Bone marrow
Blood cells are created and mature in the bone marrow, the spongy part in the centre of the bone.

marrow's ability to produce normal levels of other blood cells, which affects the way that the rest of the body works. Meanwhile, the abnormal cells spill out into the bloodstream.

As leukaemia progresses, the bone marrow produces more abnormal white blood cells and fewer normal blood cells. As the abnormal white blood cells build up, they can spread from the blood to the lymph nodes (lymph glands), spleen, liver, lungs and kidneys. Without treatment, many of the body's key functions will be increasingly affected.

Recent advances in treatment have seen the outlook for people with chronic leukaemia improve dramatically, and the disease can often be kept under control for many years.



Normal bone marrow
In healthy bone marrow, the white blood cells, red blood cells and platelets are kept in balance.

Bone marrow with leukaemia
With leukaemia, the bone marrow becomes crowded with abnormal white blood cells, so there are fewer red blood cells and platelets.

The blood

Blood is pumped around your body to provide oxygen and nutrients to your tissues, and to remove waste products. It is made up of blood cells carried in a clear fluid called plasma.

There are three main types of blood cells: white blood cells, red blood cells, and platelets. Each type has a specific job to do:

White blood cells	Red blood cells	Platelets
		
fight infection	carry oxygen around the body	help the blood clot

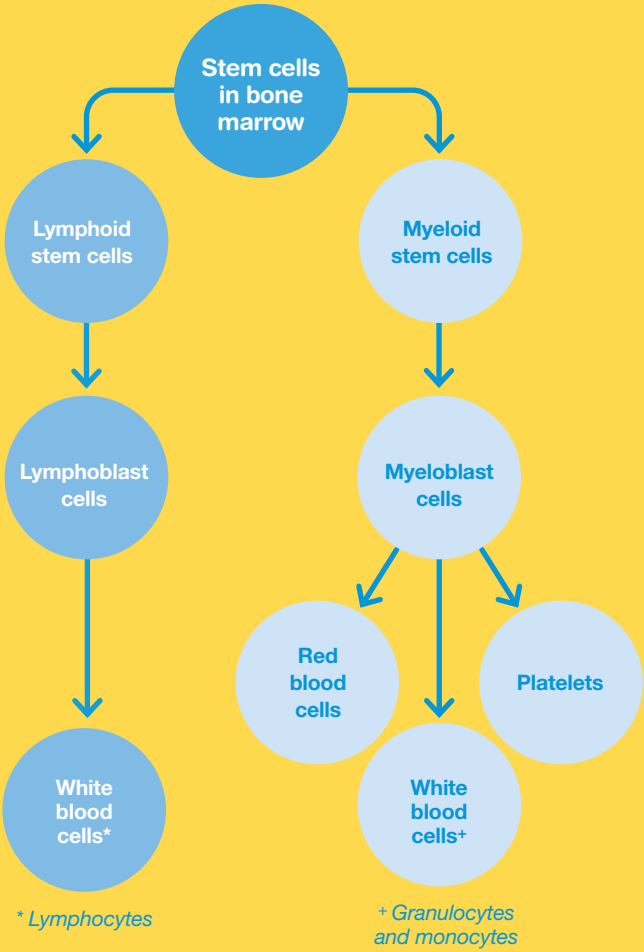
All blood cells have a limited life span and need to be continually replaced. Most are made in the bone marrow, which is the spongy part in the centre of bones.

Bone marrow contains blood stem cells. These are unspecialised blood cells that first turn into immature cells known as blast cells. Normally, the blast cells become mature white or red blood cells or platelets. If white blood cells do not mature properly or if there are too many in the blood, it can cause leukaemia.

There are two families of blood stem cells: lymphoid and myeloid (see diagram opposite). These lead to different types of white blood cells and can be affected by different types of leukaemia (see page 9 for more information).

Blood cell families

Stem cells divide into two families (lymphoid or myeloid), then become immature cells (lymphoblast or myeloblast cells). If cells are normal, they develop into different kinds of mature blood cells.



Key questions

Q: What is chronic leukaemia?

A: Chronic leukaemia is a blood cancer that develops when the body makes too many abnormal white blood cells (blast cells). These abnormal blast cells are known as leukaemia cells.

Because leukaemia cells live too long or multiply too quickly, large numbers of them circulate in the blood. They crowd out normal white blood cells and, because they don't fight infection, they increase the risk of infection. As leukaemia progresses, the bone marrow fills with leukaemia cells and there is less room for healthy red cells and platelets. This may cause various health problems, such as tiredness, dizziness, bleeding problems and bruising.

Q: Is it different to acute leukaemia?

A: While all types of leukaemia start in the bone marrow and affect white blood cell production, they are grouped according to which type of white blood cell is affected, whether there are abnormalities in the bone marrow, and how quickly the disease develops.

Chronic leukaemia usually affects partly developed cells, appears gradually, and develops slowly over months to years.

Acute leukaemia affects undeveloped cells, occurs suddenly, and develops quickly. Cancer Council NSW has a separate booklet about acute leukaemia.

› See our *Understanding Acute Leukaemia* booklet.

Q: What are CLL and CML?

A: CLL and CML are the two main types of chronic leukaemia. The difference between them is in the type of white blood cell that is affected.

Chronic lymphocytic leukaemia (CLL) – In CLL, the body has too many of the white blood cells known as lymphocytes (see diagram on page 7). The lymphocytes are part of the lymphoid family of blood cells. This disease is also called chronic lymphatic leukaemia. For information about how CLL is diagnosed and treated, see pages 16–29.

Chronic myeloid leukaemia (CML) – In CML, the body has too many of the white blood cells known as granulocytes (see diagram on page 7). The granulocytes are part of the myeloid family of blood cells. This disease is sometimes called chronic granulocytic leukaemia. For information about how CML is diagnosed and treated, see pages 30–41.

Small lymphocytic lymphoma (SLL)

Small lymphocytic lymphoma (SLL) has traditionally been classed as a non-Hodgkin lymphoma. However, it is now considered to be the same disease as CLL and is treated in a similar way.

Both SLL and CLL are diseases of the lymphocytes, but in SLL the abnormal lymphocytes are mainly in the lymph nodes, while in CLL they are mainly in the blood and bone marrow. Some doctors may refer to small lymphocytic lymphoma as CLL/SLL.

