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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We would also like to thank the health professionals and consumers who have worked on previous editions of this title.

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, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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. 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.[1–4]

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. Turn to the last page of this booklet for more details.

Cancer Council 13 11 20

Contents

What is blood cancer?

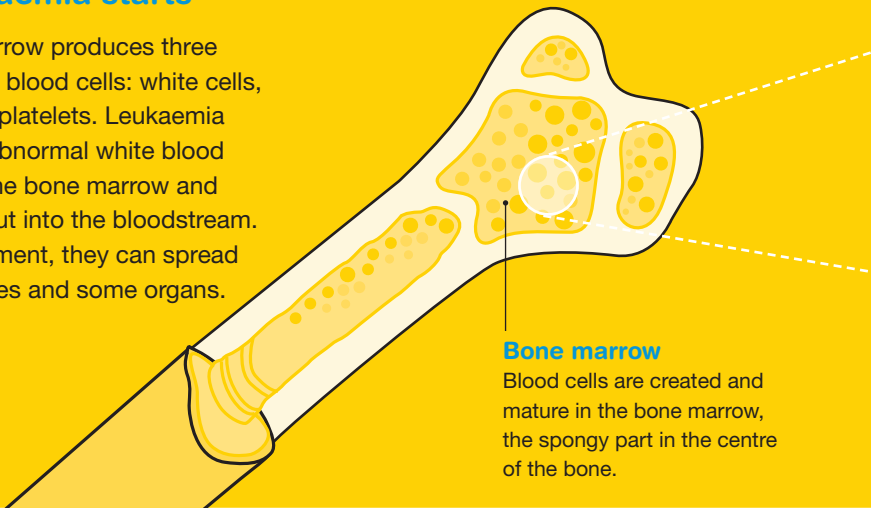
Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury. Normally cells grow and multiply in an orderly way.

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

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.

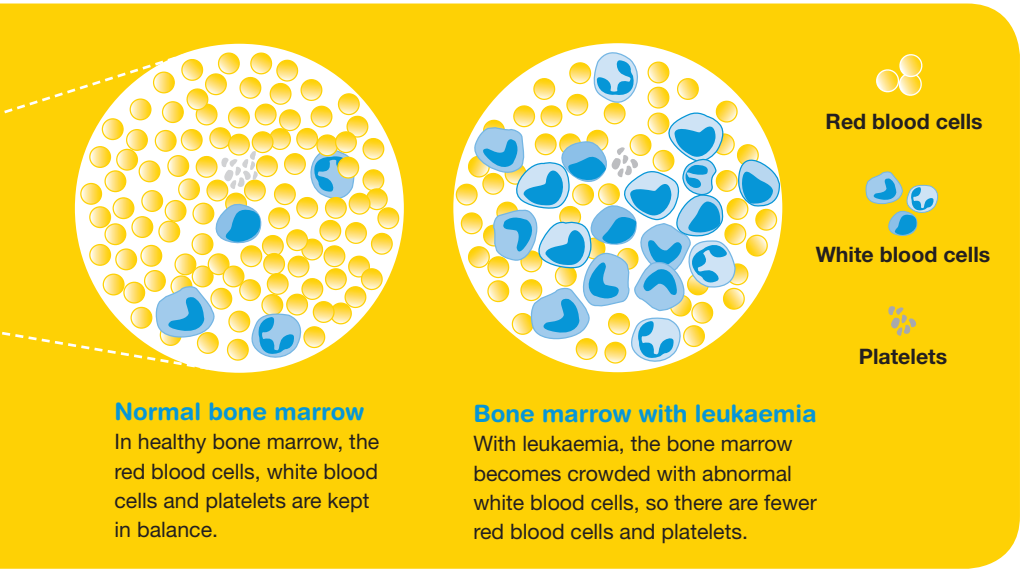


Bone marrow
Blood cells are created and mature in the bone marrow, the spongy part in the centre of the bone.

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 blood cells and fewer normal blood cells. As the abnormal blood cells build up in the blood, they can spread to the lymph glands (lymph nodes), 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 red blood cells, white 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. The three main types of blood cells have specific functions:

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

All three types of 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 the bones.

The bone marrow contains stem cells. These are unspecialised blood cells that first develop into immature cells known as blast cells. Normally, the blast cells then become mature red or white blood cells or platelets and carry out their set functions.

