



# Understanding Acute Leukaemia

A guide for people with cancer,  
their families and friends

Cancer  
information

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**13 11 20**



## **Understanding Acute Leukaemia**

A guide for people with cancer, their families and friends

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*Understanding Acute Leukaemia* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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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](http://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 acute leukaemia: acute myeloid leukaemia (AML) and acute lymphoblastic leukaemia (ALL).

Many people feel shocked and upset when told they have acute leukaemia. We hope this booklet will help you, your family and friends understand how AML and ALL 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 acute leukaemia. It is based on clinical practice guidelines for acute leukaemia.<sup>1,2</sup>

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 book for more details.



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Council  
13 11 20**

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# What is blood cancer?

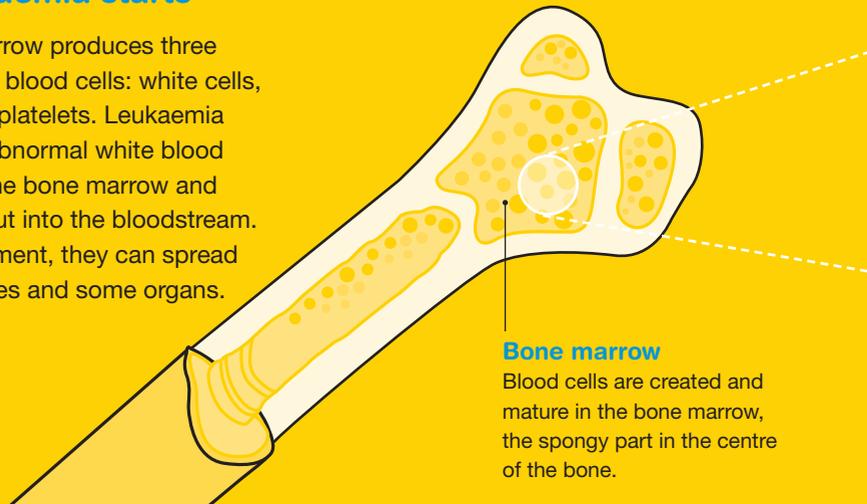
Cancer is a disease of the cells, which are the body's basic building blocks. Our body constantly makes new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury. Normally cells grow and multiply in an orderly way.

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

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

## How leukaemia starts

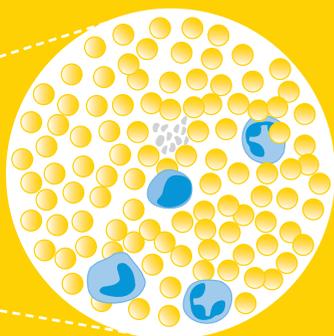
The bone marrow produces three main types of blood cells: white cells, red cells and platelets. Leukaemia starts when abnormal white blood cells crowd the bone marrow and are pushed out into the bloodstream. Without treatment, they can spread to lymph nodes and some organs.



bone marrow'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.

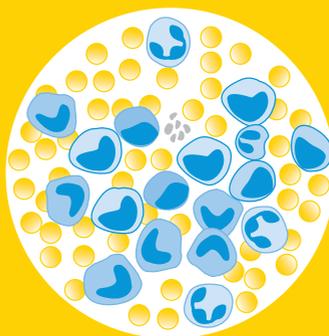
As leukaemia progresses, the bone marrow produces more abnormal blood cells and fewer normal blood cells. As the abnormal blood cells build up in the blood, they can spread to the lymph glands (lymph nodes), spleen, liver, lungs and kidneys. Without treatment, many of the body's key functions will be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

Recent advances in treatment have seen the outlook for people with acute 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.



**Red blood cells**



**White 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. 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.

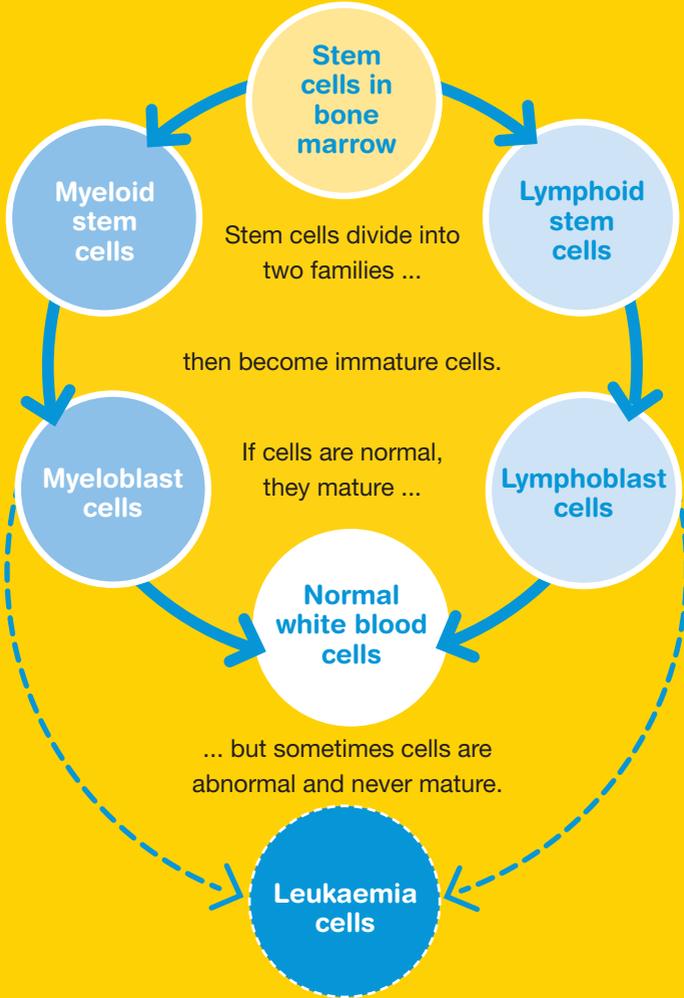
There are two families of stem cells:

- **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 acute leukaemia?

**A:** Acute leukaemia develops when the body makes too many immature white blood cells (blast cells) that multiply out of control and continue to divide but never mature into normal cells. It develops suddenly and progresses quickly.

The abnormal blast cells are known as leukaemia cells. Because they are immature and abnormal, the leukaemia cells don't carry out the usual infection-fighting function of white blood cells. They also crowd out normal white blood cells, which then can't work properly. This increases the risk of infections.

When the bone marrow fills with leukaemia cells, there is little room for healthy red cells and platelets to be produced. This causes a variety of health problems.

### Q: Is it different to chronic 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 (myeloid or lymphoid), whether there are abnormalities in the bone marrow, and how quickly the disease develops.

Acute leukaemia usually affects fully immature cells, occurs suddenly, and develops quickly.

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

Cancer Council NSW also has a separate booklet about chronic leukaemia. For a free copy, call Cancer Council 13 11 20 or visit [cancercouncil.com.au](http://cancercouncil.com.au).

## Q: What are AML and ALL?

**A:** AML and ALL are the two main types of acute leukaemia. The difference between them is in the type of white blood cells that are affected.