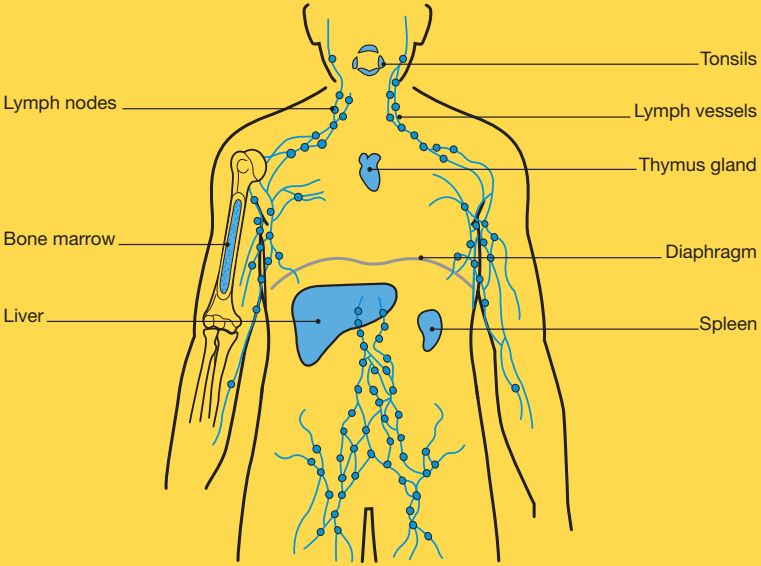
The lymphatic system

The lymphatic system works with the white blood cells to protect the body against infection. A large network of thin tubes (lymph vessels) carries a clear fluid called lymph. The lymph travels to and from areas of lymph tissue, including the lymph nodes, spleen and liver. When leukaemia causes abnormal white blood cells to build up, the lymph tissue becomes swollen.

Lymph nodes – Also known as lymph glands, these small, bean-shaped structures are found in the neck, underarms, chest, abdomen and groin. The lymph nodes filter out toxins and help fight infections, and also produce some blood cells.

Spleen – This is an organ on the left side of the body under the ribs. It clears out old or damaged blood cells.

Liver – This large organ removes toxins, controls sugar levels, and stores vitamins.



Q: What are the risk factors?

A: Chronic leukaemia is caused by changes to one or more of the genes that control the growth and development of blood cells. These changes happen over time, but it is not known why they occur in some people and not others. Exposure to some chemicals or high doses of radiation has been linked to developing leukaemia, but this doesn't explain most cases.

Some people have abnormalities in their genes that can lead to CLL. In rare cases, these abnormalities may be inherited from your family, but usually they develop during your life. If you are worried that CLL might run in your family, talk to your doctor, who may refer you to a genetic counsellor.

Most people with CML have a genetic abnormality known as the Philadelphia chromosome (see page 32). This abnormality is not inherited – it happens during your lifetime and is present only in the abnormal blood cells.

Q: How common is leukaemia?

A: Each year in Australia, about 3900 people are diagnosed with a form of leukaemia[4], and more than 1900 of these cases are chronic leukaemia.[5–6] CLL is the most common type of chronic leukaemia, with about 1600 people diagnosed each year. It is twice as likely to occur in men as in women and almost never occurs in children.[5] About 320 people are diagnosed with CML annually. It is slightly more common in men than in women and is rare in children.[6]

Q: What are the symptoms?

A: Many people with chronic leukaemia have no symptoms. Often the disease is diagnosed after a routine blood test shows a high white blood cell count. In the early stages, symptoms tend to be mild and develop slowly. Symptoms may include:

- swollen lymph nodes in the neck, underarms or groin
- pain and/or feeling of fullness in the abdomen after eating only small amounts – caused by an enlarged spleen
- tiredness – caused by a lack of red blood cells
- frequent and persistent infections – caused by a lack of normal white blood cells leading to lowered immunity
- bruising or bleeding – caused by low levels of platelets
- excessive sweating at night
- high temperature (fever) without any other signs of infection
- weight loss.

Not everyone with these symptoms has chronic leukaemia, but if you have any of these symptoms, it's best to see your doctor.

Q: Which health professionals will I see?

A: Often your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out leukaemia, you will usually be referred to a specialist called a haematologist for further tests. If chronic leukaemia is diagnosed, the haematologist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals.

Health professionals you may see

haematologist*	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy, targeted therapy and other drug therapies
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
haematology nurse	administers chemotherapy and other drugs and provides care, support and information throughout treatment
dietitian	recommends an eating plan to follow while you are in treatment and recovery
social worker	links you to support services and helps you with emotional, practical and financial issues
psychologist, counsellor	help you manage your emotional response to diagnosis and treatment
physiotherapist, occupational therapist	help you with various physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment

** Specialist doctor*

Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 12) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have leukaemia, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 50 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced leukaemia choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

› See our *Cancer Care and Your Rights* booklet.

Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with leukaemia.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit **australiancancertrials.gov.au**.

› See our *Understanding Clinical Trials and Research* booklet.

Chronic lymphocytic leukaemia (CLL)

This chapter explains how chronic lymphocytic leukaemia (CLL) is diagnosed, monitored and treated. CLL affects the white blood cells called lymphocytes.

For an overview of CLL, including its symptoms and risk factors, see the *Key questions* chapter on pages 8–13.

Diagnosis

Some combination of the following tests will help your doctor to confirm a diagnosis of CLL.

Physical examination

Your doctor will examine your body and check different areas for swelling. In particular, the doctor will feel your abdomen to work out whether the spleen and liver are enlarged, and check your neck, armpits, groin and other areas for swollen lymph nodes (see page 10 for a diagram of the lymphatic system).

Monoclonal B-cell lymphocytosis (MBL)

Some people are diagnosed with a blood abnormality called monoclonal B-cell lymphocytosis (MBL). MBL is a condition that resembles CLL, but isn't classed as leukaemia as there aren't enough abnormal cells present.

MBL doesn't require treatment, but you will need regular blood tests to monitor your lymphocyte count. A small number of people with MBL develop CLL that requires treatment.

Blood tests

A sample of your blood will be sent to a laboratory for a full blood count, which measures the number, size and maturity of each type of blood cell. A specialist doctor called a pathologist will look at the blood sample under a microscope to check for leukaemia cells and help decide what type of leukaemia is present.

A machine called a flow cytometer may be used to look for certain markers on the surface of the leukaemia cells. This is known as immunophenotyping. Finding certain markers (e.g. CD19, CD5, CD20, CD23, Kappa, Lambda) in your blood can confirm the diagnosis of CLL and help guide the choice of treatment.

Bone marrow biopsy

Some people have a bone marrow biopsy to check for leukaemia cells and to work out the type of leukaemia.

During the biopsy, the doctor uses a thin needle to remove a small amount of bone marrow, usually from your hipbone (pelvic bone). Although it can take up to 30 minutes to prepare for the biopsy, the actual procedure takes only a few minutes. You will be given a local anaesthetic to numb the area and/or light sedation to help you feel relaxed. It will be uncomfortable while the sample is taken, but you may also be given some medicine for pain.

Pain medicine may make you feel drowsy, so arrange for a family member or a friend to drive you home afterwards. The bone marrow sample will be sent to a laboratory for testing, and results are usually available within a week.