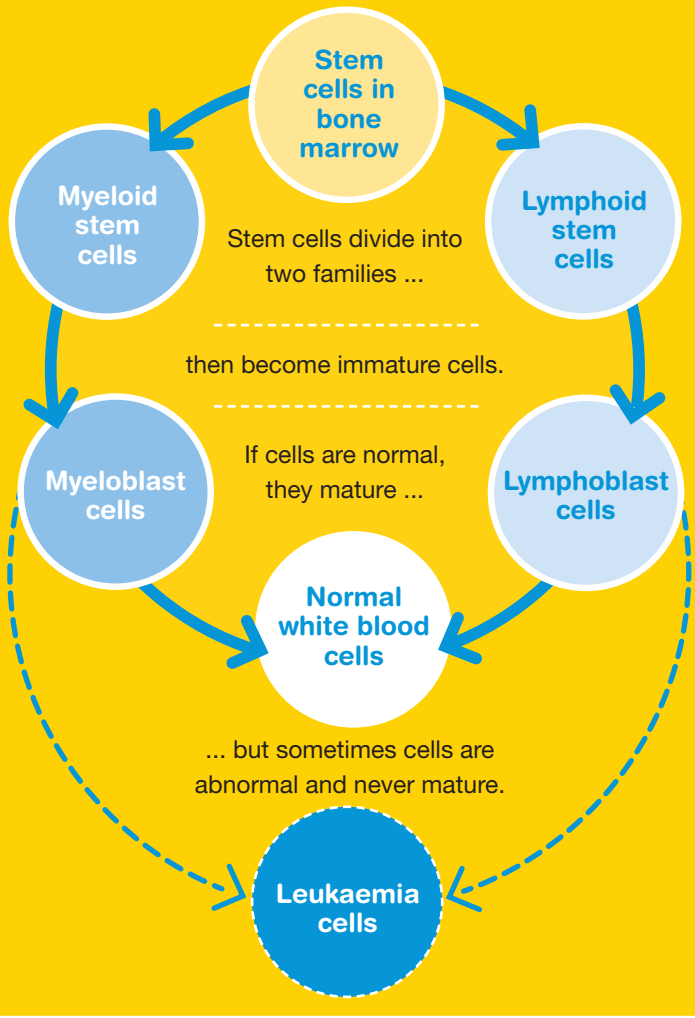
There are two families of stem cells:

- **myeloid stem cells –** develop into myeloblast cells and then into red blood cells, most types of white blood cells, and platelets
- **lymphoid stem cells –** develop into lymphoblast cells and then into lymphocytes, which are a type of white blood cell.

If myeloblast or lymphoblast cells do not mature properly or if there are too many in the blood, it can cause leukaemia.

Blood cell production

In leukaemia, blast cells never develop into mature white blood cells. These abnormal blast cells are also called leukaemia cells.



Key questions

Q: What is chronic leukaemia?

A: Chronic leukaemia develops when the body makes too many white blood cells, and these cells are immature and abnormal. Because they live too long or multiply too quickly, there will be large numbers circulating in the blood. They crowd out normal white blood cells and don't fight infection themselves, so there can be a higher risk of infection (neutropenia).

As leukaemia progresses, the bone marrow fills with leukaemia cells and there is less room for healthy red cells and platelets to be produced. This may cause various health problems, such as anaemia (from too few red cells) or bleeding or bruising (from thrombocytopenia, too few platelets).

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 (lymphoid or myeloid), whether there are abnormalities in the bone marrow, and how quickly the disease develops.

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

Acute leukaemia affects fully immature cells, occurs suddenly, and develops quickly. Cancer Council NSW has a separate booklet about acute leukaemia. For a free copy, call Cancer Council on 13 11 20 or visit cancercouncil.com.au.

Small lymphocytic lymphoma

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.

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 cells that are affected.

Chronic lymphocytic leukaemia (CLL) – The body has too many of the white blood cells known as lymphocytes. This disease is also called chronic lymphatic leukaemia. For information about how CLL is diagnosed and treated, see pages 14–25.

Chronic myeloid leukaemia (CML) – The body has too many of the white blood cells known as granulocytes. The granulocytes are part of the myeloid family of white blood cells. This disease is sometimes called chronic granulocytic leukaemia. For information about how CML is diagnosed and treated, see pages 26–36.

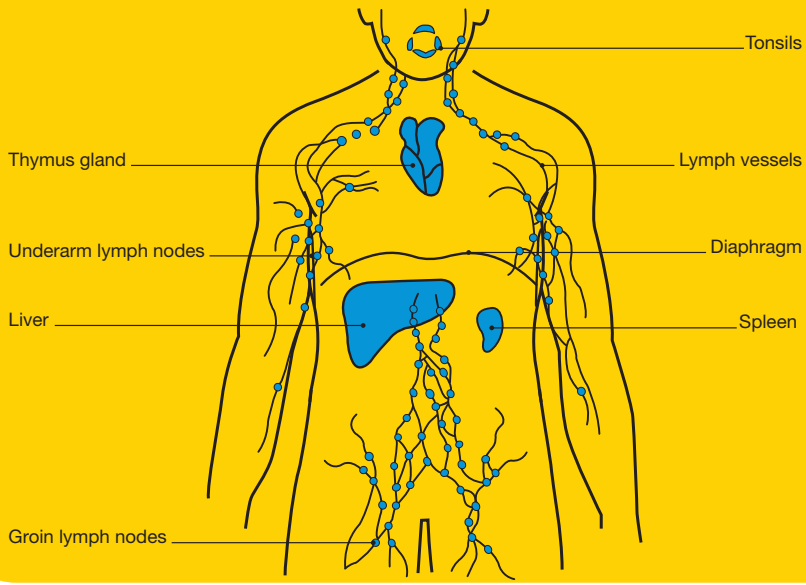
The lymphatic system

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 are small bean-shaped structures that 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 – An organ on the left side of the body under the ribs. It filters out old or damaged blood cells, and also makes some blood cells.

Liver – The body's largest internal organ. It removes toxins, stabilises sugar levels, and stores vitamins.



Q: What are the symptoms?