### Acute myeloid leukaemia (AML)

pages 16–28

The body has too many of the white blood cells known as myeloid blast cells, also called myeloblasts.

There are different subtypes of AML. This chapter covers risk factors, symptoms and causes. Information about how AML is diagnosed and treated, is covered on pages 16–28.

### Acute lymphoblastic leukaemia (ALL)

pages 29–43

The body has too many of the white blood cells known as lymphoid blast cells, also called lymphoblasts. ALL is also sometimes called acute lymphatic leukaemia.

This chapter covers risk factors, symptoms and causes. Information about how ALL is diagnosed and treated, is covered on pages 29–43.

## Q: What are the risk factors?

**A:** The exact causes of acute leukaemia are not yet understood, but some factors may increase the chance of developing the illness, including:

- previous treatment with chemotherapy or radiotherapy
- having certain genetic disorders such as Down syndrome
- viral infections
- cigarette smoking
- exposure to high levels of radiation (such as an atomic bomb explosion)
- exposure to some chemicals, such as benzene, petroleum products, paints, certain pesticides and heavy metals, over a long period of time.

### 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:** Occasionally, a person will have no symptoms or vague symptoms such as an ongoing cold, and the leukaemia is discovered during a routine blood test. However, many people with AML or ALL find that some of the following symptoms appear quickly over a few weeks.

**Anaemia** – Lack of red blood cells can cause anaemia. Signs of anaemia include a pale complexion, weakness, tiredness and breathlessness.

**Increased bruising and bleeding** – Lack of platelets can cause bruising without a bump or fall (spontaneous bruising), nosebleeds, bleeding gums, heavy periods in women, and small red or purple spots on the skin or mouth (petechiae).

**Repeated or persistent infections** – Lack of normal white blood cells can cause mouth sores, sore throats, fevers, sweats, coughing, boils, infected cuts or scratches, and frequent and painful passing of urine.

**Pain or discomfort** – You may also have pain or discomfort in your abdominal or back area from an enlarged spleen (an organ that filters and stores blood cells, see box on previous page).

**Less common symptoms** – Bone or joint pain, swollen and tender gums, skin rashes, headaches, weight loss, vision problems, vomiting, enlarged lymph nodes, and chest pains.

## Q: How common is it?

**A:** Each year in Australia, more than 3200 adults and 250 children are diagnosed with a form of leukaemia, and about 1311 of these cases are acute leukaemia. Overall, acute leukaemia is rare accounting for about 1.1% of all cancer cases in Australia.<sup>3</sup>

Leukaemia is the most common type of cancer diagnosed in people under 15.

**Acute myeloid leukaemia (AML)** – Most common type of acute leukaemia, with about 950 people diagnosed each year. It is more frequently diagnosed in men. It occurs more often in adults than in children, and becomes more common with age.<sup>4</sup> It generally occurs around age 65.

**Acute lymphoblastic leukaemia (ALL)** – Over 300 people are diagnosed each year. Of these, about 180 are children under 15. It usually occurs in children 1–4 years old.<sup>5</sup>

### Children with acute leukaemia

Children with acute leukaemia have the same types of tests and treatments as adults. Many of the side effects will be similar. This information booklet applies to children, but as no two cases of acute leukaemia are the same, you will need to discuss your child's case in detail with their doctors. For more information, see pages 55–57.

## 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 care. This is called a multidisciplinary team (MDT) and it may include some or all of the health professionals listed below:

Health professional	Role
haematologist*	specialises in treating people with diseases of the blood, the lymphatic system and bone marrow; 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	recommends an eating plan to follow while you're in treatment and recovery
social worker, clinical psychologist	help you with any emotional problems and link you to support services
physiotherapist, occupational therapist	help you with any physical or practical problems associated with cancer and treatment
palliative care team	specialise in pain and symptom control to maximise wellbeing and improve quality of life

\* Specialist doctor



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. Treatment for acute leukaemia usually starts as soon as or shortly after you have been diagnosed, so you may feel that everything is happening too fast.

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 only offers 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 leukaemia, 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 with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask for further explanation – see page 59 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 get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Acute myeloid leukaemia (AML)

This chapter explains how acute myeloid leukaemia is diagnosed, monitored and treated. AML affects the white blood cells called myeloblasts. For introductory information about AML, including its risk factors, symptoms and causes, see the *Key questions* chapter on pages 8–13.

## Diagnosis

A combination of the following tests will help your doctor confirm the diagnosis and determine the type of acute myeloid leukaemia you have.

### Full blood tests

Your doctor will take a sample of your blood and send it to a laboratory for a full blood count (FBC). This will show whether leukaemia cells are present in the blood or whether the levels of the main blood cells are different to what would be expected in a healthy person.

### Bone marrow test

Blood cells grow in your bone marrow, so your doctor may want to check a sample of your bone marrow for signs of leukaemia.

There are two different types of bone marrow tests:

- bone marrow aspiration – the doctor uses a thin needle to remove a small amount of fluid (aspirate) from the bone marrow, usually from the hipbone (pelvic bone)
- bone marrow trephine – the doctor uses a slightly larger needle to remove both a small amount of bone and marrow.

You will be given a local anaesthetic to numb the area or light sedation to help you relax. Pain medicine may make you feel drowsy, so ask a family member or a friend to drive you home afterwards. Although it can take up to 30 minutes to prepare for a bone marrow test, the actual procedure takes only a few minutes.

The bone marrow sample (biopsy) is sent to a laboratory, and a pathologist will view the sample under a microscope to work out the subtype of acute leukaemia. Doctors use this information to suggest the most suitable treatment.

Several types of tests may be done on the biopsy sample.

**Immunophenotyping** – This uses a machine (flow cytometer) to look for certain markers or signals on the surface of the cell. These markers or signals are called antigens.

**Genetic tests (cytogenetic and molecular 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 structure of the leukaemia cells, not in normal cells. The study of these gene changes is called cytogenetics or molecular genetics.

You may be tested for a chromosomal abnormality called FISH (fluorescence in situ hybridisation), or a molecular abnormality called PCR (polymerase chain reaction). The PCR test may also be used during and after treatment to check how well it has worked, and if further treatment is needed.

**Other molecular tests** – Tests to look for molecular abnormalities are becoming more routine. Such tests may include looking for changes in FLT3, NPM1 and CEBPa.

These specialised tests are used to work out the potential benefit of having complex treatments such as a stem cell transplant (see pages 23–25), and the chance of the AML coming back after a period of improvement (recurring).

### **Further tests**

You may have other tests to check your general health, and how well your kidneys, liver and other vital organs are working.

**Chest x-ray** – A chest x-ray is taken to check the heart and lungs, and to see whether there are enlarged lymph nodes in the chest. Enlarged lymph nodes are sometimes seen in AML.

**Lactate dehydrogenase (LDH)** – This enzyme is released into the blood when cells are damaged or destroyed. A blood test can check LDH levels, which will usually be raised in people with AML.