Genetic tests

Each cell in the body contains chromosomes, which are threadlike structures that hold sets of instructions known as genes. Every kind of cancer, including blood cancer, changes the genes of the affected cells. These gene faults are not the same thing as genes passed through families. The fault is only in the leukaemia cells, not in the normal cells.

A genetic test known as fluorescence in situ hybridisation (FISH) can check for abnormal chromosomes in a blood or bone marrow sample. Leukaemia cells may have damage to at least one chromosome, such as a part missing or deleted. In CLL, the chromosomes most commonly affected are 13q and 17p. By identifying any changed or damaged chromosomes, genetic tests can help the medical team make a diagnosis and plan the most effective treatment. These tests also give some information about how the CLL may behave in the long term (prognosis, see page 20).

CT scan

Some people with CLL may need a CT (computerised tomography) scan. This test uses x-rays to create a detailed, cross-sectional picture of the body. It can detect if your lymph nodes are affected and if your spleen is enlarged.

Before the scan, you may have an injection of a dye (called a contrast) to make particular areas easier to see. Let your doctor know if you have had a reaction to iodine or dyes during a previous scan. You will lie on a table while the CT scanner, which is large and round like a doughnut, takes pictures. The scan can take up to 30 minutes, and most people are able to go home straight after.

Lymph node biopsy

Rarely, an enlarged lymph node is removed to confirm the diagnosis of CLL. This is called a lymph node biopsy. Most people won't need a lymph node biopsy because CLL is diagnosed in the blood.

You will be given a general anaesthetic and/or light sedation, and part or all of a lymph node will be removed through a cut in the skin. The area is closed with a few stitches, then the lymph node is sent to the laboratory for testing. Most people can go home the same day. You'll need someone to drive you home as you may feel drowsy after the procedure.

Further tests

Some people have further tests, such as an x-ray or ultrasound. These can show how advanced the CLL is and how it is affecting your organs. Talk to your medical team for more information.

Staging

The tests described on pages 16–19 are often used by doctors to work out how far the leukaemia has progressed. This is known as staging and it helps determine a person's prognosis (outlook) and guide treatment.

There are two staging systems commonly used for CLL: the Binet system and the Rai system. In Australia, most doctors use the Binet system (see table, next page). The Rai system divides CLL into five stages and separates these stages into low-risk, intermediate-risk and high-risk groups. It is used mainly in the United States.

Binet staging system	
stage A	There are a high number of white blood cells but fewer than three enlarged areas of lymph tissue (lymph nodes, liver and/or spleen).
stage B	There are a high number of white blood cells and three or more enlarged areas of lymph tissue.
stage C	There are a high number of white blood cells with a low number of red blood cells (anaemia) and/or platelets (thrombocytopenia), and enlarged lymph nodes or spleen.

Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis with your doctor, who will be able to give you an indication of the stage of leukaemia you have (see table above).

It is not possible for anyone to know the exact course of your disease. However, your doctor might be able to tell you whether any of your test results, particularly the genetic tests, can help predict how the CLL may respond to particular forms of treatment.

While CLL is generally not a curable disease, the outlook for people with CLL is improving constantly. For many people, CLL progresses slowly and they live a normal life span without ever needing treatment. For others, CLL progresses more quickly, but treatment controls the CLL and allows them to have a good quality of life for many years.

Treatment

CLL usually develops slowly without many symptoms. People diagnosed with CLL often don't need treatment straightaway, and some people never require treatment. This may be surprising to hear, but research has shown that for people without symptoms, starting treatment immediately is not any better than delaying treatment until it is needed. Delaying treatment also means you won't have to go through the side effects of treatment until necessary.

For a small number of people (5–10%), CLL turns into a form of non-Hodgkin lymphoma called diffuse large B-cell lymphoma. This is known as Richter's transformation. Diffuse large B-cell lymphoma is a faster-growing type of lymphoma that usually needs to be treated straightaway. Your doctor will discuss the available treatments.

Active monitoring

Active monitoring is when your doctor recommends no treatment but monitors your health with regular check-ups and blood tests. This is sometimes called "careful monitoring" or "watch and wait".

CLL can lower your resistance to infection, so you may be more likely to catch infections such as shingles and the flu. It is important to talk to your doctor about symptoms of infections to watch out for, and to get treatment as soon as possible if you have these symptoms. Your doctor may also recommend that you and the other people in your household have an annual flu vaccination. (You should not have the shingles vaccination as it contains a live virus, which can be dangerous to people with lowered immunity.) You will also be advised to have regular skin checks, as people with CLL are more likely to develop skin cancer.

Living with untreated chronic leukaemia may make you feel anxious. It may help to talk to your medical team or contact the hospital social worker or psychologist for support. You can also speak to other people who have CLL (see pages 46–47).

Treatment options

Your doctor may decide to begin active treatment for CLL if:

- you have symptoms such as fevers, sweats or weight loss
- the number of red blood cells and platelets falls
- your lymph nodes become very swollen and/or put pressure on important internal structures, such as in your neck or kidneys
- your spleen becomes enlarged
- the number of lymphocytes in your blood doubles in less than six months.

The treatment you are offered will depend on the features of the leukaemia, and your age and general health.

Treatment options start with first-line treatment, which aims to reduce the number of CLL cells and get the disease under control. Although most people respond well to treatment, it's likely that the disease will come back (recur) in some people, and they will have further treatment known as second-line treatment.

Sometimes CLL doesn't respond to treatment but the disease remains stable. This is known as refractory or resistant CLL. Your specialist will talk to you about other treatments you can consider. You may also want to join a clinical trial (see page 15).

Chemotherapy and targeted therapy

If you need treatment for CLL, you will often be given a combination of chemotherapy and targeted therapy drugs. Some people have targeted therapy drugs on their own. Chemotherapy uses anti-cancer drugs called cytotoxics to kill the leukaemia cells or slow their growth. Targeted therapy uses drugs that attack specific features of leukaemia cells to stop them growing and multiplying.

Different chemotherapy and targeted therapy drugs come in different forms. Some drugs may be given as a drip into a vein (intravenous infusion) or as an injection, usually during a day visit to a treatment centre, while others are given as tablets that you take at home. There are many types of drugs for CLL, and the choice will depend on the stage, the results of genetic tests (see page 18), and your age, health and personal preferences:

- People with CLL who are otherwise fit and healthy will often have a treatment called FCR – a combination of the chemotherapy drugs fludarabine and cyclophosphamide and the targeted therapy drug rituximab. The drugs are usually given over four days, followed by a rest period of a few weeks. This cycle is repeated up to six times.

- In an older person, or someone with other medical issues, the FCR combination may cause too many side effects and a less intense treatment plan may be offered.

- People with some chromosomal abnormalities, such as 17p deletion, may not respond to certain chemotherapy drugs. Your haematologist will talk to you about suitable treatment options.

