Cancer Council

CANCER TYPE

Understanding
Chronic Leukaemia

A guide for people with cancer, their families and friends

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Understanding Chronic Leukaemia
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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 booklet 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 stands by everyone living with cancer, protecting life's moments, for life. We support people affected by cancer when they need it most, speak out on behalf of the community on cancer issues, empower people to reduce their cancer risk, and find new ways to better detect and treat cancer. Together we are tackling cancer and leading NSW towards a cancer-free future. To make a donation to help fund vital cancer research and support services, visit cancercouncil.com.au or phone 1300 780 113.

Cancer Council NSW acknowledges Traditional Custodians of Country and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.

Cancer Council NSW 153 Dowling Street, Woolloomooloo NSW 2011 ABN 51 116 463 846
Telephone 02 9334 1900 **Email** feedback@nswcc.org.au **Website** cancercouncil.com.au

About this booklet

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 also include information about support services.

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 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.[1-2]

If you or your family have any questions or concerns, 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.

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Key to icons

Icons are used throughout this booklet to indicate:

More information

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SCAN ME

What is blood cancer?

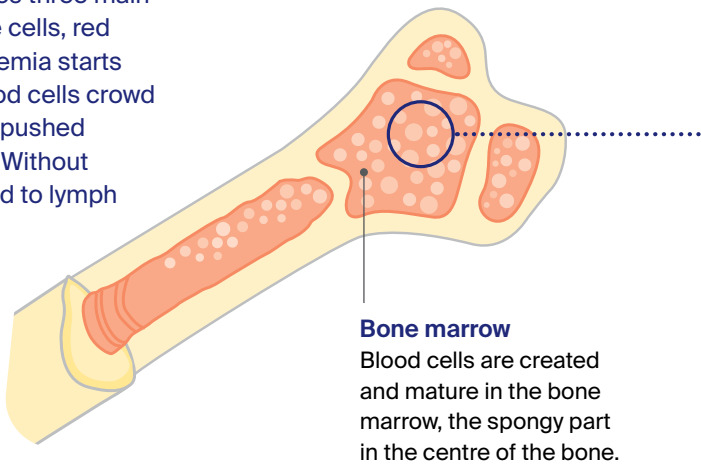
Cancer is a disease of the cells, which are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as breast cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

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.

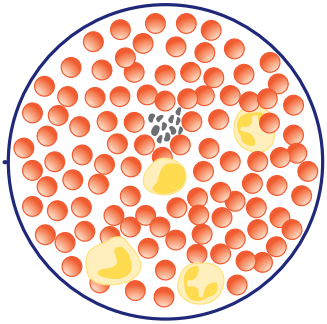


Bone marrow
Blood cells are created and mature in the bone marrow, the spongy part in the centre of the bone.

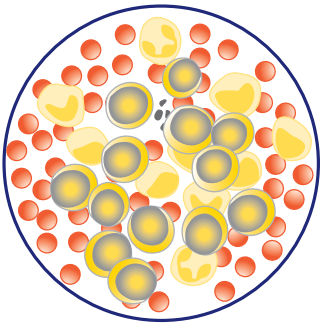
In leukaemia, white blood cells grow abnormally and multiply in such a way that they crowd the bone marrow. This can reduce the bone marrow's ability to produce normal levels of other blood cells, which affects the way that the rest of the body works. Meanwhile, the abnormal cells spill out into the 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 these organs can be increasingly affected.

Recent advances in how chronic leukaemia is treated can help keep the disease 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.

White blood cells

Leukaemia cells
(abnormal cells)