**Serology screening** – This involves a blood test that checks for HIV (human immunodeficiency virus) or hepatitis infection.

**Gated heart pool scan** – This scan is used to see how well the heart is working. A small amount of your blood is taken, mixed with some radioactive material and injected into your body. A special camera takes pictures of the blood being pumped by your heart.

**Lumbar puncture** – Once you have been diagnosed with leukaemia, you may have a lumbar puncture. This test shows if any leukaemia cells have travelled to the fluid around your spine. The fluid is called cerebrospinal fluid (CSF).

A sample of CSF is removed with a thin needle from a space between two bones in the lower back. This process can be uncomfortable, but your doctor will use a local anaesthetic to numb the area. The back of the legs may tingle when the needle goes in. This feeling is harmless and doesn't last long.

You may get a headache after a lumbar puncture. Most spinal headaches improve with time, but ask your doctor for pain relief if it's ongoing. If your doctor thinks the lumbar puncture may be difficult, or if the bones in your spine have degenerated, it can be performed under x-ray guidance.

**CT (computerised tomography) scan** – This scan uses x-rays and a computer to create a detailed cross-sectional picture of the inside of the body. It can show if your lymph nodes are affected and if your spleen is enlarged.

**Ultrasound** – This scan uses echoes from soundwaves to create a picture of organs on a computer.

**MRI (magnetic resonance imaging) scan** – An MRI uses magnetism and radio waves to take detailed cross-sectional pictures. Tell your doctor if you have a pacemaker, as the magnetic waves can interfere with some pacemakers.

## Classification

If a full blood count and a bone marrow test show that you have AML, further tests to identify any faulty genes will help work out the subtype. This is called classification. The World Health Organization classification system divides AML into several groups according to the type of myeloid cell that has become abnormal and whether:

- there are particular genetic (chromosomal) changes in the leukaemia cells
- the leukaemia developed from a particular blood disorder called myelodysplasia
- more than one type of blood cell has abnormal changes.

## 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 subtype of AML you have.

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 your test results, particularly those that show the genetic make-up of the leukaemia cells, predict how you may respond to treatment.

Test results, the rate and extent of leukaemia cell growth, how well you respond to treatment, and other factors such as age, fitness and medical history are all important factors in assessing your prognosis. For many people, treatment can reduce the symptoms of acute leukaemia for years. This is known as remission.

## Treatment

Treatment usually begins as soon as a diagnosis has been made, and will depend on the subtype of AML, the genetic make-up of the leukaemia, your general health and your age.

Chemotherapy is the main treatment. Other treatments may be recommended depending on the type of leukaemia you have and how you respond to chemotherapy. These may include stem cell transplant or radiotherapy. The aim of treatment is to destroy the leukaemia cells and allow the bone marrow to return to normal functioning.

## Chemotherapy

Chemotherapy uses anti-cancer drugs called cytotoxics to kill leukaemia cells or slow their growth. Usually treatment for AML is given in two phases (see next page).

**Side effects** – The drugs will mainly kill fast-growing cells, such as leukaemia cells. However, other fast-growing cells, such as hair follicles, blood cells, and cells inside the mouth or bowel, can also be affected. This can cause side effects such as hair loss, increased infection risk, mouth ulcers, nausea, vomiting, constipation or diarrhoea. For more information, see the *After chemotherapy* chapter on pages 44–47.

“ 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. ” *Judy*

## Phases of chemotherapy treatment for AML

Treatment for AML is given in two phases: induction and consolidation.

### 1 Induction chemotherapy

- Aims to achieve a remission. You'll have an intensive course of 3–4 chemotherapy drugs that is given over a week. You usually stay in hospital for 4–6 weeks.
- Drugs are often administered via a PICC (peripherally inserted central device) inserted into a vein in the upper arm. The PICC will be put in place under a general or local anaesthetic, and then left in throughout the induction phase. This makes having regular injections more comfortable. The PICC can also be used to take blood samples for testing.
- As the leukaemia cells die, they release a chemical called uric acid. This can build up and damage the kidneys, but can be controlled with allopurinol tablets.
- You'll have a bone marrow biopsy to see how well the treatment has worked.

### 2 Consolidation chemotherapy

- Used after remission is achieved to kill any cells that may have survived induction chemotherapy and to stop AML returning (recurring).
- It is milder than induction chemotherapy and may cause fewer side effects.
- You may be given a similar combination of chemotherapy drugs used in induction therapy, at the same or higher dose.
- Depending on the types of drugs used, you usually stay in hospital for three weeks or more.
- You may have 2–3 cycles of consolidation treatment.

## Stem cell transplant

Transplants require immature, blood-forming stem cells to be collected. 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).

Stem cells are collected in two different ways:

- allogeneic transplants (collected from another person) – these are used more often for AML, but are not suitable for everyone, especially older people. This is because of the risks involved and the difficulty finding a compatible donor. A matched donor could be a relative or an unrelated donor via the Australian Bone Marrow Donor Registry (ABMDR). The process is described on pages 24–25.
- autologous transplants (collected from your own body) – these are rarely used as a treatment for AML.

## Azacitidine treatment

If you're not suitable for a stem cell transplant, you may be offered a low-dose chemotherapy drug called azacitidine. This is given by injection under the skin for 7 days. In some cases, this can be split into 5 days and 2 days to allow for a weekend break. This cycle is repeated every 28 days for at least six cycles. Before each cycle, you will have a blood test to check your blood count has returned to normal. If it is too low, the next cycle may be delayed.

**Side effects** – Common side effects include constipation and diarrhoea, which can be controlled with medicines. The injection site will be changed frequently to avoid infection.

## Stem cell transplant steps

A general allogeneic transplant process is described here, but the process varies from person to person. More detailed information is available from [leukaemia.org.au](http://leukaemia.org.au).

### 1 Collecting stem cells

- The first stage is to collect a supply of stem cells.
- If the stem cells are being collected from the blood, the donor may be given a growth factor drug called granulocyte-colony stimulating factor (G-CSF). This helps stem cells multiply quickly and move out of the bone marrow and into the blood.
- Growth factor drugs are taken for 5–10 days.
- When enough stem cells have been made, they may be collected from the blood via a process called apheresis (see step 2).
- If the stem cells are being collected from the bone marrow, the donor is given a general anaesthetic and a needle is inserted into their pelvic bone to remove the marrow.

### 2 Separating and storing stem cells

- Apheresis usually involves inserting a needle called a cannula into a vein in each arm. Blood is taken from the donor's body through one of the cannulas and passed through a machine called a cell separator. The stem cells are removed and the rest of the blood is returned to the donor through the other cannula.
- This continuous process takes 2–4 hours. The stem cells are processed and frozen using liquid nitrogen (cryopreserved).
- If stem cells are collected at another hospital or imported from another country, they are transported at a set temperature to keep them alive and in good condition for transplant (viable).

