



# Understanding Acute Leukaemia

A guide for people with cancer,  
their families and friends

Cancer  
information

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## 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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### 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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# About this booklet

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 and your family and friends understand how AML and ALL are diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 59 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 60). You may also like to pass this booklet to family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by acute leukaemia. It is based on clinical practice guidelines for acute leukaemia.<sup>1-3</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. You can also visit our website at [cancercouncil.com.au](http://cancercouncil.com.au).



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

# Contents

<b>What is blood cancer? .....</b>	<b>4</b>
<b>The blood .....</b>	<b>6</b>
<b>Key questions .....</b>	<b>8</b>
What is acute leukaemia? .....	8
Is it different to chronic leukaemia? .....	8
What are AML and ALL? .....	9
What are the risk factors? .....	10
What are the symptoms? .....	10
How common is it? .....	12
Which health professionals will I see? .....	12
<b>Making treatment decisions .....</b>	<b>14</b>
<b>Acute myeloid leukaemia (AML) .....</b>	<b>16</b>
Diagnosis .....	16
Classification .....	20
Prognosis .....	20
Treatment .....	21
<b>Acute lymphoblastic leukaemia (ALL) .....</b>	<b>31</b>
Diagnosis .....	31
Classification .....	35
Prognosis .....	36
Treatment .....	36

<b>Managing side effects</b> .....	<b>45</b>
Easy bruising or heavy bleeding.....	45
Increased risk of infections.....	45
Fatigue.....	47
Nausea and appetite changes.....	47
Changed bowel habits .....	47
Mouth problems .....	48
Nerve and muscle effects.....	48
Hair loss.....	48
Thinking and memory changes .....	49
Infertility .....	49
 <b>Looking after yourself</b> .....	 <b>50</b>
 <b>Life after treatment</b> .....	 <b>52</b>
 <b>Seeking support</b> .....	 <b>54</b>
Support from Cancer Council .....	55
Useful websites .....	56
 <b>Caring for someone with cancer</b> .....	 <b>57</b>
Children with acute leukaemia .....	58
 <b>Question checklist</b> .....	 <b>59</b>
<b>Glossary</b> .....	<b>60</b>
<b>How you can help</b> .....	<b>64</b>



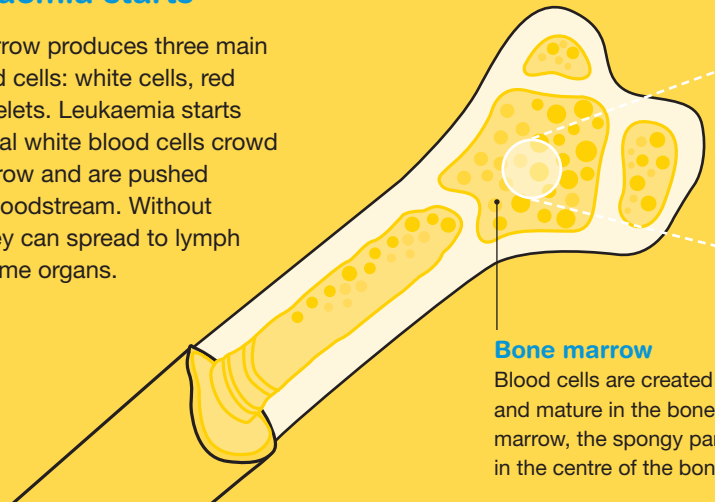
# What is blood cancer?

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 injury. Normally cells grow and multiply in an orderly way. When cells don't grow, divide and die in the usual way, it 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. The white blood cells grow abnormally and multiply in such a way that they crowd the bone marrow. This can reduce the bone marrow's ability to produce normal levels of other blood cells, which affects

## How leukaemia starts

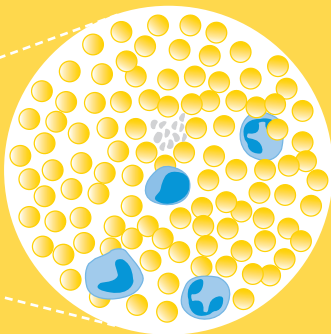
The bone marrow produces three main types of blood cells: white cells, red cells and platelets. Leukaemia starts when abnormal white blood cells crowd the bone marrow and are pushed out into the bloodstream. Without treatment, they can spread to lymph nodes and some organs.



the way that the rest of the body works. In some cases, the abnormal cells spill out into the bloodstream.

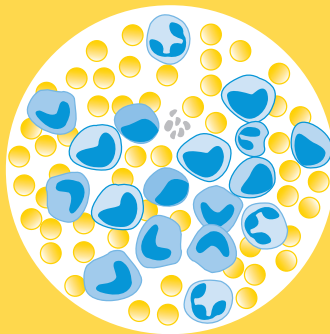
As leukaemia progresses, the bone marrow produces more abnormal blood cells and fewer normal blood cells. As the abnormal blood cells build up in the blood, they can spread to the lymph nodes, spleen, liver, lungs and kidneys. Without treatment, many of the body's key functions will be increasingly affected.

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. Many people live full lives after treatment finishes.