- If tests show that the leukaemia cells have particular genetic changes, you may be given targeted therapy drugs.

- If CLL returns after initial treatment, other chemotherapy and targeted therapy drugs may be offered.

There is a lot of research into CLL, and new drugs are becoming available. Talk to your doctor about the latest developments.

Side effects – The side effects of chemotherapy and targeted therapy vary depending on the drugs given. Signs of a reaction to an infusion include flushing, low blood pressure, high temperature or itching. Reactions can be managed by giving the drug over several hours.

Chemotherapy drugs can affect your healthy cells, which may cause a range of side effects. For example, you may bruise easily, feel very tired, experience nausea or changes to taste and smell, or have an increased risk of infections (see table opposite for ways to manage this risk). Side effects of chemotherapy tablets are usually mild, but the effects may be more troublesome if you have intravenous chemotherapy.

The side effects of targeted therapy may include an increased risk of infection, fever, sweating, chills and diarrhoea.

Your haematologist will prescribe various medicines to help ease any side effects. Some people will need a blood transfusion.

› See our *Understanding Chemotherapy* booklet and *Understanding Targeted Therapy* fact sheet.

Taking care with infections during chemotherapy

Reduce your risk

To help avoid infections:

- check with your doctor about having the flu vaccine
- ask people close to you to consider having a flu shot
- ask family and friends with a cold, flu or other contagious infection (e.g. measles, chickenpox or a cold sore) to wait until they are well before visiting
- as far as practical, avoid close contact with people you live with if they are unwell
- try to avoid crowded places, such as shopping centres or public transport in peak hour
- wash your hands with soap and water before preparing food and eating, and after using the toilet
- make sure your food is prepared and stored properly to avoid foodborne illness and food poisoning
- eat freshly cooked foods
- avoid raw fish, seafood, meat, eggs and soft cheeses
- wash fruit and vegetables well before eating.

When to seek medical help

Contact your doctor or go to the nearest hospital emergency department immediately if you experience one or more of the following symptoms:

- a temperature of 38°C or higher
- chills or shivering
- sweating, especially at night
- burning or stinging feeling when urinating
- a severe cough or sore throat
- shortness of breath
- vomiting that lasts more than a few hours
- severe abdominal pain, constipation or diarrhoea
- unusual bleeding or bruising, such as nosebleeds, blood in your urine or black bowel motions
- ongoing faintness or dizziness and a rapid heartbeat
- any sudden decline in your health.

During and after treatment, you will have ongoing check-ups with your doctor to monitor your health. See page 45 for information.

Other treatments

In some cases, your doctor may recommend other ways to manage and control symptoms of CLL and side effects of treatment.

Steroid therapy – Steroids are made naturally in the body and can also be produced in a laboratory and used as drugs. Steroid therapy can help prevent or reduce some chemotherapy side effects, such as nausea. It may also be used on its own to treat CLL if you can't have chemotherapy because your red blood cell or platelet count is too low.

Allopurinol tablets – If you have a very high white blood cell count, a chemical called uric acid may build up in the blood during treatment. This can cause pain and inflammation of the joints (gout), and may damage your kidneys. To prevent this, you may be given allopurinol tablets.

Immunoglobulin infusions – Immunoglobulin is an antibody that helps your body fight infections. CLL usually causes low immunoglobulin levels, so you may be given immunoglobulins through a drip to help boost your immune system if infections keep coming back or are severe.

Radiation therapy – Also known as radiotherapy, this uses a controlled dose of radiation to kill leukaemia cells or damage

them so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Radiation therapy is not a standard treatment for CLL, but may be used to treat a swollen spleen or swollen lymph nodes. It can also be helpful for people having palliative treatment (see page 28).

› See our *Understanding Radiation Therapy* booklet.

Surgery (splenectomy) – Occasionally, the spleen will be removed if it is very swollen and pressing on nearby organs. This treatment may be used for people who have immune thrombocytopenic purpura (ITP), an autoimmune disease that targets the platelets. Your surgeon can give you more information about this operation.

Stem cell transplant – Rarely, very high doses of chemotherapy or radiation therapy are needed to destroy the leukaemia cells. This can also damage the stem cells in the bone marrow (see page 6), and a stem cell transplant is done to help restore the bone marrow and rebuild the immune system. The stem cells are usually collected from another person (allogeneic transplant).

A stem cell transplant isn't a suitable treatment for most people with CLL. This is because the procedure is considered too risky for people with slow-growing disease.

If CLL is progressing more quickly or hasn't responded to chemotherapy, you may be offered a reduced-intensity stem cell transplant (sometimes called a mini transplant). This means lower doses of chemotherapy and radiation therapy are used for the transplant, so it is easier for the body to tolerate.

If you are having a stem cell transplant, your medical team will explain what will happen and the possible side effects. For more information on stem cell transplants for CLL, you can contact the Leukaemia Foundation on 1800 620 420 or visit their website at leukaemia.org.au/treatments/stem-cell-transplants.

Palliative treatment

In some cases of advanced CLL, the medical team may talk to you about palliative treatment (sometimes called supportive care).

Palliative treatment helps to improve your quality of life by managing the symptoms of leukaemia without trying to cure the disease. It can be used at any stage of advanced disease and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the progress of leukaemia, palliative treatment can relieve any pain and help manage other symptoms. Treatment may include blood transfusions and short courses of radiation therapy, chemotherapy, targeted therapy or other medicines. If you have ongoing symptoms, ask for a referral to the symptom management or palliative care team.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers.

› See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Key points about diagnosing and treating CLL

Diagnosis

- Your doctor will take a blood sample to check for leukaemia cells. The leukaemia cells may be tested for special markers.
- Some people may have a bone marrow biopsy (when a bone marrow sample is taken from a bone) to check for leukaemia cells.
- A blood or bone marrow sample may be tested for particular chromosomal changes to help doctors work out the best treatment for you.
- You may have further tests, such as a CT scan, lymph node biopsy, x-ray or ultrasound.
- Staging indicates how far the leukaemia has progressed and helps guide treatment.

Active monitoring

- Not everyone diagnosed with CLL needs treatment right away. It is common to wait until the CLL causes symptoms or is advanced before starting treatment.
- Your doctor will monitor your health with regular check-ups and blood tests. This is called active monitoring.

Treatment

- You may have chemotherapy and/or targeted therapy drugs to kill the leukaemia cells or stop them growing and multiplying. The side effects depend on the drugs you are given.
- Your doctor may recommend other treatments, such as steroid therapy, radiation therapy, surgery, a stem cell transplant or a clinical trial.
- Palliative treatment helps improve quality of life by managing symptoms.

Chronic myeloid leukaemia (CML)

This chapter explains how chronic myeloid leukaemia (CML) is diagnosed and treated. CML affects the white blood cells called granulocytes (which are part of the myeloid family). For an overview of CML, including its symptoms and risk factors, see the *Key questions* chapter on pages 8–13.