### 3 Having chemotherapy or radiotherapy

- Before the transplant, you will have high-dose chemotherapy or total body irradiation (see page 27). These treatments aim to destroy any remaining cancer cells in your body, and kill off the blood-forming cells in your bone marrow, making room for new cells to grow.
- Common side effects include nausea, mouth sores or hair loss. Because your stem cells have been destroyed, your blood count will also be low, making you more at risk of infections.
- For more detailed information, see the *After chemotherapy* chapter on pages 44–47.

### 4 Transplanting stem cells and engraftment

- A day or so after high-dose chemotherapy or total body irradiation, the donor's stem cells are returned to you (infused) through a cannula or via an intravenous drip. This is similar to a blood transfusion.
- The process takes about an hour. You may have stomach cramps and feel nauseous, which can be managed with medication.
- Over the next couple of weeks, your stem cells will develop into new blood cells, allowing your bone marrow to recover. This is called engraftment and takes about 10–14 days.
- You'll be given drugs to reduce the risk of the transplanted cells attacking your own cells. This is called graft-versus-host disease (GVHD) and you will be given drugs to reduce the risk.

## Treatment for APML

Treatment for a subtype of AML called acute promyelocytic leukaemia (APML) is different from most AML treatment. In APML, the leukaemia cells are immature myeloid cells called promyelocytes. Treatment is given in three phases.

**Induction phase** – A drug called all-trans retinoic acid or ATRA, which is based on vitamin A, is the main type of induction treatment. It's not a chemotherapy drug, but it may be given with chemotherapy. ATRA makes immature promyelocytes mature, so they are no longer leukaemia cells. It is taken as a tablet.

People with APML who don't respond to ATRA may be offered a chemotherapy drug called arsenic trioxide. This is given as a daily intravenous injection for 60 days. You will also have regular echocardiography (ECG tracing of the heart) and blood tests to monitor potassium levels and other electrolytes in the blood.

**Consolidation phase** – ATRA and arsenic trioxide induce a remission in most people. Further cycles of chemotherapy will be given 1–2 weeks after induction chemotherapy ends, particularly if your white cell count is high. This phase, known as consolidation, may last a number of months. It aims to prolong remission.

**Maintenance phase** – Some people then have more chemotherapy as maintenance treatment for two years or more.

**Side effects** – Common side effects of ATRA and arsenic trioxide include headaches and feeling sick (nausea).

## Radiotherapy

Radiotherapy uses radiation such as x-rays to kill cancer cells or injure them so they cannot multiply. It is sometimes used to treat AML that has spread, or is likely to spread, to the brain and spine. Radiotherapy is also sometimes given to the whole body (total body irradiation) before a stem cell transplant – see page 25. Your radiation oncologist and haematologist will discuss with you the type of radiotherapy and number of treatments you will need.

**Side effects** – The most common side effects include tiredness, dry or itchy skin and hair loss from your body and head. Most side effects are temporary and there are ways to reduce discomfort.

## Palliative treatment

Palliative treatment helps to improve quality of life by alleviating symptoms of cancer. 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 chemotherapy and/or radiotherapy.

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.

Cancer Council produces free booklets on radiotherapy, palliative care and advanced cancer. Call **13 11 20** for printed copies, or download digital versions from [cancercouncil.com.au](http://cancercouncil.com.au).





## Key points

- Several different types of tests are used to diagnose acute myeloid leukaemia (AML).
  - it's an autologous transplant. An allogeneic transplant is used most commonly for AML.
- You will have a full blood count to check if leukaemia cells are in your blood.
- Transplants are not available at every hospital, so you may have to travel for treatment.
- Some people have a bone marrow biopsy. This means a small amount of bone marrow is removed from your hipbone with a needle.
- Radiotherapy treats cancer using radiation beams to kill cancer cells. It is painless but it may cause tiredness, dry or itchy skin, and hair loss.
- You will have treatment with chemotherapy, which is usually given intravenously.
- A subtype of AML called acute promyelocytic leukaemia (APML) is treated differently. All-trans retinoic acid (ATRA), a derivative of vitamin A, and arsenic trioxide, a chemotherapy drug, may be used.
- Chemotherapy is given in two phases – first as an intensive treatment (induction chemotherapy), then it is used to kill any leftover cancer cells (consolidation chemotherapy).
- Palliative treatment may be used to improve a person's quality of life without trying to cure the cancer. It is part of palliative care.
- Some people have a stem cell transplant. If the stem cells are from a donor, it's an allogeneic transplant. If the stem cells are collected from your own body,



# Acute lymphoblastic leukaemia (ALL)

This chapter explains how acute lymphoblastic leukaemia is diagnosed, monitored and treated. ALL affects the white blood cells called lymphocytes. For introductory information about ALL, including its symptoms and causes, see the *Key questions* chapter on pages 8–13.

## Diagnosis

A combination of the following tests will help your doctor confirm the diagnosis and determine the type of acute lymphoblastic leukaemia you have.

### Full blood count

Your doctor will take a blood sample and send it to a laboratory for a full blood count (FBC). This will show whether leukaemia cells are present in the blood or whether the levels of blood cells are different to what would be expected in a healthy person.

### Bone marrow test

If the blood test shows abnormalities in the number or appearance of the white blood cells, your doctor may want to check a sample of your bone marrow for signs of leukaemia. This is because blood cells grow in your bone marrow. There are two different types of bone marrow tests:

- bone marrow aspiration – the doctor uses a thin needle to remove a small amount of fluid (aspirate) from the bone marrow, usually from the hipbone (pelvic bone)
- bone marrow trephine – the doctor uses a slightly larger needle to remove both a small amount of bone and marrow.

Bone marrow tests can be uncomfortable and, at times, painful. You will be given a local anaesthetic to numb the area or light sedation to help you feel relaxed. Children often have a general anaesthetic for this procedure.

Although it can take up to 30 minutes to prepare for the bone marrow test, 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 (biopsy) is sent to a laboratory, and a pathologist will view the sample under a microscope for chromosome and molecular changes. This information will help them work out the subtype of acute leukaemia. Doctors use the results of these tests to suggest the most suitable treatment. The biopsy may be repeated at the start and end of each course of treatment to see how well the treatment is working.

The following tests may be done on the biopsy sample.

**Immunophenotyping** – This uses a machine (flow cytometer) to look for certain markers or signals (antigens) on the surface of the cell. This test can indicate the subtype of ALL you have and determine the type of lymphocyte cell (B-cell or T-cell) in which the leukaemia cells originated. This test can be repeated during and after treatment to look for any small amounts of leukaemia.

**Genetic tests (cytogenetics and molecular 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 on your leukaemia cells, not on normal cells. The study of these gene changes is called cytogenetics or molecular genetics. Cytogenetic tests are usually done on cells from your blood or bone marrow, before treatment starts.

Some people with ALL may have an abnormal chromosome called the Philadelphia chromosome. This 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.

### 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.

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.

This 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.

Some people with ALL may be treated with drugs to block tyrosine kinase (see page 38).

## Other genetic tests

Tests to look for other chromosomal and molecular abnormalities are becoming more routine. You may be tested for a chromosomal abnormality, including:

- FISH (fluorescence in situ hybridisation) – this can find changes that can't be seen with cytogenetic testing
- PCR (polymerase chain reaction) – this looks for specific changes in the DNA of your blood cells. Doctors use the PCR test to see how well you've responded to treatment and to plan whether you need further treatment, and what type.