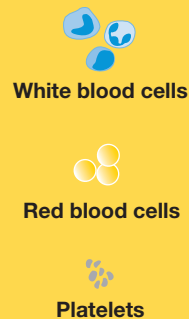
#### Normal bone marrow

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



#### Bone marrow with leukaemia




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





# The blood

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

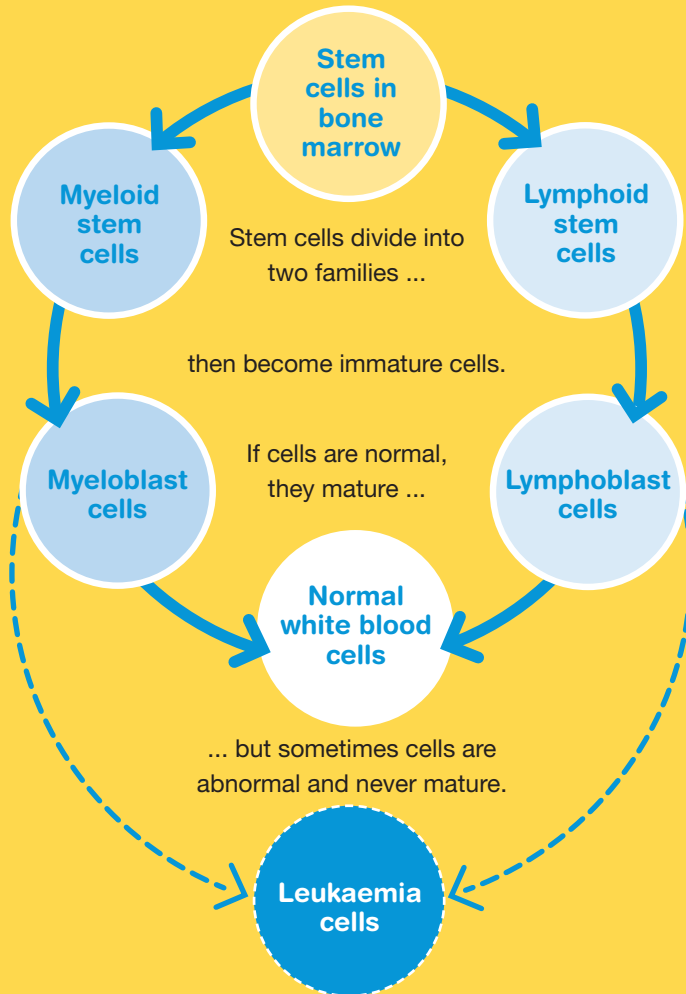
- **myeloid stem cells** – develop into myeloblast cells and then into red blood cells, most types of white blood cells, and platelets
- **lymphoid stem cells** – develop into lymphoblast cells and then into lymphocytes, which are a type of white blood cell.

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 is a blood cancer that develops suddenly and progresses quickly. It starts when the body makes too many immature white blood cells (blast cells). These abnormal blast cells are known as leukaemia cells. They multiply out of control and continue to divide but never mature into normal cells.

Because the leukaemia cells are immature and abnormal, they 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 can cause fatigue, bleeding problems and other health issues.

### 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 the type of white blood cell affected (myeloid or lymphoid), whether there are abnormalities in the bone marrow, and how quickly the disease develops.

Acute leukaemia usually affects immature cells, occurs suddenly, and develops quickly. Chronic leukaemia usually affects more mature cells, appears gradually, and develops slowly over months to years. Cancer Council NSW has a separate booklet about chronic leukaemia – call Cancer Council 13 11 20 for a free copy or visit [cancercouncil.com.au](http://cancercouncil.com.au).

## Q: What are AML and ALL?

**A:** AML stands for acute myeloid leukaemia, and ALL stands for acute lymphoblastic leukaemia (sometimes called acute lymphatic leukaemia). These are the two main types of acute leukaemia. The difference between them is the type of white blood cells affected.

	AML	ALL
White blood cells affected	The body has too many of the white blood cells known as myeloblasts.	The body has too many of the white blood cells known as lymphoblasts.
Subtypes	There are different subtypes of AML, including a subtype known as acute promyelocytic leukaemia (APML) that is treated differently.	ALL can develop from B-cells or T-cells, which are different types of lymphocytes. The main subtypes of ALL are B-cell ALL, T-cell ALL and mixed lineage ALL.
More information	This <i>Key questions</i> chapter covers risk factors, symptoms and causes of AML. Information about how AML is diagnosed and treated is covered on pages 16–30.	This <i>Key questions</i> chapter covers risk factors, symptoms and causes of ALL. Information about how ALL is diagnosed and treated is covered on pages 31–44.

## Q: What are the risk factors?

- A:** The exact causes of acute leukaemia are not yet understood, but a number of factors are known to increase the chance of developing the disease, including:
- previous treatment with chemotherapy or radiation therapy
  - having certain genetic disorders, such as Down syndrome
  - exposure to high levels of radiation (e.g. nuclear accident)
  - exposure to some chemicals, such as benzene, petroleum products, paints, certain pesticides and heavy metals, over a long period of time.

In addition, smoking, obesity and particular blood disorders (e.g. myelodysplasia) are known risk factors for AML. Some viruses (e.g. Epstein-Barr virus) increase the risk of ALL.

## 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.

**Fatigue or other signs of anaemia** – Lack of red blood cells can cause anaemia. Signs of anaemia include tiredness, weakness, a pale complexion 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.

**Enlarged spleen and lymph nodes** – The spleen is an organ in the abdomen, while lymph nodes are small structures in the neck, underarms, chest, abdomen and groin. The spleen and lymph nodes are part of the body's lymphatic system, which filters toxins, stores blood cells and helps fight infection. When leukaemia causes a build-up of abnormal white blood cells, the lymph nodes and spleen can become swollen. An enlarged spleen can cause pain or discomfort in the abdomen or back.