Red blood cells

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

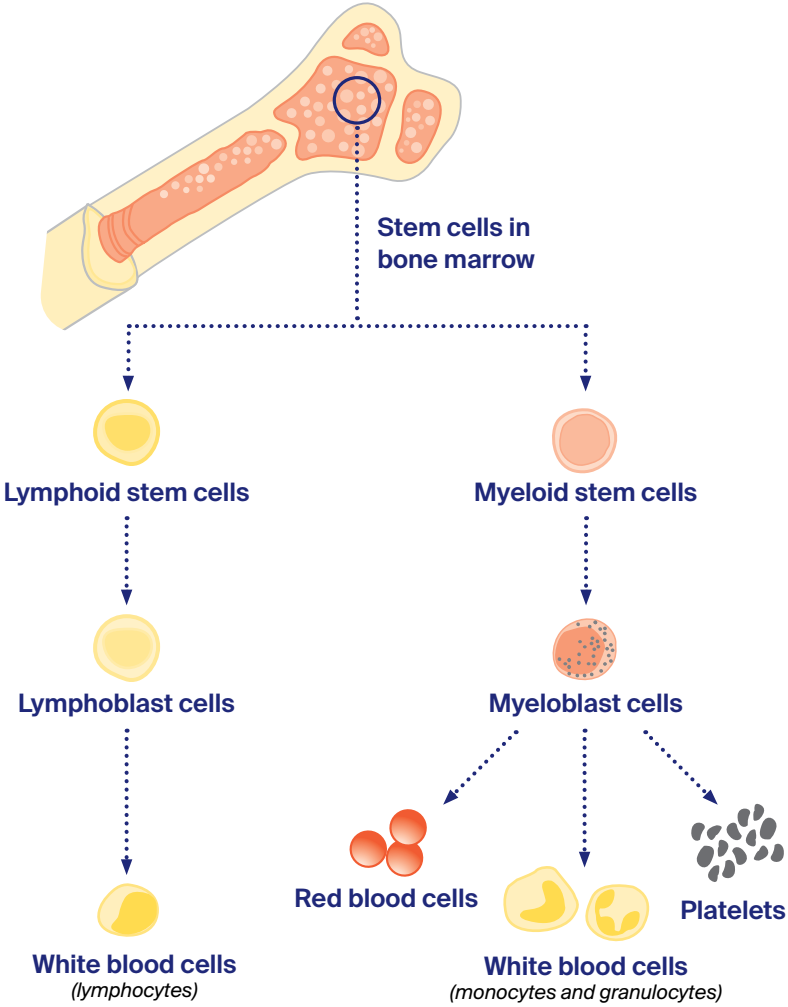
All blood cells live for a limited time and need to be continually replaced. Most are made in the bone marrow, which is the spongy part in the centre of bones.

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 develop into different types of white blood cells that can be affected by different types of leukaemia (see page 9 for more information).

Blood stem 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. These abnormal white 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, which then can't work properly. This increases the risk of infections. As leukaemia progresses, the bone marrow fills with leukaemia cells and there is little room for healthy red blood cells and platelets. This can cause fatigue, 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 how white blood cells are made, they are grouped in several ways:

- by the type of white blood cell affected
- whether there are abnormalities in the bone marrow
- how quickly the disease develops.

Chronic leukaemia usually makes white cells that are mature or partially developed, occurs gradually, and grows slowly over months to years.

Acute leukaemia makes white cells that are very immature (called blast cells), occurs suddenly, and grows quickly.

▸ 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 the type of white blood cell 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. There are two main types of lymphocytes: B-cell and T-cell. The B lymphocytes are abnormal in people with CLL. 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. There are four different kinds of granulocytes: neutrophils, eosinophils, basophils and mast 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 type of non-Hodgkin lymphoma.

Both SLL and CLL are cancers affecting the lymphocytes. In SLL, abnormal lymphocytes are mainly found in the lymph nodes. In CLL, abnormal lymphocytes are mainly found in the blood, but can be in the lymph nodes and bone marrow.

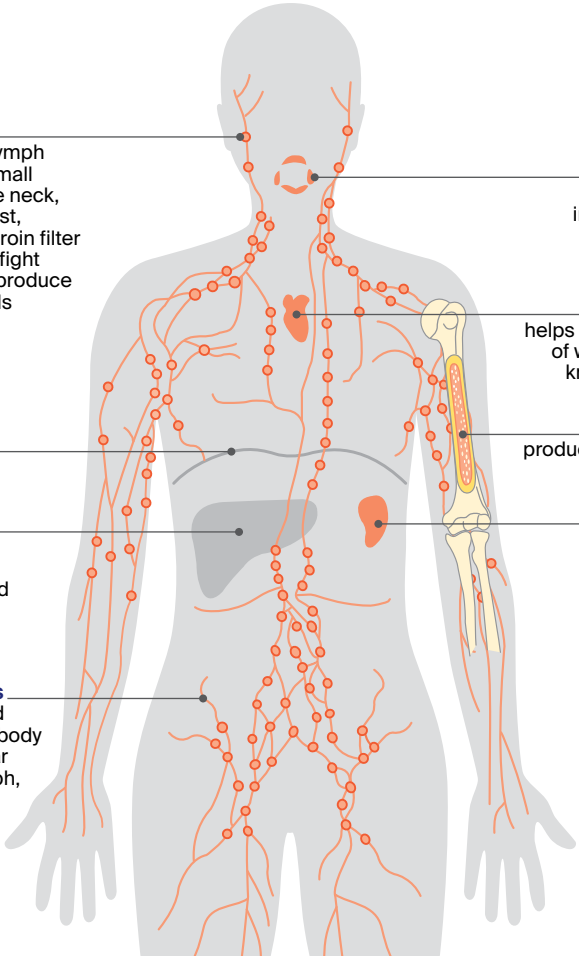
SLL and CLL are considered the same disease (with different symptoms) and are treated similarly.