A: Many people with chronic leukaemia have no symptoms. Often the disease is discovered when a routine blood test shows a high white blood cell count. At this stage, the abnormal white cells may not be causing any harm. Symptoms tend to be mild at first and get worse slowly. They may include:

- painless swelling of lymph nodes in the neck, underarms or groin (see diagram opposite)
- lump or pain in the left side of the abdomen – caused by an enlarged spleen (see diagram opposite)
- tiredness – caused by a lack of red blood cells (anaemia)
- frequent and persistent infections – caused by a lack of normal white blood cells (neutropenia)
- bruising or bleeding – caused by a low platelet count
- excessive sweating at night
- fever
- weight loss.

Not everyone with these symptoms has chronic leukaemia. Other conditions, such as viral infections, can also cause these changes. However, if you have any of these symptoms, especially over a few weeks, see your doctor for a check-up.

Q: How common is leukaemia?

A: Each year in Australia, more than 3200 people are diagnosed with a form of leukaemia, and about 1500 of these cases are chronic leukaemia.[5] CLL is the most common type, with about 1200 people diagnosed each year. About 80% of new CLL cases

are in people over the age of 60. It occurs more often in men than in women and is very rare in children.[6] About 340 people are diagnosed with CML annually. It is rare in children and slightly more common in men than in women.[7]

Q: What are the causes?

A: Chronic leukaemia is caused by changes to one or more of the genes (DNA) 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. The exact causes of CLL and CML are not yet understood.

Causes of CLL

- Some people have genetic abnormalities that can lead to CLL.
- These genetic defects are not usually inherited, but there are rare cases where CLL may occur more commonly in families. If you are worried about this, talk to your doctor, who may refer you to a genetic counsellor.

Causes of CML

- Most people with CML have a genetic abnormality known as the Philadelphia chromosome or BCR-ABL gene (see pages 26–27). This abnormality cannot be passed on from parents to children.
- Exposure to the chemical benzene or high doses of radiation may cause CML. However, this doesn't explain the majority of cases.

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 cancer, you will usually be referred to a specialist called a haematologist. The haematologist will arrange further tests and advise you about treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This multidisciplinary team may include the following roles:

Health professional	Role
haematologist*	specialises in treating people with diseases of the blood and blood-forming organs; prescribes the course of chemotherapy
radiation oncologist*	prescribes and coordinates the course of radiotherapy
nurses	give the course of treatment, and support and assist you through all stages of your treatment
dietitian	specialises in diet and disease, and supports and educates patients about nutrition and diet
social worker, clinical psychologist	help you with any emotional or practical problems and link you to support services
physiotherapist, occupational therapist	help you with any physical or practical problems associated with cancer and treatment

** Specialist doctor*

Chronic lymphocytic leukaemia (CLL)

This chapter explains how chronic lymphocytic leukaemia is diagnosed, monitored and treated. CLL affects the white blood cells called lymphocytes. For introductory information about CLL, including its symptoms and causes, 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 your spleen and liver are enlarged, and also check your neck, armpits and other areas for swollen lymph nodes.

Blood tests

A sample of your blood will be sent to a laboratory, where a disease specialist called a pathologist will examine it. There are several types of tests that can be done on a blood sample:

Full blood count – measures the number, size and maturity of different blood cells. Test results show what type of leukaemia cell is present.

Immunophenotyping – looks for markers or signals on the surface of the cell called antigens. The presence of certain antigens can confirm the diagnosis of CLL.

Genetic tests (cytogenetic and molecular tests) – test the chromosomes in the cells, which contain genetic information called DNA. Many patients with CLL have damage to at least one chromosome. Some chromosomal abnormalities make CLL harder to treat and put into remission. By identifying any damaged chromosomes, genetic tests help the medical team to make a diagnosis and plan your treatment.

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 chronic lymphocytic leukaemia, but it isn't leukaemia and it doesn't require treatment. Of people with MBL, only about 1–2% per year develop CLL requiring treatment. If you have MBL, you'll need regular blood tests to monitor your lymphocyte count.

Bone marrow biopsy

Some people have a bone marrow biopsy (sometimes called a bone marrow aspiration) to check for leukaemia cells and to determine what type of leukaemia it is.

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. You may also be given some pain medicine.

Although it can take up to 30 minutes to prepare for the biopsy, the actual procedure takes only a few minutes. 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.

Lymph node biopsy

Rarely, an enlarged lymph node is removed to confirm the diagnosis of CLL. This is called a lymph node (or gland) biopsy.

You will be given a local or general anaesthetic, depending on which lymph node is removed. 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 as the pain medicine can cause drowsiness.

CT scan

Some people with CLL may need a CT (computerised tomography) scan. This test uses x-ray beams to take pictures of the inside of your body. It can detect if your lymph nodes are affected and if your spleen is enlarged.

Before the scan, a dye may be injected into a vein, probably in your arm. This dye makes the pictures clearer. Let your doctor know if you have had a reaction to iodine or dyes during a previous scan.

A CT scan takes about 30 minutes. You will lie flat on a table while the CT scanner, which is large and round like a doughnut, takes pictures. Most people have this scan as an outpatient procedure, so they are able to go home straight after.