Less common symptoms of leukaemia include bone or joint pain, swollen and tender gums, skin rashes, headaches, weight loss, vision problems, vomiting and chest pains.

### **Children with acute leukaemia**

Children and adults with acute leukaemia have similar types of tests, treatments and side effects. Much of the information in this booklet will apply to children, but as no two cases of acute leukaemia are the same, it is important to discuss your child's case in detail with their doctors. For more information, see page 58.

## Q: How common is it?

**A:** Each year in Australia, more than 3700 people are diagnosed with a form of leukaemia, and it is the most common type of cancer diagnosed in people under 24. About 1400 of these cases are acute leukaemia, accounting for about 1.1% of cancer cases in Australia, so overall, acute leukaemia is rare.<sup>4</sup>

**Acute myeloid leukaemia (AML)** – This is the most common type of acute leukaemia in adults, with about 1050 people diagnosed each year. It becomes more common with age and mostly occurs after 65.<sup>5</sup>

**Acute lymphoblastic leukaemia (ALL)** – About 370 people are diagnosed each year. Of these, more than 200 are children under 15. ALL mostly occurs in children 1–4 years old.<sup>6</sup>

## 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 be referred to a specialist called a haematologist or to the emergency department of the nearest major hospital (as you may need immediate treatment). You will then have further tests.

If acute leukaemia is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see various health professionals who specialise in different aspects of your care.

## Health professionals you may see

<b>haematologist*</b>	specialises in treating diseases of the blood and lymphatic system; prescribes chemotherapy, as well as targeted therapy and immunotherapy
<b>radiation oncologist*</b>	prescribes and oversees the course of radiation therapy
<b>cancer care coordinator</b>	coordinates care, liaises with MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC)
<b>haematology nurse</b>	gives the course of treatment, and supports and assists you through all stages of your treatment
<b>clinical trials nurse</b>	coordinates recruitment to clinical trials and acts as a link between you and the team if you join a clinical trial
<b>pharmacist</b>	dispenses medicines and gives advice about dosage and side effects
<b>dietitian</b>	recommends an eating plan to follow while you're in treatment and recovery
<b>social worker, clinical psychologist</b>	help with any emotional problems and link you to support services
<b>physiotherapist, occupational therapist</b>	help with physical or practical problems associated with cancer and treatment
<b>palliative care team</b>	specialise in pain and symptom control to improve quality of life

\* *Specialist doctor*



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – it is often important to start treating acute leukaemia quickly. Ask the specialist to explain the options, and take as much time as you can before making a decision.

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

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

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 59 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

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



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

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

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

### Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

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

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



# Acute myeloid leukaemia (AML)

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

## Diagnosis

A combination of blood and bone marrow tests will help your doctor confirm the diagnosis and work out the subtype of AML you have.

### Blood tests

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

### Bone marrow tests

Blood cells develop in your bone marrow, so your doctor will want to check a sample of your bone marrow for signs of leukaemia. There are two ways to collect a bone marrow sample:

- 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 biopsy or trephine – the doctor uses a slightly larger needle to remove a small amount of bone and marrow.

You will be given a local anaesthetic to numb the area, pain relief that you inhale (commonly known as the green whistle) or light

sedation to help you relax. Pain medicine may make you feel drowsy, so ask a family member or 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 specialist called 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.

Various tests may be done on the biopsy sample, including:

**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. Looking at the patterns of antigens can help your doctor work out whether you have AML or ALL, and what subtype it is (see *Classification*, page 20).

**Genetic tests (cytogenetic and molecular tests)** – 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 (recurring) after a period of improvement (remission).

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.

Tests known as FISH (fluorescence in situ hybridisation) and PCR (polymerase chain reaction) are used to look for the most common gene changes in AML. The PCR test may also be used to check how well treatment has worked, and if further treatment is needed.

Other molecular tests are becoming more routine. Such tests may include looking for changes in genes that may affect treatment choice or outcomes. The commonly tested genes are known by abbreviations such as FLT3, NPM1 and CEBPA.

## Further tests

You may have other tests to find out more about the AML, and to check your general health and how well your 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 people with 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.

**Human leukocyte antigen (HLA) typing** – If having a stem cell transplant may be an option (see pages 23–25), your blood or bone marrow sample will be tested for human leukocyte antigen (HLA). HLA is found on most cells in your body and it helps your immune system recognise which cells belong in your body. A transplant can only go ahead if the stem cell donor is a close match to your HLA type. This is why your close relatives may also have an HLA test.

**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 back into your body. A special camera known as a gamma camera takes pictures of the blood being pumped by your heart.

**CT scan** – A computerised tomography (CT) scan uses x-rays and a computer to create cross-sectional pictures of the body. It can show if your lymph nodes are affected and if your spleen is enlarged. A dye (contrast) may be injected beforehand to make the pictures clearer.

**Ultrasound** – This scan uses echoes from soundwaves to create a picture of the body's organs on a screen.

**MRI scan** – A magnetic resonance imaging (MRI) scan uses a large magnet and radio waves to take detailed cross-sectional pictures of the body. Tell your doctor if you have a pacemaker, as the magnetic waves can interfere with some pacemakers. In some cases, a dye (contrast) is injected beforehand to make the pictures clearer.