Doctors may call small lymphocytic lymphoma CLL/SLL.

The lymphatic system

Lymph nodes

The lymphatic system is part of the immune system, which protects the body against infection.



Lymph nodes
also known as lymph glands, these small structures in the neck, underarms, chest, abdomen and groin filter out toxins, help fight infections, and produce some blood cells

Diaphragm*

Liver*
removes toxins, controls blood sugar levels, and stores vitamins

Lymph vessels
thin tubes found throughout the body that carry a clear fluid called lymph, which travels to and from areas of lymph tissue, including the lymph nodes, spleen and liver

Tonsils
trap inhaled or ingested germs

Thymus
helps produce a type of white blood cell known as T-cells

Bone marrow
produces blood cells

Spleen
clears out old or damaged blood cells

** Not part of the lymphatic system*

Q: What are the risk factors?

A: Chronic leukaemia is caused by changes to one or more of the genes that control how blood cells grow and develop. 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 have been linked to 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 5180 people are diagnosed with a form of leukaemia, and more than 2800 of these cases are chronic leukaemia.

CLL is the most common type of chronic leukaemia, with about 2400 people diagnosed each year. It occurs much more often in men than in women and almost never occurs in children.

About 390 people are diagnosed with CML annually. It is slightly more common in men than in women and is rare in children.[3]

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 full after eating only a small amount – caused by an enlarged spleen
- tiredness – caused by a low red blood cell count (anaemia)
- frequent and persistent infections – caused by low levels of normal white blood cells (neutropenia) leading to lowered immunity or few protective antibodies to help fight infections
- bruising or bleeding – caused by low levels of platelets (thrombocytopenia)
- drenching night sweats
- high temperature (fever) without any other signs of infection
- unexplained 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: Your general practitioner (GP) will often arrange the first tests to assess any 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. You may also see a range of other health professionals who specialise in different aspects of your case.

Health professionals you may see

haematologist	diagnoses and treats diseases of the blood, bone marrow and lymphatic system; prescribes chemotherapy, targeted therapy and other drug therapies; conducts stem cell transplants
radiation oncologist	treats cancer by prescribing and overseeing a course of radiation therapy
cancer care coordinator	coordinates 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	helps with nutrition concerns and recommends changes to diet during 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	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment

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, as it may not 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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 cancer 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 cancer.

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

Your doctor will use some of the following tests to work out whether you have CLL.

Physical examination

Your doctor will examine your body and check different areas for swelling. In particular, the doctor will feel your abdomen (belly) 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)

Monoclonal B-cell lymphocytosis (MBL) is a condition that causes an increased number of abnormal B-cells (a type of lymphocyte). This number is not high enough to be considered CLL. MBL is not cancer.

You don't need treatment for MBL, but you will need regular blood tests to monitor your lymphocyte count. A small number of people with MBL develop CLL, which may eventually need treatment.

Blood tests

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

Your blood sample will also be checked for certain markers that are on the surface of the leukaemia cells. This test is known as immunophenotyping. It is done with a machine called a flow cytometer. Finding certain markers (e.g. CD5, CD19, CD20, CD23, Kappa, Lambda) in your blood can help confirm the diagnosis of CLL.

Bone marrow biopsy

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

During the biopsy, the doctor will apply a local anaesthetic to the skin to numb the area and you may be given a light sedative to help you feel relaxed. A thin needle is used 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. It may be uncomfortable while the sample is taken, but you may be given some medicine to manage any pain.