Further tests

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

Staging

Staging systems are often used by doctors to work out how far the leukaemia has progressed. This will help determine a person's prognosis (outlook) and guide the treatment. In CLL, doctors use the results of physical examination, imaging tests (such as CT scans) and blood tests to determine the stage of the disease.

There are three staging systems commonly used for CLL: the Binet system, the Rai system and a system that combines the two called IWCLL. Most Australian doctors use the Binet system (see below). The Rai system divides CLL into low-, intermediate- and high-risk groups. It is used mainly in the United States.

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

While CLL usually develops slowly, in rare cases it can change quickly. This is called transformation. The first sign may be a high temperature, weight loss or sudden swelling of lymph nodes, especially in the abdomen. If you experience these symptoms, contact your medical team immediately.

“A cancer diagnosis is difficult for anyone to hear, no matter what the statistics say in terms of cure rates. I was shocked and upset when the doctor told me, and I spent the first few months trying not to cry.” *Jo*

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 what stage leukaemia you have (see previous page).

It is not possible for any doctor 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 or chromosomal tests, can help predict how the CLL may respond to particular forms of treatment.

CLL is not generally a curable disease but, for many people, treatment is never required and they live a normal life span. For others, 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 with CLL often don't need treatment straightaway, and some do not need it at all.

Your doctor may decide to begin treatment if your CLL starts to cause symptoms, if it causes the number of normal bone marrow cells (red cells, white cells and platelets) to fall, or if it becomes more advanced. You may also have treatment if the number of lymphocytes in your blood doubles in less than a year. Some people have treatment because they have particular genetic abnormalities. Treatments may be part of clinical trials (see page 38).

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'.

Some people with CLL don't ever require treatment. In fact, it is possible to lead a normal life without any symptoms. However, a lowered resistance to infection could make you prone to other health problems such as shingles or the flu. Talk to your doctor about symptoms of infections or viruses to watch out for, and get treatment as soon as possible if you experience these symptoms. Your doctor may also recommend an annual flu vaccination.

Living with untreated 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.

Chemotherapy

If the CLL is diagnosed at an intermediate or late stage (Binet stage B or C), you may have chemotherapy. This treatment uses anti-cancer drugs called cytotoxics to kill the leukaemia cells or slow their growth.

Chemotherapy for CLL is generally given as either tablets by mouth or injections into a vein (intravenously) each month. A common oral chemotherapy drug that is given as a tablet is called chlorambucil.

Your doctors may recommend that you have a combination of drugs. For example, the chemotherapy drugs fludarabine and cyclophosphamide are often given with the drug rituximab (see *Targeted therapies,* page 22), a treatment known as FCR.

Chemotherapy drugs can also affect your healthy cells, which can cause side effects. For example, you may have an increased risk of infections (see opposite), easy bruising, nausea or fatigue. Side effects of chemotherapy tablets are usually mild, but the effects may be more troublesome if you have intravenous chemotherapy.

Let your medical team know if you have any side effects – they can prescribe medicine or change your treatment to make the side effects easier to handle.

For information on managing side effects, call 13 11 20 and request a free copy of *Understanding Chemotherapy,* or download a digital version from cancercouncil.com.au.

Taking care with infections

Some chemotherapy drugs, as well as the leukaemia itself, can cause a low count of normal, healthy white blood cells (neutropenia). This makes you more likely to get infections such as colds or infected cuts.

You may want to ask people close to you to have a flu shot, if they are able to do so. You can also ask family and friends to wait until they feel well before visiting. Of course, this is not practical for people you live with, so just try to minimise close contact while they are unwell.

Good food hygiene is important for everybody. If the leukaemia or chemotherapy has caused neutropenia, however, you will be more susceptible to foodborne illness and will have to be especially cautious about food poisoning. Extra care needs to be taken when preparing and storing food.

Your treatment team may advise you to avoid cold meats, undercooked foods, raw eggs, prepackaged salads, pâté, some types of seafood and certain cheeses.

Talk to a dietitian about any special food handling requirements that may apply to your stage of treatment.

Contact your doctor/hospital urgently if you experience:

- fever over 38°C
- chills or constant shivering
- sweating, especially at night
- a burning feeling when urinating
- a severe cough
- a sore throat
- vomiting that lasts more than a few hours
- severe constipation, diarrhoea or abdominal pain
- unusual bleeding or bruising
- prolonged faintness and a rapid heartbeat
- any sudden deterioration in your health.

Targeted therapies

Targeted therapies are drugs that destroy or stop the growth of cancer cells while minimising harm to healthy cells. They may be given together with chemotherapy or alone. The most common type of targeted therapy for CLL is a group of drugs called monoclonal antibodies. Tyrosine kinase inhibitors are another type of targeted therapy that is sometimes used for CLL.

Monoclonal antibodies – These drugs bind to certain cells, including leukaemia cells, and cause them to die or make them more susceptible to being killed by the body's own immune system. Common monoclonal antibodies include rituximab, alemtuzumab, ofatumumab and obinutuzumab. The side effects vary depending on which drug you are given, but may include an increased risk of infection, fever, sweating, chills and diarrhoea.