For an overview of what to expect during all stages of your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/acute-myeloid-leukaemia](https://cancerpathways.org.au/optimal-care-pathways/acute-myeloid-leukaemia). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Classification

Working out the subtype of AML is called classification. It helps doctors to plan treatment and work out prognosis. AML is divided into more than 20 different subtypes according to the type of myeloid cell that has become abnormal and whether:

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

One subtype of AML develops from immature myeloid cells called promyelocytes. This is called acute promyelocytic leukaemia (APML). It is treated differently to other forms of AML (see pages 28–29).

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor. It is not possible for anyone to predict the exact course of the disease, but your doctor can give you an idea about the issues that affect people with your type of AML.

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 signs and symptoms of acute leukaemia for years. This is known as remission.

Leukaemia sometimes becomes active again (recurs) after a period of remission because a small number of cancer cells were left behind. This is known as minimal residual disease (MRD). Doctors may

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 markers or signals on the surface of leukaemia cells (see page 17)
- PCR – looks for genetic changes in cells (see pages 17–18).

## 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, and your overall health and age. Chemotherapy is the main treatment for AML. You may have further treatments depending on the subtype of AML and how you respond to the chemotherapy.

## Chemotherapy

Chemotherapy uses anti-cancer drugs to kill leukaemia cells or slow their growth. There are protocols that set out how much and how often to have particular chemotherapy drugs. You can find information about protocols at [eviq.org.au](http://eviq.org.au), although your haematologist may need to tailor the drugs to your individual situation. For AML, there are usually two phases of high-dose chemotherapy (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 risk of infection, mouth ulcers, nausea, vomiting, constipation or diarrhoea.

- See the *Managing side effects* chapter on pages 45–49 and our *Understanding Chemotherapy* booklet.

## Phases of high-dose chemotherapy for AML

Treatment for AML is usually given in two phases: induction and consolidation. People who are not well enough for the intensive chemotherapy of the induction phase may be offered low-dose drug therapy instead (see page 26).


### Induction chemotherapy

- Aims to achieve a remission.
- You'll have an intensive course of 3–4 drugs given over a week. You usually stay in hospital for 4–5 weeks.
- Drugs are often administered via a central venous access device (CVAD) inserted into a vein in the upper arm or chest. The CVAD 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.
- As the leukaemia cells die, they release uric acid. This can build up and damage the kidneys, but can be controlled with allopurinol tablets and intravenous fluids.
- You'll have a bone marrow biopsy (see pages 16–18) to see how well the treatment has worked.

### Consolidation chemotherapy

- Given after remission is achieved and once you have recovered from the induction chemotherapy.
- Aims to kill any cells that may have survived induction chemotherapy and to stop AML returning (recurring).
- You may be given a similar combination of drugs to those used in induction, at the same or a higher dose. Over several days, you will have 2–4 chemotherapy sessions (cycles) with rest periods in between.
- Depending on the types of drugs used and your general health, you will usually stay in hospital for 3–4 weeks. Some people can have their consolidation treatment as an outpatient and do not need to stay in hospital at all.



“It’s taken me a number of years to get my stamina back to where I feel like I’m not constantly lacking energy. That’s something I’ll have to deal with for a while, but at least I’m healthy now.”  *Kim*

## Stem cell transplant

Some people may be offered a stem cell transplant after induction and consolidation chemotherapy. This involves a further course of intensive chemotherapy and/or radiation therapy followed by a transplant of stem cells.

Stem cells are unspecialised, blood-forming cells that can be taken from the bloodstream (peripheral blood stem cell transplant), bone marrow (bone marrow transplant), or umbilical cord blood (cord blood transplant).

For AML, stem cells are usually collected from another person. This is known as an allogeneic transplant. A matched donor could be a relative or an unrelated donor via the Australian Bone Marrow Donor Registry, but it can sometimes be hard to find a suitable donor. In this case, the doctor will consider other options, such as a partially matched donor, a cord blood transplant, or an overseas donor. A transplant that uses stem cells collected from your own body is called an autologous transplant, but this is rarely used for AML in Australia.

A stem cell transplant is a demanding treatment and is not suitable for everyone, especially people with other health problems. The main steps in the process are described on the next two pages.

## Stem cell transplant steps

A general allogeneic transplant process is described here. For more details, ask the Leukaemia Foundation (**1800 620 420** or **leukaemia.org.au**), the Australian Bone Marrow Donor Registry (**abmdr.org.au**), and your transplant team.

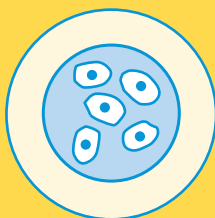
### 1 Donor stem cells stimulated



A genetically matched donor is found. They may be a close relative, or an unrelated donor from an Australian or overseas donor registry.

In some cases, the donor is given injections of a growth factor drug known as granulocyte-colony stimulating factor (G-CSF) for 5–10 days. This helps stem cells multiply quickly and move out of the bone marrow into the blood.

### 2 Stem cells collected



Stem cells are usually collected from the donor via a process called apheresis. A needle called a cannula is inserted into a vein in each arm, then blood is taken 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 3–4 hours.

Less often, stem cells may be 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.

### 3 Cryopreservation



The stem cells are processed and frozen using liquid nitrogen (cryopreserved).

If the stem cells are being collected at another hospital or imported from another country, they will be transported at a set temperature to keep them alive and in good condition for transplant (viable).

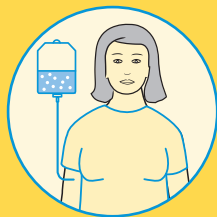
#### 4 Conditioning treatment



You may have high-dose chemotherapy or total body irradiation (see page 29) before the transplant. These treatments aim to destroy any remaining cancer cells. They kill the blood-forming stem cells in your bone marrow, making room for new cells to grow. Some people will have a less intensive treatment known as reduced intensity conditioning (RIC).