## Further tests

Other tests provide information on your general health, and how well your kidneys, liver and other vital organs are working.

**Chest x-ray** – A chest x-ray is taken to check the heart and lungs, and to see whether there are enlarged lymph nodes in the chest. Enlarged lymph nodes are sometimes seen in ALL.

**Lumbar puncture** – Once you have been diagnosed with leukaemia, you may have a lumbar puncture. This test shows if any leukaemia cells have travelled to the fluid around your spine. The fluid is called cerebrospinal fluid (CSF).

CSF is removed from a space between the bones in the lower back with a thin needle. This takes only a few minutes, but as it can be uncomfortable, your doctor will use a local anaesthetic to numb the area. In some people, the back of the legs may tingle when the needle goes in. This is harmless and doesn't last long.

You may get a headache after a lumbar puncture. This usually improves without treatment, but ask your doctor for pain relief if it's ongoing. If your doctor thinks the lumbar puncture may be difficult, or if the bones in your spine have degenerated, it can be performed under x-ray guidance.

**Imaging tests** – These tests may be used to learn more about what is causing your symptoms or to help diagnose infections.

- CT (computerised tomography) scan – uses x-rays to make detailed cross-sectional pictures of the inside of your body
- MRI (magnetic resonance imaging) – uses magnetism and radio waves to create detailed cross-sectional pictures of areas inside the body.

## Classification

Doctors divide ALL into subtypes. This is called classification. It helps them to plan treatment and work out prognosis.

The World Health Organization classification system divides ALL into several subtypes according to the type of lymphocyte that has become abnormal (B-cell or T-cell) or whether the Philadelphia chromosome is present. The tests described on pages 30–32 look for these changes.

Some people have a type of leukaemia called biphenotypic acute leukaemia, also called ambiguous lineage leukaemia or, simply, acute leukaemia. This means the disease has characteristics of both ALL and acute myeloid leukaemia (AML).

## 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.

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 can predict how the acute leukaemia may respond to particular forms of treatment.

Test results, the exact type of ALL, whether you have certain changes in the genes (including the Philadelphia chromosome), your white cell count, and other factors such as age, fitness and medical history are all important factors in assessing your prognosis. Your doctor will also look at how quickly the initial treatment controlled the leukaemia (achieved remission).

For many people, treatment can achieve remission that lasts for years. However, some will have a recurrence due to a small number of cancer cells being left behind. This is known as minimal residual disease or MRD. Doctors can measure a person's MRD to determine risk of recurrence and the need for more treatment.

Techniques used to find MRD include:

- immunophenotyping – tests for antigens made by leukaemia cells (see page 30)
- PCR – looks for genetic changes in cells (see page 32).

For more information on further treatment options, see page 51.

## Treatment

Treatment usually begins as soon as a diagnosis has been made, and will depend on what type of ALL you have. Chemotherapy is the main treatment. Other treatments may be recommended depending on how you responded to chemotherapy. These may include radiotherapy, steroid therapy, or a stem cell transplant.

## Chemotherapy

Chemotherapy uses anti-cancer drugs called cytotoxics to kill leukaemia cells or slow their growth. Treatment is given in three main phases and can take up to 2–3 years to complete. During the first two phases, induction and consolidation, you will probably need to stay in hospital for several weeks. The length of time will depend on any side effects you experience. The process is described on pages 36–37.

Chemotherapy can be given in different ways. You'll have several different chemotherapy drugs in various combinations in each phase of treatment. Some drugs are given into a vein (intravenously) and others are given as a tablet. Some chemotherapy drugs are given into the fluid around the spine. This is called intrathecal chemotherapy – see page 38 for more information.

**Side effects** – Chemotherapy drugs mainly kill fast-growing cells, such as leukaemia cells. However, other fast-growing cells, such as hair follicles, blood cells, and cells inside the mouth or bowel, can also be affected. This can cause hair loss, increased infection risk, mouth ulcers, nausea, vomiting, constipation or diarrhoea. See the *After chemotherapy* chapter on pages 44–47.

## Phases of chemotherapy treatment for ALL

Treatment for ALL is given in three phases: induction, consolidation and maintenance.

### 1 Induction chemotherapy

- The aim of induction chemotherapy is to bring about (induce) remission. This means leukaemia cells are no longer found in bone marrow samples, the normal marrow cells return and blood counts become normal.
- You'll have an intensive course of 3–4 drugs that is given at frequent intervals over about 4 weeks, and you'll need to stay in hospital during this time.
- Drugs are often administered via a central venous access device (CVAD) inserted into a vein in your upper arm. The CVAD will be put in place under a general or local anaesthetic and then left in throughout treatment. This makes regular injections more comfortable. The CVAD can also be used to take blood samples for testing.
- Different types of plastic tubing, called lines, may be used with the CVAD. Nurses will care for the line to prevent infections or blockages.
- As the leukaemia cells die, they release a chemical called uric acid. This can damage the kidneys, but can be controlled with tablets.
- You will have a bone marrow biopsy (see pages 16–17) to check how well the chemotherapy drugs have worked. If no leukaemia cells are visible, this is called remission.
- If the biopsy shows that there are still leukaemia cells in the bone marrow, you may be given more chemotherapy, at similar or higher doses.

## 2 Consolidation chemotherapy

- This is also called post-remission therapy or intensification.
- After remission is achieved, you will have several courses of chemotherapy to kill any cells that may have survived the first treatment and to stop ALL coming back and/or spreading to the central nervous system.
- This phase is milder than induction chemotherapy and will cause fewer side effects.
- The type of chemotherapy drugs you are offered will depend on your risk of recurrence.
- Depending on the types of drugs used, you will either visit the hospital for treatment as an outpatient or stay in hospital for one or more nights.
- If the chance of recurrence is high, you may be offered further induction chemotherapy or a stem cell transplant (see pages 24–25).
- This phase lasts 4–6 months.

## 3 Maintenance chemotherapy

- The aim of maintenance chemotherapy is to prolong remission and prevent the leukaemia from recurring.
- It is given as tablets, taken either daily or weekly.
- You may also have intravenous chemotherapy and/or be offered steroids (see pages 40–41).
- Maintenance chemotherapy is usually given as an outpatient. You may need to be admitted to hospital for some types of chemotherapy drugs.
- This phase usually lasts between 18 months and 2 years.

## Other treatments

**Intrathecal chemotherapy** – Some people with ALL have leukaemia cells in their spine at the time of diagnosis. In other people, the leukaemia cells spread to the spine after remission. Chemotherapy drugs given intravenously or as tablets cannot get into the fluid around the spine, so the drugs need to be injected directly into the spinal area using a lumbar puncture. This is called intrathecal chemotherapy. See pages 32–33 for information about a lumbar puncture.