Tyrosine kinase inhibitors – These drugs work by blocking a protein that tells leukaemia cells to grow and divide. Without this signal, the cells die. Bruton's tyrosine kinase inhibitors (BTKIs) block a protein called Bruton's tyrosine kinase. A BTKI called ibrutinib has recently been approved in Australia for some people with CLL, but access may be difficult because of the high cost.

Always let your doctors know if you are taking any herbal remedies. Even though these products are labelled as natural, it doesn't mean they are safe. Some can have serious side effects and may interact with the drugs used in your cancer treatment.

Other treatments

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

Steroid therapy – Steroids are made naturally in the body and can also be produced artificially and used as drugs. They may be used with chemotherapy to treat CLL, or alone if you have a sudden drop in your red blood cell count.

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

Radiotherapy – This is a type of x-ray treatment, which can be used to treat swollen lymph nodes or to prepare for a transplant (see below). Call 13 11 20 for a free copy of our *Understanding Radiotherapy* booklet, or visit cancercouncil.com.au.

Surgery (splenectomy) – Occasionally, your spleen will be removed if it is very swollen. Your surgeon can give you more information about this operation.

Stem cell transplant – A reduced intensity stem cell transplant (sometimes called a mini transplant) may be performed for patients who haven't responded to chemotherapy. This means lower doses of chemotherapy and radiotherapy are used for the transplant, so it is easier for the body to tolerate. See page 34 for information about stem cell transplants.

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.

Emerging treatments – Medical research continues to improve the outcomes for people with CLL. Before new treatments become generally available, they are studied in clinical trials to see if they are safe and effective. Read more about clinical trials on page 38.

During and after treatment, you will have ongoing check-ups with your doctor to monitor your health. See page 42 for information.

Palliative treatment

In some cases of advanced CLL, the medical team may talk to you about palliative treatment. Palliative treatment improves quality of life by alleviating symptoms of cancer without trying to cure the disease. It can be used at any stage of advanced cancer.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include blood transfusions, radiotherapy, chemotherapy, targeted therapies or other therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. For free booklets on palliative care or advanced cancer, call Cancer Council 13 11 20 or download digital versions from cancercouncil.com.au.

Key points

- Your doctor will take a blood sample to check for leukaemia cells. Other blood tests may include immunophenotyping and genetic tests. These tests examine genetic information from your cells to confirm that you have CLL.
- Some people may have a bone marrow biopsy (when bone marrow is taken from your hipbone) to check for leukaemia cells.
- You may have further tests, such as a lymph node biopsy, CT scan, x-ray or ultrasound.
- Staging indicates how far the leukaemia has progressed and helps doctors work out the best treatment for you.
- Your doctor will talk to you about your prognosis. This is a general prediction about the course of the disease.
- Not everyone diagnosed with CLL will need treatment right away. It is common to wait until the leukaemia causes symptoms or reaches a more advanced stage before starting treatment. This is called active monitoring.
- You may have treatment with chemotherapy drugs to kill leukaemia cells. The side effects depend on the drugs you are given.
- Some people with CLL have targeted therapies such as monoclonal antibodies or tyrosine kinase inhibitors.
- Your doctor may recommend other treatments, such as radiotherapy, steroid therapy, surgery, a stem cell transplant or a clinical trial.
- Palliative care includes treatment that helps improve your quality of life without trying to cure the leukaemia.

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 introductory information about CML, including its symptoms and causes, 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.

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. Nearly all people with CML have an abnormal chromosome in their blood and bone marrow cells called the Philadelphia chromosome, and this chromosome contains the BCR-ABL gene.

BCR-ABL is considered a cancer gene because it is present only in developing cancer cells. It tells the body to produce an abnormal type of enzyme called tyrosine kinase, which instructs leukaemia cells to grow and multiply. All patients with CML are treated with drugs to block tyrosine kinase (see pages 30–31).

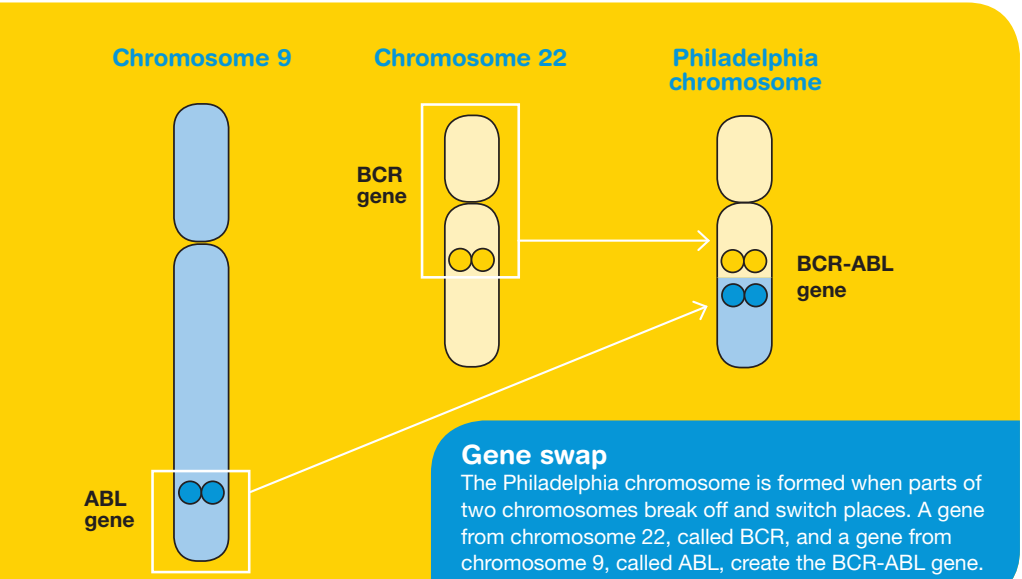
The Philadelphia chromosome is not inherited and cannot be passed on to your children – it is a genetic change that happens to some people over the course of life. The diagram opposite explains the process.