Side effects may include nausea, mouth sores, hair loss, flu-like symptoms such as body aches, and high risk of infections. For ways to manage some common side effects, see pages 45–49.

#### 5 Stem cells transplanted



A day or so after high-dose conditioning treatment, the donor's stem cells are given to you (infused) through a cannula or via an intravenous drip. This is similar to a blood transfusion and takes about an hour.

You may have stomach cramps and feel nauseous, which can be managed with medicine.

#### 6 Engraftment



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. You'll be given drugs to reduce the risk of the transplanted cells attacking your own cells (graft-versus-host disease or GVHD).

You will usually stay in hospital for 1–4 weeks until you are well enough to go home. In some cases, you may be able to have the transplant as an outpatient.

Once you go home, you'll need check-ups every week or so, but these will usually become less frequent over time.

## Low-dose drug therapy

If you're not well enough for intensive chemotherapy or a stem cell transplant, you may be offered a low dose of a drug called azacitidine. This is given by injection under the skin for several days, and the treatment is repeated once a month for at least six months. Another option is a low dose of a chemotherapy drug called cytarabine, also given by injection under the skin. This is given in combination with chemotherapy tablets and may need to continue for up to two years.

**Side effects** – Side effects include nausea, constipation and diarrhoea for azacitidine, and flu-like symptoms and skin rash for cytarabine. These effects can be controlled with medicines.

## Targeted therapy

Targeted therapy uses drugs that attack specific features of cancer cells, known as molecular targets, to stop the cancer growing and spreading. There are now a few targeted therapy drugs for AML with changes in particular genes. However, these drugs are not yet subsidised by the government through the Pharmaceutical Benefits Scheme (PBS), so they are available only through compassionate access schemes or clinical trials (see page 15).

➤ See our *Understanding Targeted Therapy* fact sheet.



A new type of drug treatment called immunotherapy uses the body's own immune system to fight cancer. This is still experimental for AML, but it is being tested in some clinical trials (see page 15). Ask your doctor if there are any recent advances that might be relevant for you.



## Sue's story

One Monday in August, I noticed a huge ulcer on my bottom lip. It was excruciating. I saw my GP on the Friday, had blood tests and was sent straight to hospital.

The ER doctor came into my room and asked me if I knew what it meant if my white blood cells were very low. Then she told me it meant I had leukaemia. I asked when I could go home and she said I couldn't, I needed to stay in hospital.

Four days later, I started what they call Big ICE, which was really strong chemo for about 10 days. I stayed in hospital for more than a month while my neutrophils recovered. A bone marrow biopsy showed I was in remission. Then I needed Little ICE, but I could have that as an outpatient.

I was told that my best chance was to have a bone marrow transplant, but it would depend on finding a suitable donor. Lots of people offered to help but even my brother was only a 5 out of 10 match, so the Red Cross

searched for a donor overseas. By November, they had two male donors in Germany and they were both 10 out of 10 matches.

I was in hospital for a month for the bone marrow transplant and then had weekly check-ups for over three months.

The year after my transplant, I ended up in intensive care many times with complications, including painful ulcers in my throat, a serious bleed from ulcers in the bowel, and severe pneumonia. The doctors aren't sure whether this was part of graft-versus-host disease or just my body reacting to the high-dose chemo.

I'm a practising artist and when I became ill all my ideas disappeared, all my effort went into surviving. But since I've started feeling better, I've had a flood of ideas. My work was always a celebration of life, but now it has extra meaning. I do become tired and I have to be careful, but if I pace myself, I can achieve what I want to achieve.

## Treatment for APML

Treatment for the subtype of AML known as acute promyelocytic leukaemia (APML) is different from most other AML treatment and is given in three phases.

**Induction phase** – A drug called all-trans retinoic acid (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 are also treated with arsenic trioxide. This is given as a daily injection.

Induction with ATRA and arsenic trioxide is usually given over 5–6 weeks. You will have regular echocardiography (ECG tracing of the heart) and blood tests to monitor the levels of potassium and other electrolytes.

In most people with APML, treatment with ATRA and arsenic trioxide leads to a remission. Some people with high white cell counts may also need intravenous chemotherapy. Samples of your bone marrow (see pages 16–18) may be tested for a genetic change known as PML-RARA. This can help doctors work out whether you are in remission.

**Consolidation phase** – Further cycles of chemotherapy will be started 1–2 weeks after the induction phase ends. This phase, known as consolidation, may last for several months. It aims to destroy any cells that may have survived the induction phase and to stop APML returning (recurring).

**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). An uncommon but serious reaction known as APML differentiation syndrome can cause breathing difficulties, fever, weight gain and high blood pressure. Tell your treatment team if you experience any of these side effects.

## Radiation therapy

Also known as radiotherapy, radiation therapy uses targeted radiation to kill cancer cells or damage them so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Radiation therapy is not often used for AML. However, it may be recommended for AML that has spread, or is likely to spread, to the brain and spine. It is also sometimes given to the whole body (total body irradiation) before a stem cell transplant (see pages 23–25).

➤ See our *Understanding Radiation Therapy* booklet.