Diagnosis

Your doctor will do a physical examination and organise tests of your blood or bone marrow to work out whether you have CML. You may have other tests such as a CT scan or ultrasound to confirm the diagnosis.

Physical examination

Your doctor will examine your body and feel your abdomen to check whether your spleen and liver are enlarged (see diagram, page 10).

Blood tests

A sample of your blood will be sent to a laboratory for a full blood count, which measures the number, size and maturity of each type of blood cell. A specialist doctor called a pathologist will look at the sample under a microscope to check for leukaemia cells.

Bone marrow biopsy

Your doctor may arrange a bone marrow biopsy to confirm that you have CML and to check how many blood cells are affected. The doctor uses a thin needle to remove a small amount of bone marrow, usually from your hipbone (pelvic bone). You will be given a local anaesthetic to numb the area, or light sedation to help you feel relaxed.

Although it can take up to 30 minutes to prepare for the biopsy, the actual procedure takes only a few minutes. It will be uncomfortable but you may also be given pain medicine. Pain medicine may make you feel drowsy, so arrange for someone to drive you home afterwards. The bone marrow test results will usually be available in 1–2 weeks.

Genetic tests

Every kind of cancer, including blood cancer, changes the genes of the affected cells. These gene faults are not the same thing as genes passed through families. The fault is only in the leukaemia cells, not in the normal cells.

Genetic tests, such as FISH (fluorescence in situ hybridisation) and PCR (polymerase chain reaction), can check for gene faults in the leukaemia cells in a blood or bone marrow sample. For CML, the most common gene fault is the presence of the Philadelphia chromosome, which results in the formation of the abnormal BCR-ABL gene (see box, next page).

The PCR test is used again during treatment to check how well you are responding, and whether you need a change in treatment.

Further tests

Some people also have an ultrasound. This scan uses soundwaves from a handheld device called a transducer that is moved over your belly area. The soundwaves echo when they meet something solid, such as an organ, and a computer turns the echoes into pictures. An ultrasound may be useful for recording the size of your spleen. Talk to your medical team for more information.

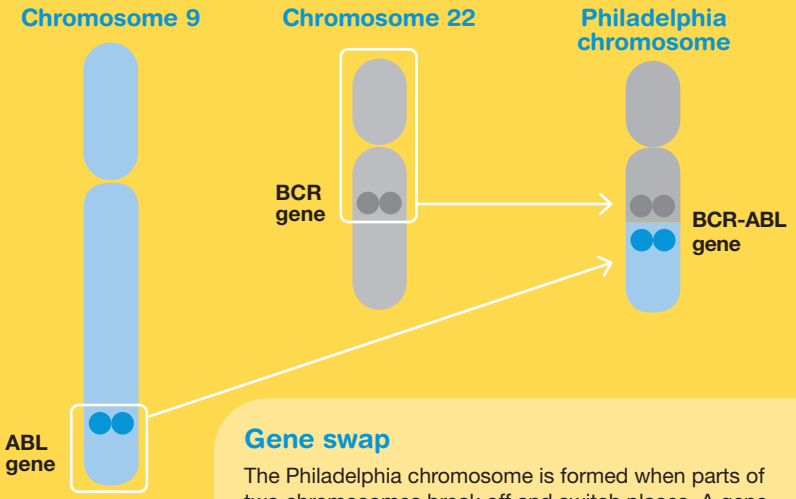
The Philadelphia chromosome

Most cells in the human body contain 23 pairs of chromosomes. Chromosomes are threadlike structures that contain sets of instructions known as genes.

In nearly all people with CML, chromosome 22 is abnormal and is known as the Philadelphia chromosome (see diagram below).

The Philadelphia chromosome is not inherited and cannot be passed on to your children – it is a genetic change that happens to some people during their lifetime. This chromosome contains the BCR-ABL gene. The diagram below explains the process.

BCR-ABL is considered a cancer gene because it is present only in developing leukaemia cells. It tells the body to produce an abnormal protein called tyrosine kinase, which instructs leukaemia cells to grow and multiply. All people with CML are treated with drugs to block the abnormal tyrosine kinase (see pages 35–36).



Gene swap

The Philadelphia chromosome is formed when parts of two chromosomes break off and switch places. A gene from chromosome 22, called BCR, and a gene from chromosome 9, called ABL, create the BCR-ABL gene.

Staging

The tests described on pages 30–31 allow the doctor to work out how far the leukaemia has progressed. This process is called staging, and it helps the doctor decide on the best treatment for you. CML is classified into three groups, which are called phases instead of stages. The phases are based on the number of immature white blood cells found in the blood and bone marrow.

CML is most often diagnosed in the chronic phase. Most people stay in this phase for a few years without treatment. With treatment, this phase can last more than 20 years.

If the disease progresses, it doesn't always do it in a step-by-step way. In some cases, it moves straight from chronic to blast phase, skipping the accelerated phase.

Phases of CML	
chronic	The white blood cell count is increased and a small number of immature cells called blast cells are found in the blood and bone marrow.
accelerated	After several years, the leukaemia may suddenly change and progress quickly. At this time, your spleen may become enlarged and your white blood cell count may rise rapidly.
blast	The number of blast cells increases, symptoms worsen, and blast cells often spread to other organs. This is sometimes called blast crisis. Bleeding, infections and anaemia can occur.

Prognosis

Prognosis means the expected outcome of a disease. It is not possible for anyone to know exactly what will happen, but your medical team can predict how the CML will respond to treatment based on the phase of the disease, your blood counts and if your spleen is enlarged. They will also arrange tests throughout your treatment to check how well the CML is responding.

Recent advances in CML treatment have dramatically improved outcomes. For most people, the goal of treatment is to prevent the disease progressing from the chronic phase. If the CML does move into the accelerated or blast phases, however, there are good treatment options.

Treatment

All people with CML will be offered treatment to control the disease regardless of the phase at diagnosis. The type of treatment will depend on how far the leukaemia has progressed and your health. Some treatments are part of clinical trials (see page 15).

The main aim of treatment is to achieve long-term control of the CML so the signs of the disease reduce or disappear. This is known as remission. Another goal is to stop the CML from progressing to a more advanced phase.

The initial treatment of the leukaemia is known as first-line treatment. In most cases, this treatment continues long term and your specialist will check your blood regularly to confirm that the leukaemia is still

responding to treatment. If the treatment stops working, you will be offered second-line treatment. Sometimes if you respond very well to treatment, the specialist may offer the option of stopping treatment. If CML starts to come back, you will start treatment again.