Pain medicine may make you feel drowsy, so organise for a family member or a friend to drive you home afterwards. You may feel pain at the affected area for a week after the bone marrow biopsy.

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.

Genetic tests, including karyotyping, fluorescence in situ hybridisation (FISH) and next-generation sequencing molecular techniques, are used to look for abnormal chromosomes or genes in the blood or bone marrow.

Leukaemia cells may have damage to at least one chromosome, such as a part missing or deleted. Common CLL abnormalities include deletions of parts of chromosomes 11, 13 or 17 or an extra copy of chromosome 12. There may be other genes, such as the IGHV mutation, that can be tested.

Genetic test results help doctors recommend suitable treatment and give some information about how CLL may progress (prognosis, see page 20).

CT scan

This imaging test uses x-rays to create a detailed, cross-sectional picture of the body. Only some people with CLL will need a CT (computerised tomography) scan. It can show 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

Most people won't need a lymph node biopsy because CLL is usually diagnosed from blood tests. But if you have an unusually enlarged lymph node, your doctor will check if this is due to a type of lymphoma called Richter's transformation (see page 21).

There are different types of lymph node biopsy. For a core biopsy, you will have a local anaesthetic and a CT scan or ultrasound will be used to guide a needle to the enlarged lymph node to collect a sample. For an excision biopsy, you will be given a general anaesthetic and/or light sedation, and the doctor will make a cut in the skin and remove the whole lymph node. They close the area with a few stitches, and send it to the laboratory for testing. Most people can go home the same day.

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 guide the best treatment options for your situation.

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 of 0 to 4. Rai also 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 abnormal 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 haematologist, 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 predict the exact course of the disease. Factors used to assess your prognosis include your test results, particularly the genetic tests. Your doctor can give you an idea about how CLL may respond to treatment and common issues that affect people with CLL.

While CLL is generally not a curable disease, advances in how CLL is treated have improved the outlook for people. For some 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

At first you might not need treatment if you have early-stage CLL and no symptoms. Some people never have treatment. If you need treatment, it usually includes targeted therapy, with or without immunotherapy (monoclonal antibodies). Chemotherapy is less commonly used.

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

▸ See our *Understanding Non-Hodgkin Lymphoma* booklet.

Active monitoring

Having regular check-ups and blood tests instead of treatment is called active monitoring, careful monitoring or watch and wait. For people with no symptoms, starting treatment immediately is no better than waiting until treatment is needed. Waiting means that you delay any side effects.

CLL can make you more likely to catch infections such as shingles, the flu and COVID-19. See page 25 for signs of infections to watch out for, and get treatment as soon as possible if they appear. 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 recommend you begin active treatment for CLL if:

- you develop symptoms such as fevers, drenching night sweats or weight loss
- the number of red blood cells and platelets in your blood falls
- your lymph nodes become very swollen and/or put pressure on important internal structures, such as 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 will aim to get the disease under control. This is known as first-line treatment. Although most people respond well to treatment, it's likely that the disease will come back (relapse) in some people. They may 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).

Targeted therapy and immunotherapy

Before the recent approval of several targeted therapies, chemotherapy (usually in combination with immunotherapy) was the main treatment for CLL. However, chemotherapy has many side effects. If you need treatment for CLL, targeted therapy (sometimes with immunotherapy) is now the usual main treatment. Targeted therapy drugs attack specific features of leukaemia cells to stop them growing and multiplying.

Targeted therapy drugs are usually given as tablets or capsules that you swallow, and can be taken at home. Targeted therapy drugs may be given alone, or in combination with immunotherapy drugs (such as rituximab or obinutuzumab). Immunotherapy drugs are usually given through a drip into a vein (intravenous infusion). This is usually during a day visit to a treatment centre.

The targeted therapy or immunotherapy drugs you are offered will depend on the stage of the CLL, the results of genetic tests, your general health, what side effects you can tolerate, and your preferences. The main types of targeted therapy drugs are:

- BTK inhibitors (bruton-tyrosine kinase inhibitors), including acalabrutinib, ibrutinib and zanubrutinib
- BCL-2 inhibitors (B-cell lymphoma-2 inhibitors), including venetoclax (usually given with rituximab or obinutuzumab)
- PI3K inhibitors (phosphoinositide 3-kinase inhibitors), including idelalisib.