**Tyrosine kinase inhibitors (TKIs)** – This is a type of targeted therapy. 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 are often used to treat Philadelphia chromosome positive ALL (see page 31).

TKIs come in tablet form, such as imatinib and dasatinib. Side effects may include: fatigue; nausea and vomiting; diarrhoea; skin rashes; facial, hand or leg swelling; and anaemia, bruising or infections.

**Monoclonal antibodies** – Monoclonal antibodies target specific proteins on the surface of the cells. They destroy the leukaemia cells by triggering the body's immune system to attack the leukaemia cells and can cause the cells to kill themselves.

Blinatumomab is a type of monoclonal antibody. It may be given as a drip into a vein (intravenously) or as an injection under the skin (subcutaneously). It may be given on its own or with chemotherapy.

## Radiotherapy

Radiotherapy uses radiation such as x-rays to destroy cancer cells or injure them so they cannot multiply. It is sometimes used to treat ALL that has spread, or is likely to spread, to the cerebrospinal fluid in and around the brain and spine. Radiotherapy is also sometimes given to the whole body (total body irradiation) before a stem cell transplant. The transplant process is described on pages 24–25.

Treatment is carefully planned to make sure as many cancer cells as possible are destroyed while causing the least possible harm to normal tissue. If you are having radiotherapy to the brain you will be fitted for a mask. This keeps your head still during treatment. Your radiation oncologist and haematologist will discuss the type of radiotherapy and the number of treatments you will need.

**Side effects** – Radiotherapy most commonly causes tiredness, dry or itchy skin, and hair loss from your body and head. These are temporary and there are ways to reduce discomfort.

Total body irradiation will cause reduced sperm production in men and early menopause in premenopausal women. This means you will not be able to have a child (infertility). Speak to your doctor before treatment starts about your options for preserving fertility. These are also outlined in Cancer Council's *Fertility and Cancer* booklet. For more information about radiotherapy, its side effects and how to manage them, call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*, or download a digital version from [cancercouncil.com.au](http://cancercouncil.com.au).

## Steroids

Steroids (also known as corticosteroids) are made naturally in the body. They can also be produced artificially and used as a drug. Steroids are often given with chemotherapy to help destroy leukaemia cells or to reduce allergic reactions to some chemotherapy drugs.

The most commonly used steroids for ALL include prednisolone and dexamethasone. Steroids are usually given as tablets. They are often taken for a few weeks, but sometimes need to be taken for several months.

**Side effects** – These will vary depending on how long you have to take steroids. Most are temporary and will gradually disappear when you stop taking the drugs. Your medical team will monitor your progress, but if you are concerned about particular side effects talk to your doctor or medical team.

Steroids prescribed for a short time cause few side effects. Steroids taken for several months may cause more side effects, including:

- hyperactivity
- difficulty sleeping
- mood changes
- increased appetite and weight gain
- heartburn
- high blood pressure
- high blood glucose levels
- fluid retention – this can make your eyelids, face, hands, fingers and feet puffy, and may blur your vision.

Take steroids in the morning with food or milk. This will reduce the risk of sleeplessness at night and irritation to your stomach. Some steroids can affect blood sugar levels, so people with diabetes will need to monitor their blood sugars more often and may need to have their diabetes medicines adjusted. Discuss these changes with your GP. You can also call Diabetes Australia on 1300 136 588 to talk to a diabetes educator.

If used for a long period, steroids may cause diabetes and contribute to thinning of the bones (osteoporosis).

## Stem cell transplant

Transplants require immature, blood-forming stem cells to be collected, usually from another person (allogeneic transplant). Transplants that use cells collected from your own body are called autologous. 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).

Allogeneic transplants are used more often for ALL, but are not suitable for some patients because of the risks involved and the difficulty finding a compatible donor. Autologous transplants are rarely used as a treatment for ALL. Your doctor will tell you if a transplant might help, and which type is suitable.

The stem cell transplant process is described in more detail on pages 24–25. You may also want to call the Leukaemia Foundation on 1800 620 420 or visit their website at [leukaemia.org.au](http://leukaemia.org.au), or visit the Australian Bone Marrow Donor Registry website, [abmdr.org.au](http://abmdr.org.au).

## Recovery

The time it takes to recover varies depending on your situation. You can go home from hospital when your white blood count has risen and becomes stable, and your general health has improved.

## Palliative treatment

Palliative treatment helps to improve quality of life by reducing 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 chemotherapy and/or radiotherapy.

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 more details, call Cancer Council 13 11 20 for free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*, or download digital versions from [cancercouncil.com.au](http://cancercouncil.com.au).



## Key points

- Several different types of tests are used to diagnose acute lymphoblastic leukaemia (ALL).
- You will have a full blood count to check if leukaemia cells are in your blood.
- Some people have a bone marrow biopsy. This means a small amount of bone marrow is removed from your hipbone with a needle.
- If you have ALL, your doctor may remove some fluid from your lower spine (lumbar puncture). This shows if any leukaemia cells have travelled to the fluid around your spine.
- You will have treatment with chemotherapy, which is usually given intravenously. If the cancer is in your spine, drugs will be injected into this area (intrathecal chemotherapy).
- Chemotherapy is given in three phases – first as an intensive treatment (induction chemotherapy), then to kill any leftover cancer cells (consolidation chemotherapy). The final phase is chemotherapy in low doses to prolong remission (maintenance chemotherapy).
- Some people have a stem cell transplant. Stem cell transplants aren't suitable for everyone. Your doctor will let you know if this is an option.
- Transplants are not available at every hospital, so you may have to travel for treatment.
- Radiotherapy treats cancer using radiation to kill cancer cells. It is painless but it may cause tiredness, dry or itchy skin, and hair loss.
- Palliative treatment may be used to improve a person's quality of life without trying to cure the cancer. It is part of palliative care.



## After chemotherapy

Chemotherapy drugs affect both cancerous cells and healthy fast-dividing cells in your body. This can cause side effects such as digestive problems, nausea, mouth ulcers, headaches, hair loss and fatigue. Side effects vary depending on the types of drugs given, but most are temporary and there are ways to prevent or reduce them.

Before treatment, discuss potential side effects and how to manage them with your haematologist. Tell your treatment team about your side effects or anything unusual you experience. They may change or prescribe a break in your treatment, or give you medication to relieve these side effects. The side effects discussed in this chapter are common in people who are having treatment for acute leukaemia.



Check with your doctor before using aspirin, ibuprofen or other pain medicines, including herbal medicines. These may affect how chemotherapy works in your body and may make side effects worse.

### **Easy bruising or heavy bleeding from cuts or scrapes –**

Chemotherapy can lower the number of platelets in your blood, which means you will bruise and bleed more easily from cuts and scrapes. Women who are menstruating will be given drugs to stop monthly periods and prevent any unnecessary blood loss while platelet counts are low. Your doctor may recommend you have a platelet transfusion to help elevate your platelet count.

**Increased risk of infections –** Chemotherapy drugs lower your normal white blood cell count. See opposite page.

## 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 can make 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 are well before visiting. Of course, this is not practical for people you live with, so try to minimise close contact while they are unwell.