Targeted therapy

The main treatment for CML uses a group of targeted therapy drugs called tyrosine kinase inhibitors (TKIs). These drugs work by blocking a protein called tyrosine kinase, which is much too active in CML due to the effect of the Philadelphia chromosome. Tyrosine kinase tells the leukaemia cells to divide and grow. Without this signal, the cells die.

The type of TKI you are prescribed will depend on several factors, including what other medical problems you have. In Australia, TKIs used for CML include imatinib, dasatinib, nilotinib and ponatinib. They are taken as tablets once or twice a day.

TKIs can cause the signs and symptoms of CML to reduce or disappear. This means most people can return to their usual activities. The drugs will need to be taken long term, and you will need to have regular blood tests (see *Follow-up appointments,* page 45) to check CML hasn't returned.

For some people, stopping TKIs may be an option. People who have had an excellent response to a TKI for at least three years may be able to stop taking these drugs. If you stop, frequent checks are needed. Half the people who stop have no further issues, and the other half have a recurrence and need to start taking TKIs again.

Each TKI works in a slightly different way. This means that if one TKI doesn't control the CML or it stops working for you, your doctor may switch to another type of TKI.

Side effects – The side effects of TKIs vary depending on the drug and how your body responds, but most side effects are mild. These may include: fatigue; nausea and vomiting; headache; diarrhoea; itchy skin rashes; facial, hand or leg swelling; anaemia, bruising or infections; and build-up of fluid around the lungs or heart. In rare cases, TKIs affect how the heart works, which can be life-threatening.

Tell your treatment team if you have any of these side effects and make sure they know if you have a history of heart disease. The team will monitor your response to the TKI and explain what side effects to watch out for or report, and who to contact after hours. For information about specific TKIs and their side effects, visit eviq.org.au.

Your doctor may be able to prescribe medicine to prevent or reduce side effects. Sometimes side effects mean your doctor has to change the dose of the TKI or give you a different TKI.

› See our *Understanding Targeted Therapy* fact sheet.

"When I was first diagnosed I was put on imatinib, but I had severe side effects so my haematologist put me on dasatinib. I've been on this for over eight years with excellent results. As the leukaemia is still detected in the regular blood tests, there's no plan to discontinue treatment in the foreseeable future." *Patricia*

Women who want to become pregnant while having treatment for CML should speak to their doctor. Many TKIs, such as imatinib, are not safe to use during pregnancy or while breastfeeding. Ask your doctor for advice about contraception. If you become pregnant, let your medical team know immediately.

Chemotherapy

Chemotherapy uses anti-cancer drugs called cytotoxics that kill or slow the growth of the leukaemia cells.

Most people will be prescribed TKIs as the first treatment for CML in the chronic phase. However, some people may be given a mild chemotherapy tablet called hydroxyurea for a short time to lower their white blood cell count and get symptoms under control before having TKI treatment.

For the small number of people who can't take TKIs, chronic-phase CML may be treated with hydroxyurea for several months.

Other chemotherapy drugs may be given to people who have not responded to TKI therapy or who are preparing for a stem cell transplant (see pages 39–40). You might also have chemotherapy if the CML is in the blast phase. These chemotherapy drugs are often given into a vein (intravenously) and tend to be much stronger, so you may need to have the treatment in hospital.

Side effects – The side effects depend on the type of chemotherapy drugs you have. Hydroxyurea tablets may cause dry skin, nausea,

drowsiness and a small amount of hair loss. These side effects tend to be mild, and there are medicines available to help manage them. Intravenous chemotherapy uses stronger drugs and usually has more side effects, such as an increased risk of infections (see page 25), bruising easily, nausea, taste and smell changes, or fatigue.

To find out more about chemotherapy for CML, talk to your medical team, call Cancer Council 13 11 20, or contact the Leukaemia Foundation on 1800 620 420 or at leukaemia.org.au.

› See our *Understanding Chemotherapy* booklet.

Other treatments

Less commonly, your doctor may recommend other therapies to treat the CML or to manage symptoms and side effects.

Allopurinol tablets – If your white blood cell count is very high, a chemical called uric acid can build up in the blood during treatment. This can cause pain and inflammation of the joints (gout) and may damage the kidneys. To prevent uric acid building up, you will probably be given allopurinol tablets.

Leukopheresis – If you have an extremely high white blood cell count – for example, during a blast crisis – you may have a procedure called leukopheresis. This procedure skims white cells out of your blood to quickly reduce your white blood cell count to a safer level. It is used to control symptoms, not to treat or cure the disease.

During the procedure, you will have a needle or tube called a catheter inserted in each arm. One tube removes your blood and passes it

through a machine that separates the blood into its individual components. The extra white cells are removed, and the rest of the blood components are returned to your body through the second tube in a continuous process.

Only about 250 ml of your blood is outside your body at any one time. This process can take 2–4 hours, but is not painful.

Immunotherapy – Immunotherapy treatment aims to alter the response of your body's immune system to the leukaemia. The immunotherapy drug interferon alfa was the main form of treatment for CML before TKIs were developed. Although it is not used very often now, some clinical trials are using it to see whether people can stop their TKIs.

Stem cell transplant – This treatment is not used often for CML, but it may be offered to some people with accelerated-phase or blast-phase CML that has stopped responding to TKI drugs, or to people whose disease is not controlled with chemotherapy. The process involves destroying the leukaemia cells with very high doses of chemotherapy or radiation therapy. This can also damage the stem cells in the bone marrow (see page 6), and a stem cell transplant is done to help restore the bone marrow and rebuild the immune system. The stem cells are usually collected from another person (allogeneic transplant).

A stem cell transplant is a demanding treatment and isn't suitable for everyone, especially older patients. Your doctors will tell you if a transplant might help.

Transplants are not done at every hospital, so you may need to travel to have this treatment. Your medical team will explain transplant procedures for your situation and possible side effects. There are several stages of treatment, and the whole process may take many months.

For more information on stem cell transplants for CML, contact the Leukaemia Foundation on 1800 620 420 or visit their website at leukaemia.org.au/treatments/stem-cell-transplants.

Palliative treatment

In some cases of advanced CML, the medical team may talk to you about palliative treatment (sometimes called supportive care).

Palliative treatment helps to improve your quality of life by managing the symptoms of leukaemia without trying to cure the disease. It can be used at any stage of advanced disease and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the progress of leukaemia, palliative treatment can relieve any pain and help manage other symptoms. Treatment may include blood transfusions and short courses of radiation therapy, chemotherapy, targeted therapy or other medicines.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers.

› See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Key points about diagnosing and treating CML

Diagnosis

- In most people with CML, the leukaemia cells have a genetic abnormality known as the Philadelphia chromosome. The Philadelphia chromosome contains the BCR-ABL gene, which produces tyrosine kinase, an abnormal protein that tells leukaemia cells to grow.
- To test for CML, a blood sample will be taken. A small amount of bone marrow may also be removed with a needle (bone marrow biopsy).
- Genetic tests analyse a blood or bone marrow sample to look for the Philadelphia chromosome or the BCR-ABL gene.
- CML is divided into three phases – chronic, accelerated and blast. These phases help guide treatment.