If the CLL returns after initial treatment, you may be offered a different targeted therapy drug, immunotherapy or possibly chemotherapy. There is a lot of research into CLL, and new drugs are regularly becoming available. Talk to your doctor about the latest developments and if there is a suitable clinical trial you can join (see page 15).

Side effects – The side effects of targeted therapy and immunotherapy drugs vary depending on the drugs given. Ask your haematologist about the specific side effects of the drugs you are taking. Some people have a reaction to the infusion – signs of this include flushing, low

blood pressure, high temperature or itching. Giving the drug over several hours can help reduce reactions.

The side effects of targeted therapy may include an increased risk of infection, fever, sweating, chills and diarrhoea. Side effects specific to certain types of targeted therapy drugs include:

BTK inhibitors – may cause irregular heartbeat, increased risk of bleeding and infections, high blood pressure, and headaches

BCL-2 inhibitors – may reduce red cells, white cells, and platelets, and may cause the release of toxic chemicals from tumour cells, which needs to be closely monitored

PI3K inhibitors – significantly increases the risk of serious infections.

Side effects of immunotherapy include a reaction during the injection and increased risk of infection.

If used, chemotherapy drugs can affect some of your healthy cells, which may cause a range of side effects. For example, you may bruise easily, feel very tired, feel sick (nauseous), have changes to taste and smell, or have an increased risk of infections (see table opposite for ways to manage this risk). If you are having chemotherapy as tablets, side effects are usually mild, but the effects may be stronger if you have intravenous chemotherapy.

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

▸ See our *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets and *Understanding Chemotherapy* booklet.

Taking care with infections during treatment

If your white blood cell levels drop during treatment, you are more likely to catch colds or more serious infections and need to go to hospital.

How to reduce your risk

To prevent the spread of infections:

- check with your doctor about having vaccines for the flu and COVID-19
- ask people close to you to consider having vaccines for the flu and COVID-19, and if they have a contagious infection (e.g. cold, flu, COVID-19, measles, 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
- prepare and store food properly to avoid foodborne illness and food poisoning
- eat freshly cooked foods and avoid raw fish, raw seafood, raw meat, uncooked 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.

Other treatments

Stem cell transplant – Rarely, very high doses of chemotherapy or radiation therapy are used to destroy the leukaemia cells. This can also damage the stem cells in the bone marrow (see page 6). A stem cell transplant can 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 not suitable for most people with CLL. This is because the procedure can have a lot of side effects and is considered too risky for people with slow-growing CLL.

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

The process involved in a stem cell transplant is complex. 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, contact the Leukaemia Foundation on 1800 620 420 or visit leukaemia.org.au and search for "stem cell transplants".

Clinical trials – To find out more about how clinical trials can help and how to join one, see page 15.

"I had no idea that I would still be feeling tired five months after finishing treatment. I didn't know how to make it better and I was scared that's how it would be: that I wouldn't go back to normal, that I would never go back to having energy again." JUDY

Supportive treatments

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 medicine. Steroid therapy can help prevent or reduce some chemotherapy side effects, such as nausea. It may also be used on its own to treat immune problems which may be related to CLL.

Allopurinol tablets – If your white blood cell count is very high, a chemical called uric acid may build up in the blood during treatment. This can cause red, painful and swollen joints (gout), and may damage your kidneys. You may be prescribed tablets called allopurinol, which prevent gout by helping your kidneys to get rid of uric acid.

Immunoglobulin infusions – Immunoglobulin is a protein that helps your body to fight infections. CLL usually causes low immunoglobulin levels. If infections keep coming back or are severe, you may be given immunoglobulins through a drip to help strengthen your immune system. The infusion can take several hours.

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 can be helpful for people having palliative treatment (see next page).

You don't often have radiation therapy for CLL, but it may be used to treat symptoms such as pain caused by a swollen spleen or swollen lymph nodes. The aim is to shrink your spleen and lymph nodes to reduce the pain.

▸ See our *Understanding Radiation Therapy* booklet.

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. Many people think that palliative treatment is for people at the end of their life; however, it can help people at any stage. It is about living 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. Your care may be led by a specialist palliative care team or by your GP and a community nurse.

- See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets or listen to *The Thing About Advanced Cancer* podcast series.