## Palliative treatment

Palliative treatment can be used at any stage of advanced AML to improve quality of life. As well as slowing the spread of leukaemia, it can relieve pain and help manage other symptoms. Treatment may include chemotherapy and/or radiation therapy. Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social needs. The team also provides support to families and carers.

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



## Key points about AML

### What it is

Acute myeloid leukaemia (AML) is a blood cancer that causes the body to make too many of the white blood cells known as myeloblasts. Symptoms can include anaemia, bruising and bleeding, persistent infections, and pain in the abdomen or back.

### Tests

To diagnose AML, you may have a:

- full blood count – a sample of blood is checked for leukaemia cells
- bone marrow biopsy – a sample of bone marrow is removed from your hipbone with a needle and checked for leukaemia cells.

### Main treatment

The main treatment for AML is chemotherapy, which uses drugs to kill or damage cancer cells. There are usually two treatment phases:

- induction phase – intensive chemotherapy
- consolidation phase – chemotherapy to kill any leftover cancer cells.

A subtype of AML called acute promyelocytic leukaemia (APML) is treated differently, often with three phases of treatment: induction, consolidation and maintenance.

### Other treatments

Some people with AML may have other treatments such as a stem cell transplant, low-dose drug therapy, or radiation therapy. People with advanced AML can have palliative treatment to improve quality of life.





# Acute lymphoblastic leukaemia (ALL)

This chapter explains how acute lymphoblastic leukaemia (ALL) is diagnosed, monitored and treated. ALL affects the white blood cells called lymphocytes. For general information about ALL, including 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 work out the subtype of ALL you have.

### Blood tests

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 tests

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. This is because blood cells grow in your bone marrow.

There are two ways to collect a bone marrow sample:

- 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 biopsy or trephine – the doctor uses a slightly larger needle to remove a small amount of bone and marrow.

You'll have a local anaesthetic to numb the area, pain relief that you inhale (commonly known as the green whistle) or light sedation to

help you relax. Pain medicine may make you feel drowsy, so ask a family member or 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 specialist called a pathologist will view it under a microscope to work out the subtype of acute leukaemia. Various 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. Looking at the patterns of antigens can help your doctors work out whether you have ALL or AML, what subtype it is and the type of lymphocyte cell (B-cell or T-cell) affected (see *Classification*, page 35).

**Genetic tests (cytogenetics and molecular tests)** – These tests are used to work out the best course of treatment and assess the chance of ALL coming back (recurring). Every kind of cancer, including blood cancer, changes the genes of the affected cells. These gene faults are not the same thing as genes passed through families. The fault is only in the leukaemia cells, not in the normal cells. The study of gene changes is called cytogenetics or molecular genetics.

A test called FISH (fluorescence in situ hybridisation) can look for chromosomal abnormalities such as the Philadelphia chromosome (see box opposite), while a test called PCR (polymerase chain reaction) looks for other gene changes.

## 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.

Some people with ALL may have an abnormal chromosome called the Philadelphia chromosome. This isn't inherited and can't be passed on to your children – it is a genetic change that may happen over the course of life.

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, combine to create 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 protein called tyrosine kinase, which instructs leukaemia cells to grow and multiply. Drugs are sometimes used to block tyrosine kinase (see pages 40–41).

## Further tests

You may have other tests to find out more about the ALL, and to check your general health and how well your 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 people with ALL.

**Human leukocyte antigen (HLA) typing** – If having a stem cell transplant may be an option (see pages 23–25), your blood or bone marrow sample will be tested for human leukocyte antigen (HLA). HLA is found on most cells in your body and helps your immune

system recognise which cells belong in your body. A transplant can only go ahead if the stem cell donor is a close match to your HLA type. This is why your close relatives may also have an HLA test.

**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 back into your body. A special camera known as a gamma camera takes pictures of the blood being pumped by your heart.

**Lumbar puncture** – Once you have been diagnosed with ALL, 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 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.

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

**Ultrasound** – This scan uses echoes from soundwaves to create a picture of the body's organs on a screen.

**MRI scan** – A magnetic resonance imaging (MRI) scan uses a large magnet and radio waves to take detailed cross-sectional pictures.

**PET-CT scan** – For some types of ALL, you may be offered a positron emission tomography (PET) scan combined with a CT scan (see above). Before the scan, you will be injected with a small amount of radioactive glucose solution. Cancer cells show up brighter on the scan because they take up more of the glucose than normal cells do.

## Classification

Working out the subtype of ALL is called classification. It helps doctors to plan treatment and work out prognosis. ALL is divided into several subtypes according to the type of lymphocyte (B-cell or T-cell) that has become abnormal and whether the Philadelphia chromosome is present. The tests described on pages 31–33 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 features of both ALL and acute myeloid leukaemia (AML).

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor. It is not possible for anyone to predict the exact course of the disease, but your doctor can give you an idea about issues that affect people with your type of ALL.

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, and the longer the remission has lasted, the lower the risk of recurrence. In some cases, however, ALL becomes active again (recurs) because a small number of cancer cells were left behind. This is known as minimal residual disease (MRD). Doctors can measure a person's MRD at different stages throughout treatment to work out the risk of recurrence and whether more treatment is needed. Ways to measure MRD include immunophenotyping and PCR (see page 32).

## 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, such as a stem cell transplant, steroid therapy or targeted therapy, may be recommended depending on how the ALL responds to chemotherapy.

## Chemotherapy

Chemotherapy uses anti-cancer drugs to kill leukaemia cells or slow their growth. There are protocols that set out how much and how often to have particular chemotherapy drugs. You can find information about protocols at [eviq.org.au](http://eviq.org.au), although your haematologist may need to tailor the drugs to your individual situation.