Physical examination

Your doctor will examine your body and feel different areas. In particular, the doctor will feel your abdomen to check whether your spleen and liver are enlarged.

Blood tests

Your doctor will take a blood sample and send it to a laboratory for a full blood count (FBC). This test measures the number, size and maturity of different blood cells. The pathologist may also run cytogenetic and molecular tests. These examine the genetic make-up of the blood cells to see if you have the Philadelphia chromosome and BCR-ABL gene (see box) or another abnormality.



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.

Bone marrow biopsy

Your doctor may arrange a bone marrow biopsy to see if you have the Philadelphia chromosome and how many of your blood cells are affected. Some laboratories are able to provide this information by analysing a blood sample, so a bone marrow biopsy is not always needed. Discuss the options with your doctor.

During the 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 or light sedation to help you feel relaxed. You may also be given pain medicine.

Although it can take up to 30 minutes to prepare for the biopsy, the actual procedure lasts only a few minutes. 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 for testing, and the results are usually available in a week.

CT scan

Some people may have a CT (computerised tomography) scan. This test uses x-ray beams to create pictures of your organs. It can detect if the CML has affected your lymph nodes and spleen.

Before the scan, a dye may be injected into a vein, probably in your arm. This dye makes the pictures clearer. (Let your doctor know if you have had a reaction to iodine or dyes during a previous scan.) You will lie flat on a table while the CT scanner, which is large and round like a doughnut, takes pictures. The scan takes about 30 minutes, and most people are able to go home straight after.

Further tests

Some people also have an ultrasound, which uses sound waves to create pictures of the inside of your body. Talk to your medical team for more information.

Staging

Diagnostic tests allow the doctor to work out how far the disease has progressed. This process is called staging, and it helps the doctor decide on the best treatment for you. The staging for CML is described in three phases. The disease is most often diagnosed in the chronic phase. Most people stay in this phase for a few years without treatment, but the disease can progress quickly at any time.

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. This phase usually lasts a few years, but with treatment it can last more than 20 years.
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 any doctor to know the exact course of your disease, but your medical team can predict how the CML will respond to treatment based on your initial test results. They will also arrange tests throughout your treatment that show how well the treatment is working.

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 have treatment to control the disease regardless of the phase at diagnosis. The type of treatment you have will depend on how far the leukaemia has progressed and your health. Some treatments are part of clinical trials (see page 38).

Targeted therapy: tyrosine kinase inhibitors (TKIs)

The main treatment for CML is a targeted therapy that uses drugs called tyrosine kinase inhibitors (TKIs). These drugs work by blocking a chemical called tyrosine kinase, which tells the leukaemia cells to divide and grow. Without this signal, the cells die.

TKIs come in tablet form. They include imatinib, dasatinib, nilotinib and ponatinib.

Treatment with TKIs can reduce the number of leukaemia cells growing in your body. However, it can't cure CML in most patients, so you will probably have to continue taking the medicine on a long-term basis and you will need to have regular blood tests (see *Follow-up appointments,* page 42). Some people eventually become resistant to the drugs. In this case, your doctor may switch to another type of TKI to try to control the CML.

All TKIs are well tolerated. However, as with any medicine, each has particular side effects. These side effects may include: fatigue; nausea and vomiting; diarrhoea; skin rashes; facial, hand or leg swelling; anaemia, bruising or infections; and build-up of fluid around the lungs or heart.

Talk to your medical team if you have any of these side effects. Your doctor may be able to prescribe medicine to prevent or reduce them. Sometimes these side effects make it necessary to change the dose of the TKI you are taking or change to a different TKI.

For more information about TKIs and their side effects, visit the Leukaemia Foundation at leukaemia.org.au.

Women who want to become pregnant while receiving treatment for CML should speak to their doctor. Some 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 is treatment with anti-cancer drugs called cytotoxics that kill or slow the growth of the cancer cells.

Most people will be prescribed TKIs as their first treatment for CML. However, some may be given a short course of chemotherapy tablets to get the disease under control before TKI treatment begins.

The chemotherapy tablets commonly given before TKI therapy are called hydroxyurea. The side effects of hydroxyurea may include dry skin, nausea, drowsiness and a small amount of hair loss. Side effects are usually mild, and there are medicines available to help manage them.

For various reasons, a small number of people can't take TKIs. In this case, chronic-phase CML may be treated with a course of hydroxyurea lasting several months.

Different chemotherapy drugs may be given to people who have not responded to TKI therapy or who are preparing for a stem cell transplant (see page 34). These drugs are often given through a vein (intravenously) and tend to be much stronger, so you may need to have the treatment in hospital. The side effects depend on the type of chemotherapy you have.