Good food hygiene is important for everyone. 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 immediately if you experience:

- fever over 38°C
- chills or constant shivering
- sweating, especially at night
- burning or stinging when urinating
- severe cough
- 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.

**Changed bowel habits** – Hard, dry bowel movements (constipation) can be caused by chemotherapy and other types of medicines prescribed during treatment. Speak to your doctor if you are constipated, as it is important to act early to prevent potential complications. They may suggest you eat more fibre or prescribe some laxatives.

**Fatigue** – The level of your red blood cells may drop, causing you to feel tired and breathless (anaemia). You may be given blood transfusions for this. Some people feel tired for weeks or months.

**Dental problems** – Lowered immunity can cause tooth or gum problems. Have regular dental check-ups, but talk to your haematologist before you have any major dental work.

**Nerve and muscle effects** – Some chemotherapy drugs can cause tingling ('pins and needles'), pain or loss of sensation in your fingers and/or toes, and muscle weakness in your legs. This is called peripheral neuropathy.

If you experience these side effects, tell your doctor or nurse before your next treatment. Your treatment may need to be changed or the problem may need to be carefully monitored.

For many people, peripheral neuropathy is a short-term issue, but for others, it can last a long time or even be permanent.

**Hair loss** – Hair loss is a common side effect of some chemotherapy drugs and is usually temporary.

Some people find it better to cut their hair short when it starts to fall out. Wear some form of head covering to avoid being cold and to protect your head from direct sunlight.

Look Good Feel Better runs free programs for women, men and teenagers on how to manage the appearance-related side effects of cancer treatments. Call 1800 650 960 or visit [lgfb.org.au](http://lgfb.org.au) to book into a workshop.

For more detailed information about chemotherapy and managing other side effects such as nausea, mouth sores and hearing changes, see Cancer Council's *Understanding Chemotherapy* and *Nutrition and Cancer* booklets at [cancercouncil.com.au](http://cancercouncil.com.au).

**Infertility** – Some women's periods become irregular during treatment, but return to normal when it finishes. For other women, chemotherapy and total body irradiation may cause periods to stop permanently (menopause). Menopausal women can no longer conceive a child naturally. Early menopause may also cause bones to become weaker and break more easily. This is called osteoporosis.

In men, chemotherapy may lower the number of sperm produced and reduce their ability to move. This can cause infertility, which may be temporary or permanent. Total body irradiation can also reduce sperm production. Talk to your doctor about infertility before treatment starts. For more information, call 13 11 20 and request a copy of *Fertility and Cancer*, or download a digital version from [cancercouncil.com.au](http://cancercouncil.com.au).



# Looking after yourself

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

**Nutrition** – Eating healthy food 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 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 details 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 for a free copy of the *Understanding Complementary Therapies* booklet, or download a digital version from [cancercouncil.com.au](http://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** or visit [cancercouncil.com.au](http://cancercouncil.com.au) for free copies of *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*.



## 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 that 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](http://beyondblue.org.au) has information about coping with depression and anxiety. Visit [beyondblue.org.au](http://beyondblue.org.au) or call **1300 22 4636** to order a fact sheet.

## Follow-up after treatment

After your treatment, you will need regular check-ups to confirm that the leukaemia hasn't come back. At first, check-ups may be every few weeks, but will become less frequent if you have no further problems. During these regular check-ups, you will have a physical examination, blood tests and, possibly, chest x-rays and scans. Sometimes a bone marrow test will be done to check whether there are any cancer cells in your bone marrow.

Between follow-up appointments, tell your doctor immediately if you have any health problems or notice any new symptoms.

## What if the leukaemia returns?

For some people, leukaemia does come back (recur) after the initial treatment.

Leukaemia may be found in the bone marrow again or, for those with acute lymphoblastic leukaemia (ALL), in the fluid around the brain and the spinal cord. For men, leukaemia cells may also be found in their testicles. Having regular check-ups means tests may detect a recurrence before there are symptoms. Detecting a recurrence early offers the best chance for successful treatment.

If you have a recurrence, further treatment can usually be given to control the leukaemia and this may lead to a second remission. You may have a different combination of chemotherapy drugs to those you were given before. If you did not have a bone marrow or stem cell transplant before, and you meet the criteria, your 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 you 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 services 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 feel 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 open and honest because they aren't trying to protect 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](http://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 people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway – visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737. Carers NSW, a statewide organisation specifically for carers, can also provide support – visit [carersnsw.org.au](http://carersnsw.org.au) or call 1800 242 636. You can also call Cancer Council 13 11 20 to find out more about carers' services and to request 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 acute leukaemia is by becoming a bone marrow donor. Bone marrow donors are usually related, but sometimes donors are matched through the Australian Bone Marrow Donor Registry. Visit [abmdr.org.au](http://abmdr.org.au) for more information.

## Children with acute leukaemia

If your child has been diagnosed with acute leukaemia, the following sections may help you, your child and other family members communicate with each other and cope during this difficult time.

There are many resources that may be useful:

- Hospital staff may specialise in working with children (paediatrics) and can offer valuable advice and support.
- Some hospitals and treatment centres employ play therapists, music therapists or art therapists who work with children.
- Organisations such as CanTeen, Camp Quality, Redkite and the Leukaemia Foundation offer practical and emotional support for families and children, camps for children and other services. See page 58 for website details.
- The Leukaemia Foundation has several booklets for children about leukaemia. Download them from [leukaemia.org.au](http://leukaemia.org.au), or call 1800 620 420.

### Should I tell my child?

It is natural to want to protect your child from the news of the diagnosis, but children often pick up that something is wrong. Your child may not be feeling well or may wonder why they are seeing the doctor so frequently.

Talking openly and honestly about the leukaemia will help your child feel less anxious and more in control of the situation. What you tell your child depends on how old they are and how much they understand. See pages 56–57 for suggestions.

## What should I tell my child?

The following is a guide to what a child understands about cancer and how you might discuss the diagnosis.

### Newborns, infants and toddlers, 0–2 years



Children this young don't understand illness but will react to being separated from you and to changes in routine. Although they may not be able to talk about it, they often pick up on physical and emotional changes.

- ✓ Create a familiar environment that can travel with the child, such as their travel cot and favourite blanket and toys.
- ✓ Be honest about hospital trips and explain tests that may hurt.
- ✓ Give your toddler choices where possible, e.g. "Would you like to wear the red t-shirt or the blue t-shirt to hospital?"

### Preschool children, 3–5 years



Children in this age group are beginning to understand the difference between being well and being sick. They often believe their actions can make things happen. They will want to know how the cancer relates to them.

- ✓ Assure your child they have not caused the illness by their behaviour or thoughts.
- ✓ Explain tests and treatments might hurt, but reassure them that you will be there.



**Further information:** Call Cancer Council **13 11 20** for a free copy of *Talking*

### Young schoolchildren, 6–12 years



By this age, some children know about cancer, but do not know its causes. They may fill in the gaps with their own theories. They can understand what cancer cells are. They need regular reassurance that they will be cared for.