Treatment

- The main treatment for CML uses targeted therapy drugs called tyrosine kinase inhibitors (TKIs). TKIs block the protein tyrosine kinase.
- Some people also have chemotherapy. Most often, this will be a mild drug called hydroxyurea that comes as a tablet. Stronger chemotherapy drugs are sometimes needed.
- To manage symptoms and side effects, you will be given allopurinol tablets and you may have a procedure called leukopheresis to remove excess white blood cells from the blood.
- In rare cases, you may be given an immunotherapy drug called interferon alfa or a stem cell transplant.
- Palliative treatment aims to improve quality of life by managing symptoms.

Looking after yourself

Leukaemia can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit cancercouncil.com.au.

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

› See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

› See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

› See our *Understanding Complementary Therapies* booklet.

Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Leukaemia can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

› See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having leukaemia can affect your relationships with family, friends and colleagues in different ways. Leukaemia is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

› See our *Emotions and Cancer* booklet.

Sexuality – Leukaemia can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

› See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

› See our *Fertility and Cancer* booklet.

Life after treatment

For most people, the leukaemia experience doesn't end on the last day of treatment. Life after treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the leukaemia is coming back.

Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had leukaemia, and provide you with information about the emotional and practical aspects of living well after treatment.

› See our *Living Well After Cancer* booklet.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit **beyondblue.org.au**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **lifeline.org.au**.

Follow-up appointments

After your treatment, you will have regular appointments to monitor your health, manage any long-term side effects and check that the leukaemia hasn't come back or progressed. During these check-ups, you will usually have a physical examination and blood tests, and you may have a chest x-ray and scans. If you are taking TKIs for CML on a long-term basis, you will also need to have ongoing blood tests to measure the BCR-ABL gene (see page 32). This is a requirement of the Pharmaceutical Benefits Scheme (PBS), which covers most of the cost of the TKIs.

When a follow-up appointment or test is approaching, many people find that they think more about the leukaemia and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety. Between check-ups, let your doctor know immediately of any symptoms or health problems.

What if the leukaemia returns?

In many cases, treatment will make the leukaemia symptoms ease or disappear for a period of time. This is called remission. It is common for CLL to come back (recur or relapse) after treatment and following a period of remission. People with CML who are being treated with TKIs may also have times when the leukaemia is no longer controlled by their current drugs or transforms to a more advanced phase.

If you have a recurrence or the disease transforms, further treatment can usually be given to control the leukaemia and may lead to another remission. In some situations, doctors may recommend a stem cell transplant (see pages 27–28 and 39–40).

Seeking support

A leukaemia diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Leukaemia also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the leukaemia experience, including:

- information about leukaemia and its treatment
- access to benefits and programs to ease the financial impact of leukaemia treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“My family members don’t really understand what it’s like to have cancer thrown at you, but in my support group, I don’t feel like I have to explain.” *Sam*

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).

Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit our website at **cancercouncil.com.au**.

Practical help

Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.

Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit **cancercouncil.com.au/OC**.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council NSW	**cancercouncil.com.au**
Cancer Council Online Community	**cancercouncil.com.au/OC**
Cancer Council podcasts	**cancercouncil.com.au/podcasts**
Arrow Bone Marrow Transplant Foundation	**arrow.org.au**
Australian Cancer Trials	**australiancancertrials.gov.au**
Beyond Blue	**beyondblue.org.au**
Cancer Australia	**canceraustralia.gov.au**
Cancer Institute NSW	**cancer.nsw.gov.au**
Carer Gateway	**carergateway.gov.au**
Carers NSW	**carersnsw.org.au**
Department of Health	**health.gov.au**
Healthdirect Australia	**healthdirect.gov.au**
Leukaemia Foundation	**leukaemia.org.au**
Radiation Oncology: Targeting Cancer	**targetingcancer.com.au**
Services Australia (including Medicare and Centrelink)	**servicesaustralia.gov.au**
International	
American Cancer Society	**cancer.org**
Cancer Research UK	**cancerresearchuk.org**
Leukemia & Lymphoma Society (US)	**lls.org**
Macmillan Cancer Support (UK)	**macmillan.org.uk**
National Cancer Institute (US)	**cancer.gov**

Caring for someone with leukaemia

You may be reading this booklet because you are caring for someone with leukaemia. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It's important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or call Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

Services such as Meals on Wheels, home help or visiting nurses can help you in your caring role, and other organisations can provide information and support. Carers NSW is a statewide organisation for carers – call 1800 242 636 or visit carersnsw.org.au. Many leukaemia support groups and education programs are open to carers as well as to people with leukaemia. You can call Cancer Council 13 11 20 or visit cancercouncil.com.au to find out more about carers' services.

- See our *Caring for Someone with Cancer* booklet and listen to our "Cancer Affects the Carer Too" podcast episode.

Bone marrow and blood donations

One way to offer indirect support to someone with chronic leukaemia is by becoming a bone marrow donor or a blood donor. Bone marrow donors need to be matched to the patient, so the first step is to join the Australian Bone Marrow Donor Registry – visit **abmdr.org.au** to find out more. Many people are eligible to donate blood at the Australian Red Cross Blood Service. Call **13 14 95** or go to **donateblood.com.au**.

Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of chronic leukaemia do I have?
- Are the latest tests and treatments for this type of leukaemia available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of leukaemia?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment

- How often will I need check-ups after treatment?
- If the leukaemia returns, how will I know? What treatments could I have?

Glossary

abdomen
The part of the body between the chest and hips that contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys. Also known as the belly.

active monitoring
When a person does not receive immediate treatment, but instead has their health monitored regularly, with the option of future treatment if necessary. Sometimes called careful monitoring or watch and wait.

acute leukaemia
A fast-growing cancer that produces large numbers of immature white blood cells that then enter the bloodstream.

advanced cancer
Cancer that is unlikely to be cured. Treatment can often still control the cancer and manage symptoms.

allogeneic transplant
A process that involves taking stem cells or tissues from one person and giving them to another.

anaemia
A reduction in the number or quality of red blood cells in the body.

anaesthetic
A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

antibody
A protein made by the blood in response to an invader (antigen) in the body. As part of the immune system, antibodies help protect the body against viruses, bacteria and other foreign substances.

antigen
Any substance that causes the immune system to respond, often prompting the blood to make antibodies.