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.
Prognosis	• Advances in how CLL is treated have improved the outlook for many people.
Active monitoring	• Not everyone diagnosed with CLL needs treatment right away. Your doctor will usually monitor your health with regular check-ups and blood tests. This is called active monitoring. • Treatment will start when CLL causes symptoms or progresses.
Treatment	• You may have targeted therapy and immunotherapy drugs to stop the leukaemia cells from 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, stem cell transplant, chemotherapy 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

A combination of the following tests will help work out whether you have CML. You may have 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. This 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

A bone marrow biopsy is used to confirm that you have CML and to check how many blood cells are affected. During a bone marrow biopsy, 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 sample is tested at a laboratory and the results will usually be available within a week.

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.

Doctors use the blood or bone marrow sample to check for gene faults in leukaemia cells. Genetic tests may include:

- FISH (fluorescence in situ hybridisation)
- PCR (polymerase chain reaction).

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 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

Ultrasound – Some people also have an ultrasound to check the size of the spleen and liver. 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. Talk to your medical team for more information.

The Philadelphia chromosome

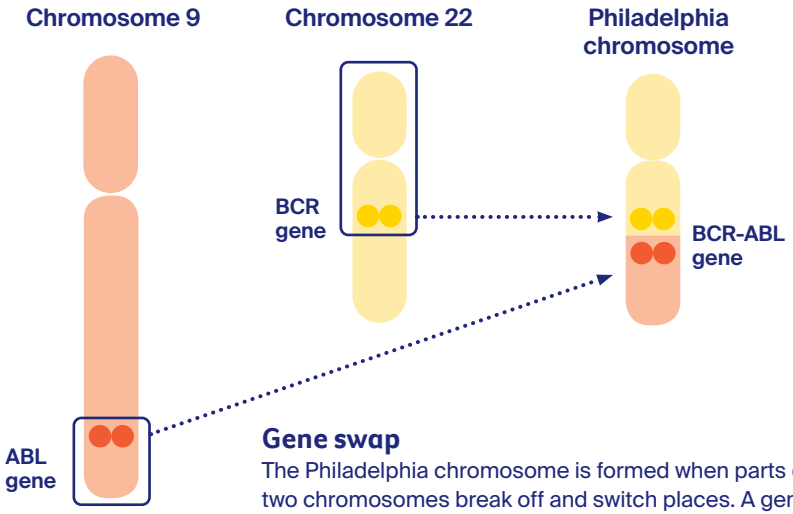
Most cells in the human body have 23 pairs of chromosomes. Chromosomes are threadlike structures that contain sets of instructions known as genes.

In nearly all people with CML, chromosome 22 is abnormal and is known as the Philadelphia chromosome.

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 (see diagram below).

BCR-ABL is considered a cancer gene because it is present only in developing leukaemia cells. It switches on one of the proteins of the leukaemia cells, called tyrosine kinase. This protein tells leukaemia cells to grow and multiply.

All people with CML are treated with drugs to block 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 recommend 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.

Most people have chronic phase CML when diagnosed. They stay in this phase for a few years without treatment. With treatment, the disease can go into remission and people with well-controlled CML can have a normal life span. 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 number of blast cells may suddenly increase. At this time, your spleen may become enlarged and your white blood cell count may rise rapidly.
blast	The number of blast cells significantly 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 predict the exact course of the disease, but your medical team can give you an idea about how the CML will respond to treatment. Factors used to assess your prognosis include the phase of the disease, your blood counts and if your spleen is enlarged. Your team will also arrange tests throughout your treatment to check how well the CML is responding.

Recent advances in how CML is treated have dramatically improved outcomes. For most people, the goal of treatment is to get the disease into remission. If the CML does move into the accelerated or blast phases, treatment does become more challenging, but there are still good treatment options available.

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 offered through 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 the majority of cases, you'll need to continue this treatment for life. 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 say you can stop treatment. If CML starts to come back, you will begin treatment again.

Targeted therapy

The main treatment for CML is a group of targeted therapy drugs called tyrosine kinase inhibitors (TKIs). These drugs work by blocking a protein called tyrosine kinase. Tyrosine kinase tells the leukaemia cells to divide and grow. Without this signal, the cells die. Each TKI works in a slightly different way. This means that if one TKI doesn't control the CML or stops working for you, your doctor may increase the dose or switch you to another type of TKI.