For ALL, chemotherapy is usually given in three main phases over 1–3 years. The first two phases (induction and consolidation) involve high-dose chemotherapy, so most people need to stay in hospital for several weeks. The process is described on the next two pages.

**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, high risk of infection, mouth ulcers, nausea, vomiting, constipation or diarrhoea (see pages 45–49).

► See our *Understanding Chemotherapy* booklet.

### Intrathecal chemotherapy

Some people with ALL have leukaemia cells in the fluid around their brain and spinal cord (cerebrospinal fluid) at the time of diagnosis. In other people, the leukaemia cells spread to the cerebrospinal fluid after remission.

Chemotherapy drugs given intravenously or as tablets cannot get into the cerebrospinal fluid, so the drugs need to be injected directly into the spinal column using a lumbar puncture (see page 34). This is called intrathecal chemotherapy.

## Phases of chemotherapy treatment for ALL

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

You will have several different drugs in various combinations in each phase of treatment. Some drugs are given into a vein (intravenously) and others are given as a tablet.

The entire process can take 1–3 years, with the maintenance chemotherapy phase taking up most of this time.

### 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 three or four drugs given at frequent intervals over 1–4 weeks, and you'll need to stay in hospital for 2–5 weeks.
- Drugs are often given via a central venous access device (CVAD) inserted into a vein in your upper arm or chest. The CVAD will be put in place under a general or local anaesthetic, and then left in throughout the induction phase. This makes injections more comfortable. The CVAD can also be used to take blood samples for testing.
- As the leukaemia cells die, they release a chemical called uric acid. This may build up and damage the kidneys, but can be controlled with allopurinol tablets.
- You will have a bone marrow biopsy (see pages 31–32) to check how well the treatment has 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.



## Consolidation chemotherapy

- Consolidation chemotherapy is also called post-remission therapy or intensification. It is given after remission is achieved.
- The aim is 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.
- You will have several courses of high-dose chemotherapy over 6–12 months.
- 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 several nights.
- If the chance of recurrence is high, you may be offered further induction chemotherapy or a stem cell transplant (see next page).

## Maintenance chemotherapy

- Maintenance chemotherapy is given after consolidation chemotherapy has finished. (It will not be needed if you have a stem cell transplant, see next page.)
- The aim is to extend the period of remission and prevent the leukaemia from coming back.
- You will take chemotherapy tablets either daily or weekly. You may also have intravenous chemotherapy and/or be offered steroids (see pages 42–43). This maintenance phase usually lasts between 18 months and 2 years.
- Maintenance chemotherapy is usually given as an outpatient. However, you may need to stay in hospital for some types of chemotherapy drugs.

## Stem cell transplant

Some people may be offered a stem cell transplant after induction or consolidation chemotherapy. This involves a further course of intensive chemotherapy and/or radiation therapy followed by a transplant of stem cells. The steps in the process are described on pages 24–25. A stem cell transplant is not suitable for everyone, especially people with other health problems.

Stem cells are unspecialised, blood-forming cells that can be taken from the bloodstream (peripheral blood stem cell transplant), bone marrow (bone marrow transplant), or umbilical cord blood (cord blood transplant).

For ALL, stem cells are usually collected from another person. This is known as an allogeneic transplant. A matched donor could be a relative or an unrelated donor via the Australian Bone Marrow Donor Registry, but it can sometimes be difficult to find a suitable donor. In this case, the doctor will consider other options, such as a partially matched donor or a cord blood transplant.

## Targeted therapy

Targeted therapy uses drugs that attack specific features of cancer cells, known as molecular targets, to stop the cancer growing and spreading.

**Tyrosine kinase inhibitors (TKIs)** – These targeted therapy drugs are often used to treat people with ALL who have the Philadelphia chromosome (see page 33). They work by blocking a protein called tyrosine kinase, which tells the leukaemia cells to divide and grow. Without this signal, the cells die. TKIs such as imatinib, dasatinib



You may be able to access new drugs to treat ALL through clinical trials (see page 15). These may include immunotherapy drugs, which use the body's own immune system to fight cancer. Ask your doctor about recent developments and whether you are a suitable candidate.

and ponatinib come in tablet form. 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 are manufactured (synthetic) versions of immune system proteins called antibodies. The synthetic antibodies lock onto specific proteins on the surface of leukaemia cells to interfere with their growth or survival. Monoclonal antibodies such as rituximab and blinatumomab are sometimes used for particular types of ALL. They are given through a drip into a vein (intravenously), either on their own or with chemotherapy.

► See our *Understanding Targeted Therapy* fact sheet.

## Radiation therapy

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

Radiation therapy may be given:

- to the brain or spine when ALL has spread, or is likely to spread, to the cerebrospinal fluid
- to the whole body (total body irradiation) before a stem cell transplant (see opposite page).

If you are having radiation therapy to the brain, you will be fitted for a special mask. This keeps your head still during treatment. Your radiation oncologist and haematologist will discuss the type of radiation therapy and the number of treatments you will need.

**Side effects** – Radiation therapy 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.

➤ See our *Understanding Radiation Therapy* booklet.

## **Steroids**

Steroids (also known as corticosteroids) are made naturally in the body, but they can also be produced artificially and used as drugs. 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 months.