BCR-ABL gene
A gene created when cells don't divide properly. It leads to an abnormal protein called tyrosine kinase being made.

biopsy
The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease.

blast cells
Immature blood cells. Blast cells in the lymphoid family are called lymphoblasts, while blast cells in the myeloid family are called myeloblasts.

bone marrow
The soft, spongy material inside bones, which produces white blood cells, red blood cells and platelets.

bone marrow biopsy
The removal of a small amount of bone marrow with a needle for examination under a microscope.

cells
The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

chemotherapy
A treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or with other treatments.

chromosome
A threadlike structure found in all body cells (except red blood cells). Chromosomes are made up of strings of proteins called genes.

chronic leukaemia
A slow-growing leukaemia that starts in the bone marrow and produces large numbers of abnormal white blood cells that then enter the bloodstream.

chronic lymphocytic leukaemia (CLL)
A slow-growing leukaemia in which too many abnormal lymphocytes (white blood cells of the lymphoid family) are found in the blood and bone marrow.

chronic myeloid leukaemia (CML)
A slow-growing leukaemia in which too many abnormal granulocytes (white blood cells of the myeloid family) are found in the blood and bone marrow.

diffuse large B-cell lymphoma
A fast-growing type of non-Hodgkin lymphoma that starts in lymph nodes in the neck, groin or armpit. Chronic lymphocytic leukaemia can turn into diffuse large B-cell lymphoma.

first-line treatment
The first treatment used to target cancer.

fluorescence in situ hybridisation (FISH)
A test that uses special dyes to look for abnormal chromosomes.

full blood count
A test that measures the number, size and maturity of each type of cell in the blood. Also known as a complete blood count.

genes
The microscopic units that determine how the body's cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

granulocyte
A type of white blood cell of the myeloid family. There are four different kinds of granulocytes: neutrophils, eosinophils, basophils and mast cells.

haematologist
A doctor who specialises in studying and treating diseases of the blood, bone marrow and lymphatic system.

immune system
A network of cells and organs that defends the body against attacks by foreign invaders (antigens), such as bacteria and viruses. Includes the lymphatic system.

immunoglobulin
A protein that is produced by plasma cells and fights infections.

immunophenotyping
A test that looks for certain markers on the surface of cells.

immunotherapy
Treatment that uses the body's own immune system to fight cancer.

interferon alfa
A substance that occurs naturally within the body and which enhances the immune system's fight against viruses.

intravenous (IV)
Injected into a vein.

leukaemia
A cancer of the white blood cells, usually causing large numbers of abnormal white blood cells to be made.

leukopheresis
A procedure to quickly reduce the white blood cell count to a safe level.

lymphatic system
A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and makes immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph node
Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

lymphocyte
A type of white blood cell of the lymphoid family.

lymphoid
One of the two families of white blood cells. The lymphoid family only produces white blood cells.

mini transplant
See reduced intensity stem cell transplant.

monoclonal B-cell lymphocytosis (MBL)
A blood condition that resembles chronic lymphocytic leukaemia, but is not classed as leukaemia as there are not enough abnormal cells present. It sometimes turns into chronic lymphocytic leukaemia.

myeloid
One of the two families of white blood cells. The myeloid family produces some types of white blood cells and all red blood cells and platelets.

neutropenia
A drop in the number of normal, healthy neutrophils (a type of white blood cell in the myeloid family).

nutrients
Nourishing substances that help living things to survive, repair and reproduce. Nutrients from food are processed by the digestive system and carried by the blood to cells throughout the body.

palliative treatment
Medical treatment for people with advanced disease to help manage pain and other physical and emotional symptoms. Treatment may include radiation therapy, chemotherapy or other therapies. It is an important part of palliative care.

pathologist
A specialist who interprets the results of tests (e.g. blood tests, biopsies).

Pharmaceutical Benefits Scheme (PBS)
A government-funded scheme that subsidises some prescription medicines.

Philadelphia chromosome
An abnormal chromosome associated with chronic myeloid leukaemia and acute lymphoblastic leukaemia. It carries instructions for the body to make tyrosine kinase, an abnormal protein that tells leukaemia cells to grow and multiply.

plasma
The clear fluid part of blood that carries blood cells.

platelets
One of the three main types of cells found in the blood. Platelets help the blood to clot and stop bleeding. Also called thrombocytes.

prognosis
The expected outcome of a particular person's disease.

radiation therapy
The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply and spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

recurrence
The return of a disease after a period of improvement (remission). Also known as a relapse.

red blood cells
One of the three main types of cells found in the blood. They carry oxygen around the body. Also called erythrocytes.

reduced intensity stem cell transplant
An allogeneic transplant that uses lower doses of chemotherapy and radiation therapy than normal, so it is easier for the body to tolerate. Sometimes called a mini transplant.

refractory disease
Disease that does not respond to treatment. Also called resistant disease.

relapse
See recurrence.

remission
When the signs and symptoms of the leukaemia reduce or disappear. A partial remission is when there has been a significant reduction in symptoms but some leukaemia is still present. A complete remission is when there is no evidence of active leukaemia. This may not mean that the leukaemia is cured.

Richter's transformation
When chronic lymphocytic leukaemia cells transform into a type of non-Hodgkin lymphoma known as diffuse large B-cell lymphoma.

second-line treatment
Treatment that is given if the first-line treatment doesn't work or the disease comes back.

side effect
Unintended effect of a drug or treatment. Most side effects can be managed.

small lymphocytic lymphoma (SLL)
A slow-growing lymphoma that is similar to chronic lymphocytic leukaemia.

spleen
An organ in the lymphatic system located on the left side of the abdomen under the ribs. The spleen produces lymphocytes, filters the blood, and destroys old blood cells, abnormal cells and bacteria.

splenectomy
Surgery to remove the spleen.

staging
Performing tests to work out how far the leukaemia has progressed.

stem cells
Unspecialised cells from which mature cells can develop. Stem cells are found in the bone marrow.

stem cell transplant
A treatment in which diseased blood cells are destroyed by high-dose chemotherapy or radiation therapy, then replaced by healthy stem cells. The healthy stem cells may come from the bone marrow (bone marrow transplant), bloodstream (peripheral blood stem cell transplant) or umbilical cord blood (cord blood transplant).

subcutaneous
Injection under the skin.

targeted therapy
Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

thrombocytopenia
A low level of platelets. It makes you more prone to bleeding and bruising.

tissue
A collection of cells of similar type that make up an organ or structure in the body.

tyrosine kinase
An abnormal protein that tells leukaemia cells to grow and multiply.

tyrosine kinase inhibitor (TKI)
A targeted therapy drug that blocks the protein tyrosine kinase.

white blood cells
One of the three main types of cells found in the blood. They help fight infection. Types of white blood cells include granulocytes, lymphocytes and monocytes. Also called leucocytes.

x-ray
A type of high-energy radiation that can be used for imaging or radiation therapy.

Can't find a word here?

For more cancer-related words, visit cancercouncil.com.au/words.

References

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How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.

Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).

If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au

For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

For further information and details, visit our website, **cancercouncil.com.au**.

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