You usually have TKIs as the first treatment, whether CML is in the chronic, accelerated or blast phase. 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.

A new generation TKI, asciminib, is available for people with CML who cannot tolerate or have developed resistance to older TKIs.

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

Side effects – The side effects of TKIs vary depending on the drug and how your body responds. Most side effects are mild and can be treated.

Common side effects 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 can affect how the heart works, which can be life-threatening.

Tell your treatment team if you have any of these side effects and let them know if you have a history of heart disease. The team will monitor how you respond 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 your doctor may have to change the dose of the TKI or give you a different TKI.

▸ See our *Understanding Targeted Therapy* fact sheet.

Continuing to take targeted therapy drugs

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

Some 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 are able to stop, you'll need frequent check-ups. Half the people who stop have no further issues, and the other half have a relapse and need to start taking TKIs again.

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. For CML, chemotherapy is used:

- before starting a TKI – you may be given a mild chemotherapy tablet called hydroxyurea for a short time to lower your white blood cell count and get symptoms under control
- for people in the chronic phase who can't take TKIs – they may be treated with hydroxyurea tablets for several months
- for people who have not responded to TKI therapy or who are preparing for a stem cell transplant (see page 38)
- for people in the blast phase – these drugs are often given into a vein (intravenously) and tend to be much stronger, so the treatment may be given 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

Immunotherapy – Immunotherapy aims to change how your immune system responds to the leukaemia. The immunotherapy drug interferon alfa was the main treatment for CML before TKIs were developed. Although this drug is not used very often now, it's being used in some clinical trials to see whether people can stop their TKIs. Interferon alfa is also used in people who are pregnant and can't have 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 TKIs, or to people whose disease is not controlled with chemotherapy.

A stem cell transplant 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). A stem cell transplant can 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 people. 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 and search for "stem cell transplants".

Supportive treatments

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

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 red, painful and swollen joints (gout) and may damage your kidneys.

You may be prescribed tablets called allopurinol, which prevent gout by helping your kidneys to get rid of uric acid.

Leukapheresis – You may have a very high number of white blood cells (e.g. during blast-phase CML). The extra blood cells can block blood vessels and cause problems.

A procedure called leukapheresis can quickly reduce your white blood cell count to a safer level.

You may have leukapheresis to control symptoms, not to treat or cure the disease.

During the leukapheresis procedure, your blood passes through a machine that takes out the white blood cells and returns all the other blood cells and plasma back into the bloodstream.

- 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 blood cells are removed, and the rest of the blood components are returned to your body through the second tube in a continuous process.
- This process can take 2–4 hours.

Only about 250 ml of your blood is outside your body at any one time. Leukapheresis is not painful, but some people find having the catheter put in uncomfortable.

Palliative treatment

In rare cases of advanced CML – such as CML that is not responding to available treatments – 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. Many people think that palliative treatment is for people at the end of their life; however, it can help people at any stage. It is about living as long as possible in the most satisfying way you can.

As well as slowing the progress of leukaemia, palliative treatment can help to relieve pain and 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. Your care may be led by a specialist palliative care team or by your GP and a community nurse.

- See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets or listen to *The Thing About Advanced Cancer* podcast series.

Key points about diagnosing and treating CML

Diagnosis

- To test for leukaemia cells, a blood sample will be taken. A small amount of bone marrow may also be removed with a needle (bone marrow biopsy).
- In most people with CML, the leukaemia cells have a genetic change known as the Philadelphia chromosome. The Philadelphia chromosome contains the BCR-ABL gene, which produces tyrosine kinase, a protein that tells leukaemia cells to grow.
- Genetic tests analyse a sample of blood or bone marrow 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.

Prognosis

Advances in how CML is treated have improved outcomes.

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.
- In rare cases, you may have an immunotherapy drug called interferon alfa or a stem cell transplant.
- You may be given allopurinol tablets to help prevent gout, and you may have a procedure called leukapheresis to reduce your white blood cell count.
- Palliative treatment helps 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 for People Living with 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, may prevent successful treatment of the leukaemia and can be harmful. Cancer Council does not recommend the use of alternative therapies as a leukaemia 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▸ See our *Cancer and Your Finances* and *Cancer, Work and 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. The experience of having leukaemia 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.