- ✓ Be open and truthful so they don't fill in the gaps with their own interpretations.
- ✓ Tell the school about your child's cancer, and work with the school to maintain schoolwork when possible.
- ✓ Call Cancer Council **13 11 20** for a copy of *Cancer in the School Community*.

### Teenagers, 13–18 years



Many teenagers have an adult understanding of cancer and often want detailed information. They are starting to separate from the family. This is a vulnerable time, as they don't want to appear different from their peers.

- ✓ Encourage teenagers to talk about their feelings, but realise they may find it easier to confide in friends, teachers or other trusted people.
- ✓ Provide some support and information resources.

to *Kids About Cancer*, or download a digital version from [cancercouncil.com.au](http://cancercouncil.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

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Cancer Council NSW .....	<a href="http://cancercouncil.com.au">cancercouncil.com.au</a>
Cancer Australia .....	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Cancer Institute NSW .....	<a href="http://cancerinstitute.org.au">cancerinstitute.org.au</a>
Department of Health .....	<a href="http://health.gov.au">health.gov.au</a>
healthdirect Australia .....	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
beyondblue .....	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Cancer Connections .....	<a href="http://cancerconnections.com.au">cancerconnections.com.au</a>
Carer Gateway .....	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Carers NSW .....	<a href="http://carersnsw.org.au">carersnsw.org.au</a>
Arrow Bone Marrow Transplant Foundation .....	<a href="http://arrow.org.au">arrow.org.au</a>
Australasian Leukaemia & Lymphoma Group .....	<a href="http://allg.org.au">allg.org.au</a>
Australian Bone Marrow Donor Registry .....	<a href="http://abmdr.org.au">abmdr.org.au</a>
Australian Cancer Trials .....	<a href="http://australiancancertrials.gov.au">australiancancertrials.gov.au</a>
Australian New Zealand Clinical Trials Registry .....	<a href="http://anzctr.org.au">anzctr.org.au</a>
Camp Quality .....	<a href="http://campquality.org.au">campquality.org.au</a>
CanTeen .....	<a href="http://canteen.org.au">canteen.org.au</a>
Leukaemia Foundation .....	<a href="http://leukaemia.org.au">leukaemia.org.au</a>
Redkite .....	<a href="http://redkite.org.au">redkite.org.au</a>

## International

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American Cancer Society .....	<a href="http://cancer.org">cancer.org</a>
Leukemia & Lymphoma Society (US) .....	<a href="http://lls.org">lls.org</a>
Macmillan Cancer Support (UK) .....	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
National Cancer Institute (US) .....	<a href="http://cancer.gov">cancer.gov</a>



# Question checklist

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

- What type of acute 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?
- Are there other treatment choices for me? If not, why not?
- 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?
- Will the treatment affect my fertility?
- Will the treatment affect my sex life?
- How often will I need check-ups after treatment?
- Are there any clinical trials or new treatments?
- Are there any complementary therapies that might help me?



# Glossary

## **acute leukaemia**

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

## **acute lymphoblastic leukaemia (ALL)**

A fast-growing leukaemia in which too many immature white blood cells from the lymphoid family (called lymphoblasts) are in the blood and bone marrow. Also called acute lymphatic leukaemia.

## **acute myeloid leukaemia (AML)**

A fast-growing leukaemia in which too many immature white blood cells from the myeloid family (called myeloblasts) are in the blood and bone marrow.

## **acute promyelocytic leukaemia (APML)**

A type of AML accounting for about 10% of all acute myeloid leukaemias. APML is treated differently to other types of AML.

## **allogeneic stem cell transplant**

A transplant where the stem 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.

## **antigen**

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

## **autologous stem cell transplant**

A transplant where stem cells are taken from a person's body and then given back following chemotherapy.

## **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 aspiration**

The removal of a small amount of bone marrow liquid (aspirate) with a needle for examination under a microscope.

## **bone marrow trephine**

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

## **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.

### **classification**

Performing tests to determine how far the leukaemia has progressed.

### **cytogenetic test**

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

### **full blood count (FBC)**

A test that counts the number of red blood cells, white blood cells and platelets in the blood.

### **graft-versus-host disease (GVHD)**

A possible complication of an allogeneic bone marrow transplant. The immune system in the person receiving the tissue (the graft) attacks the cells in the recipient's body (the host).

### **granulocyte-colony stimulating factor (G-CSF)**

A protein used to stimulate the growth of stem cells before collection for a transplant, or to increase the number of white blood cells if they are low.

### **growth factor**

A protein that stimulates the development and growth of cells.

### **haematologist**

A doctor who specialises in the study and treatment of diseases of the blood, bone marrow and lymphatic system.

### **immunophenotyping**

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

### **intrathecal chemotherapy**

Chemotherapy drugs that are delivered via a lumbar puncture.

### **intravenous (IV)**

Injected into a vein.

### **leukaemia**

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

### **lumbar puncture**

A test in which a needle is inserted into the base of the spine to collect fluid for testing or to inject drugs for treatment.

### **lymph nodes**

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

### **lymphatic system**

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

### **lymphocyte**

A type of white blood cell of the lymphoid family.

### **lymphoid**

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

### **minimal residual disease (MRD)**

Small number of leukaemia cells left behind after treatment.

### **monoclonal antibodies**

A group of targeted therapy drugs that lock onto a specific protein on the surface of cancer cells and interfere with the cells' growth or survival.

### **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 of cancer. It is an important part of palliative care.

### **petechiae**

Small red or purple spots on the skin or mouth. A symptom of leukaemia.

### **Philadelphia chromosome**

An abnormal chromosome associated with acute lymphoblastic 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 the three main types of cells found in the blood. These help the blood to clot and stop bleeding.

### **prognosis**

The predicted outcome of a person's disease.

### **radiation oncologist**

A doctor who specialises in treating cancer with radiotherapy.

### **radiotherapy**

The use of radiation, such as 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 the three main types of cells found in the blood. They carry oxygen around the body.

### **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.

### **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. It produces lymphocytes, filters the blood, stores blood cells, and destroys old blood cells. Leukaemia can cause an enlarged spleen.

### **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. Stem cells are collected from the blood of the donor or patient beforehand.

### steroids

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

### targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread. The two main types of targeted therapy at present are monoclonal antibodies and small molecule inhibitors.

### 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 the three main types of cells found in the blood. They help fight infection. Types of white blood cells include neutrophils, lymphocytes and monocytes.

### Can't find a word here?

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

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3. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia: an overview 2014*, AIHW, Canberra, 2014.
4. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Acute myeloid leukaemia (AML)*, AIHW, Canberra, 2016.
5. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Acute lymphoblastic leukaemia (ALL)*, AIHW, Canberra, 2016.



## 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 your local Cancer Council.



# Cancer Council 13 11 20

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

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

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

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

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



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



**If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.**  
[www.relayservice.gov.au](http://www.relayservice.gov.au)



**Cancer  
Council**  
**13 11 20**

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](http://cancercouncil.com.au).

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