To find out more, talk to your medical team, call Cancer Council Information and Support on 13 11 20, or contact the Leukaemia Foundation on 1800 620 420.

Other treatments

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

Immunotherapy – Immunotherapy is when the treatment aims to boost the response of your body's immune system to the cancer. The immunotherapy drug interferon alpha was the main form of treatment for CML before TKIs were developed. Although it is not used very often now, some clinical trials use it to see if patients can stop their TKIs.

Interferon alpha is a protein that is produced naturally by the body when it is fighting an infection. It also helps the immune system cells communicate with each other. The drug is a copy of this protein that is made in a lab. It is given as an injection under the skin (subcutaneously). Side effects can include chills, fever, weight loss and fatigue, and are most noticeable after the first few injections. Your doctor may be able to prescribe medicine to manage your side effects.

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

Leukopheresis – An extremely high level of white blood cells can interfere with your organ function. If your white blood cell count is dangerously high – for example, during blast crisis – you may have a procedure called leukopheresis. This will quickly reduce

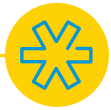
your white blood cell count to a safer level. It is used to control symptoms, and not to treat or cure the disease.

During leukopheresis treatment, 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 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.

Stem cell transplant – This treatment is not often used for CML, but it may be offered to some people with accelerated or blast phase CML who have become resistant to TKI drugs, or to people whose disease is not controlled with chemotherapy. Transplants aren't suitable for everyone, especially older patients. Your doctors will tell you if a transplant might help.

Transplants require immature, blood-forming stem cells to be collected, usually from another person (allogeneic transplant). Stem cells can be taken from the bloodstream (peripheral blood stem cell transplant), bone marrow (bone marrow transplant), or umbilical cord blood (cord blood transplant). Transplants are not done at every hospital, so you may have to travel for treatment.

Your health care team will explain transplant procedures for your situation and possible side effects. There are several stages of treatment, and the entire process may take many months.



For more information on stem cell transplants for CML, contact the Leukaemia Foundation on **1800 620 420** or visit **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. Palliative treatment improves quality of life by alleviating symptoms of cancer without trying to cure the disease. It can be used at any stage of advanced cancer and is not just for end-of-life care. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. It may include blood transfusions, radiotherapy, chemotherapy, targeted therapies or other therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. For free booklets on palliative care or advanced cancer, call Cancer Council 13 11 20 or download digital versions from cancercouncil.com.au.

Key points

- The blood and bone marrow cells of most people with CML have genetic abnormalities. The Philadelphia chromosome contains the BCR-ABL gene, which instructs leukaemia cells to grow.
- To test for CML, a blood sample will be taken with a needle. A small amount of bone marrow may also be removed with a needle (bone marrow biopsy).
- You may have a CT scan or ultrasound, which is a painless scan of the inside of your body.
- Staging helps the doctor determine how far the leukaemia has progressed so they can work out what treatment is best for you.
- Your doctor will talk to you about your prognosis. This is a general prediction about the course of your disease.
- You will be treated with tyrosine kinase inhibitors (TKIs). These are drugs that block a chemical that tells the leukaemia cells to grow.
- You may have anti-cancer drugs (chemotherapy). The side effects depend on what drugs you are given.
- You may also have injections of interferon alpha, a protein that is produced by the body when it is fighting an infection.
- It is rare, but some people may have a stem cell transplant to help destroy the remaining leukaemia cells.
- Palliative care includes treatment that helps improve your quality of life without trying to cure the leukaemia.

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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask your doctor questions – see page 47 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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 may decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in 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.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call 13 11 20 for a free copy of *Understanding Clinical Trials and Research,* or visit australiancancertrials.gov.au.

Looking after yourself

Cancer can cause physical and emotional strain, so it's important to try to look after your wellbeing.

Nutrition – Eating well can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 or visit cancercouncil.com.au for a free copy of the *Nutrition and Cancer* booklet.

Staying active – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

Complementary therapies – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to 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. Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful.

For more information, call 13 11 20 and request a free copy of the *Understanding Complementary Therapies* booklet, or download a digital version from cancercouncil.com.au.

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and fertility

Cancer 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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call 13 11 20 for free copies of *Sexuality, Intimacy and Cancer, Fertility and Cancer* and *Emotions and Cancer,* or download the digital versions from cancercouncil.com.au

Life after treatment

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

Some people say they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

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

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 are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation beyondblue has information about coping with depression and anxiety. Visit **beyondblue.org.au** or call **1300 22 4636** to order a fact sheet.

Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back. Your doctor may want to see you two to four times a year during the first few years.

During these regular check-ups, you will have a physical examination, blood tests and, possibly, chest x-rays and scans. If these tests show no further problems, your appointments will become less frequent. Tell your doctor immediately if you have any health problems or notice new symptoms between check-ups.

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 pages 26–27). This is a requirement of the Pharmaceutical Benefits Scheme (PBS), which covers most of the cost of the TKIs.

What if the leukaemia returns?

In many cases, treatment for CLL or CML will make the symptoms of the leukaemia 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 like imatinib may also have times when their 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.

Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council NSW offers free legal and financial advice for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups –** often held in community centres or hospitals
- **telephone support groups –** facilitated by trained counsellors
- **peer support programs –** match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums –** such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

"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*

Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as to people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role, and other organisations can provide information and support. Carers NSW is a statewide organisation specifically for carers – you can contact them on 1800 242 636 or visit carersnsw.org.au. You can also call Cancer Council 13 11 20 to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet.

Bone marrow and blood donations

One way people can 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 – find out more at **abmdr.org.au**. Many people are eligible to donate blood at the Australian Red Cross Blood Service. Call **13 14 95** or go to **donateblood.com.au**.

Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

Australian

Cancer Council NSW ..... **cancercouncil.com.au**
Cancer Council Australia..... **cancer.org.au**
Cancer Institute NSW..... **cancerinstitute.org.au**
healthdirect Australia..... **healthdirect.gov.au**
Leukaemia Foundation..... **leukaemia.org.au**
Arrow Bone Marrow Transplant Foundation..... **arrow.org.au**
Australian Cancer Trials..... **australiancancertrials.gov.au**

International

American Cancer Society..... **cancer.org**
National Cancer Institute (US)..... **cancer.gov**
Leukemia & Lymphoma Society (US)..... **lls.org**
Macmillan Cancer Support (UK)..... **macmillan.org.uk**
Cancer Research UK..... **cancerresearchuk.org**

Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about chronic leukaemia and its treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of chronic leukaemia do I have?
- What tests do I need?
- What treatment do you recommend and why?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? How much will it affect what I can do?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What side effects should I report?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- What happens if the leukaemia comes back?
- Are there any clinical trials of new treatments?
- Who should I go to for my check-up appointments and how often will I have them?
- Are there any complementary therapies that might help me?
- Will the treatment affect my sex life and fertility?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?

Glossary

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

allogeneic transplant
A transplant where the cells or tissues are taken from one person and given to another.

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

antibody
Part of the body's immune system. Antibodies are proteins made by the blood in response to an invader (antigen) in the body. They help protect against viruses, bacteria and other foreign substances.

antigen
Any substance that causes the immune system to respond. This response often involves making antibodies.

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

blast cells
Immature blood cells belonging to two families – myeloid and lymphoid. Blast cells are called myeloblasts in the myeloid family, and lymphoblasts in the lymphoid family.

bone marrow
The soft, spongy material inside bones. Bone marrow contains stem cells that produce red blood cells, white blood cells and platelets.

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

bone marrow transplant
A type of stem cell transplant that uses healthy stem cells collected from the bone marrow.

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

chemotherapy
A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination 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 immature 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 immature and mature

granulocytes (white blood cells of the myeloid family) are found in the blood and bone marrow.

cytogenetic test
A test that checks whether cells have an abnormality in their chromosomes.

fine needle aspiration
A type of biopsy where a thin needle is inserted into a lump to extract cells.

full blood count (FBC)
A test that measures the number, size and maturity of each type of cell in the blood. Sometimes called a complete blood count.

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.

immunophenotyping
A way of characterising cells by the signals they display on their surface.

immunotherapy
The prevention or treatment of disease using substances that alter the immune system's response. Also called biological therapy.

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

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

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

lymph node
Small structures in the lymphatic system that collect and destroy viruses and bacteria. Also called lymph glands.

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

mini transplant
See reduced intensity stem cell transplant.

monoclonal antibodies
A group of medicines made from proteins that target, attach to and destroy specific diseased cells.

myeloid
One of the two groups 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 granulocytes (a type of white blood cell in the myeloid family).

palliative treatment
Medical treatment for people with advanced cancer to help manage pain and other symptoms. Treatment may include radiotherapy, chemotherapy or other therapies. Part of palliative care.

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

Philadelphia chromosome
An abnormal chromosome associated with chronic myeloid leukaemia. It carries instructions for the body to produce tyrosine kinase, a protein that makes too many white blood cells.

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

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

prognosis
The predicted outcome of a person's disease.

radiotherapy
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

recurrence
The return of a disease after a period of improvement (remission).

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

reduced intensity stem cell transplant
A transplant that uses lower doses of chemotherapy and radiotherapy than normal, so it is easier for the body to tolerate. Also called a mini transplant.

relapse
See recurrence.

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

side effect
Unintended effect of a drug or treatment.

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. Leukaemia can cause an enlarged spleen.

stage
Performing tests to determine how far the leukaemia has progressed.

stem cells
Unspecialised cells from which various types of 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 radiotherapy, 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). The healthy cells also attack the leukaemia directly. This is known as graft-versus-leukaemia.

subcutaneous
Injection under the skin.

targeted therapy
Treatment that attacks specific weaknesses of cancer cells while minimising harm to healthy cells.

thrombocytopenia
Too few platelets in the blood. Can cause bleeding and bruising.

tissue
A collection of cells that make up a part of the body.

tyrosine kinase
A chemical messenger that tells cells when to divide and grow.

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

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

Can't find a word here?

For more cancer-related words, visit the Cancer Council NSW website at cancercouncil.com.au/words.

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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 Pink Ribbon Day, 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 Cancer Council 13 11 20.

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.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).

Interpreter

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

NATIONAL RELAY SERVICE

If you are deaf, or have a hearing or speech impairment, 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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