Living with chronic leukaemia

For most people, treatment for leukaemia can continue on and off for years. Life between treatments can present its own challenges. You may 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 have depression. This is quite common among people who have had leukaemia.

Talk to your GP, because counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. 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 have regular blood tests to measure BCR-ABL levels (see page 32). These blood tests are a condition 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 (relapse) after treatment, 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 or transforms to a more advanced phase.

If you have a relapse or the disease transforms, further treatment can usually be given to control the leukaemia. This may lead to another remission. In some situations, doctors may recommend a stem cell transplant (see pages 26 and 38).

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 having leukaemia, 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 by location.

Cancer Council 13 11 20

Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Legal and financial support

If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Council 13 11 20.

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.

Information resources

Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Practical help

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

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**
Cancer Australia	**canceraustralia.gov.au**
Carer Gateway	**carergateway.gov.au**
Carers NSW	**carersnsw.org.au**
Department of Health and Aged Care	**health.gov.au**
eviQ (cancer treatment information)	**eviq.org.au**
Healthdirect Australia	**healthdirect.gov.au**
Leukaemia Foundation	**leukaemia.org.au**
Radiation Oncology: Targeting Cancer	**targetingcancer.com.au**
Services Australia (including Centrelink and Medicare)	**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 is 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 try calling Cancer Council 13 11 20.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with leukaemia. Carers NSW, a statewide organisation for carers, can provide support. Call (02) 9280 4744 or visit carersnsw.org.au.

▸ See our *Caring for Someone with Cancer* booklet.

Bone marrow and blood donations

You can indirectly support someone with chronic leukaemia 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 Australian Red Cross Lifeblood. Call 13 14 95 or visit 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 or while I am taking long-term TKIs?
- 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.

accelerated phase
The second phase of chronic myeloid leukaemia progression. This is when the number of blast cells increases.

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 a 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.

blast phase
The final phase of chronic myeloid leukaemia progression. It has the highest number of blast cells in the blood and bone marrow, and can be life-threatening.

bone marrow
The soft, spongy material in the centre of 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.

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.

chronic phase
The first phase of chronic myeloid leukaemia. The number of white blood cells is higher than normal but may not cause symptoms.

CT scan
Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

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

first-line treatment
The first treatment used to treat 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.

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.

genetic tests
Genetic tests aim to detect gene changes that are more commonly seen in certain types of cancer.

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 called leukaemia cells to be made.

leukapheresis
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 nodes
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. Lymphocytes destroy bacteria, viruses and other harmful substances.

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). Neutropenia can be caused by the cancer or it can be a side effect of some cancer treatments.

non-Hodgkin lymphoma
One of the two main groups of cancer of the lymphatic system. Also called non-Hodgkin's disease.

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.

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, a 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 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
See 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 initial treatment. Also called resistant disease.

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

resistance
When cancer does not respond to a drug treatment.

response
When lymphoma shrinks or disappears after treatment.

Richter's transformation
When chronic lymphocytic leukaemia cells transform into a type of fast-growing 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, stops working 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. The spleen makes lymphocytes, filters the blood and destroys old blood cells.

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

stem cells
Unspecialised blood cells in the bone marrow. They can grow into mature cells.

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), from the bloodstream (peripheral blood stem cell transplant) or from umbilical cord blood (cord blood transplant).

steroids
A class of drugs that are mostly used to reduce inflammation. Also called corticosteroids.

steroid therapy
Treatment with drugs to reduce inflammation, pain and swelling.

targeted therapy
Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

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
A 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

1. B Eichhorst et al. on behalf of the ESMO Guidelines Committee, "Chronic lymphocytic leukaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 32, issue 1, 2021, pp. 23–33.
2. A Hochhaus et al. on behalf of the ESMO Guidelines Committee, "Chronic myeloid leukaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 28, suppl. 4, 2017, pp. iv41–iv51.
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2023, viewed 7 March 2024, available from aihw.gov.au/reports/cancer/cancer-data-in-australia.

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 experienced health professionals 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.

TIS TRANSLATING AND INTERPRETING SERVICE

If you need information in a language other than English, an interpreting service is available. Call 131 450.

National Relay Service

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

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

For information & support
on cancer-related issues,
call Cancer Council 13 11 20

Visit our website: cancercouncil.com.au

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