**Side effects** – The side effects of steroids tend to be milder if you need them for only a short time, but may include hyperactivity, difficulty sleeping, mood changes, heartburn and high blood glucose levels. If you need to take steroids for several months, these side

effects may be stronger. You may also experience increased appetite, weight gain, high blood pressure and muscle weakness, as well as fluid retention that 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. Tell your treatment team if you experience heartburn, as it can be relieved with medicines. Your team can also offer strategies if your sleep is disturbed. Some types of steroids can affect blood sugar levels, so people with diabetes need to monitor their blood sugars more often and may need to have their diabetes medicines adjusted. Discuss these changes with your treatment team and 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).

## Palliative treatment

Palliative treatment can be used at any stage of advanced ALL to manage symptoms and improve quality of life. As well as slowing the spread of the leukaemia, it can relieve pain, nausea and other symptoms. Treatment may include chemotherapy and/or radiation therapy. Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social needs. The team also provides support to families and carers.

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



## Key points about ALL

### What it is

Acute lymphoblastic leukaemia (ALL) is a blood cancer that causes the body to produce too many of the white blood cells called lymphoblasts. Symptoms include anaemia, bruising and bleeding, persistent infections, and pain in the abdomen or back.

### Tests

To diagnose ALL, you may have:

- a full blood count – a sample of blood is checked for leukaemia cells
- bone marrow biopsy – a sample of bone marrow is removed from your hipbone with a needle and checked for leukaemia cells
- lumbar puncture – a sample of cerebrospinal fluid (CSF) is taken from your lower spine.

### Main treatment

The main treatment for ALL is chemotherapy, which uses drugs to kill or damage cancer cells. There are usually three treatment phases:

- induction phase – intensive chemotherapy
- consolidation phase – chemotherapy to kill any leftover cancer cells
- maintenance phase – low doses of chemotherapy to prolong remission.

### Other treatments

Some people with ALL may have other treatments such as a stem cell transplant or radiation therapy. People with advanced ALL can have palliative treatment to improve their quality of life.



# Managing side effects

Chemotherapy drugs affect both cancerous cells and healthy fast-dividing cells. This can cause side effects such as nausea, hair loss and fatigue. Side effects vary depending on the drugs, but most are temporary and there are ways to prevent or reduce them. This chapter discusses some common side effects of treatment for acute leukaemia.

Tell your treatment team about your side effects or anything unusual you experience. Check with your doctor before using ibuprofen, aspirin or other medicines, including herbal medicines. These may affect how the chemotherapy works and may make side effects worse.

## Easy bruising or heavy bleeding

Chemotherapy can lower the number of platelets in your blood. This is called thrombocytopenia and it 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 raise your platelet count.

## Increased risk of infections

The combination of chemotherapy drugs, as well as the leukaemia itself, will lower your levels of the white blood cells called neutrophils. This is known as neutropenia and it can make you more likely to get infections such as colds or infected cuts, so it is important to take extra precautions (see table, next page). To speed up the production of new white blood cells, your doctor may prescribe a growth factor drug called granulocyte-colony stimulating factor (G-CSF).

## Taking care with infections during chemotherapy

### Reduce your risk

To prevent the spread of infection:

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

### When to seek medical help

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

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



## Fatigue

The level of your red blood cells may drop (anaemia), causing you to feel tired and breathless. This can be treated with blood transfusions. However, some people feel fatigued for weeks or months after cancer treatment, even once their blood count returns to normal. To manage this, plan activities for the time of day you feel most energetic. Exercise can reduce fatigue and improve mood. Talk to your health care team or call Cancer Council 13 11 20 to find out about exercise programs.

## Nausea and appetite changes

You will be given anti-nausea medicine to take before and during chemotherapy. If you still feel sick (nauseous) or vomit after taking the medicine, let your doctor know so another can be tried. Your appetite may change during chemotherapy. The drugs sometimes change how food tastes (e.g. it may taste metallic), cause mouth ulcers, and, less often, make you feel nauseous. Try having frequent snacks instead of large meals. You can also enrich drinks with powdered milk, yoghurt, eggs or honey. A dietitian at the treatment centre can help you work out an eating plan.

## Changed bowel habits

Hard, dry bowel movements (constipation) or loose, watery stools (diarrhoea) can be caused by chemotherapy and other medicines. Speak to your doctor if you are experiencing bowel changes, as it is important to act early to prevent further problems. For constipation, they may suggest you eat more fibre or prescribe some laxatives. Your doctor can also prescribe medicines to control diarrhoea.

## Mouth problems

Chemotherapy can cause mouth sores (such as ulcers), tooth or gum infections, and a dry mouth. To keep your mouth comfortable, sip water throughout the day and eat moist foods such as casseroles and soups. Your team may prescribe mouthwashes to help with mouth care, or you can rinse your mouth four times a day with a teaspoon of bicarbonate of soda or salt in a glass of warm water. Have regular dental check-ups, but talk to your haematologist before you have any dental work during your leukaemia treatment.

## Nerve and muscle effects

Some chemotherapy drugs can cause tingling (“pins and needles”), pain or loss of feeling in your fingers and/or toes, and muscle weakness in your legs. This is called peripheral neuropathy and it is usually a short-term issue, but for some people, it can last a long time or even be permanent. 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.

## 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 keep warm and to protect your head from direct sunlight. Look Good Feel Better runs free programs on how to manage the appearance-related side effects of cancer treatments. To book into a workshop, call 1800 650 960 or visit [lgfb.org.au](http://lgfb.org.au).

## Thinking and memory changes

Some people say they have difficulty concentrating, focusing and remembering things after they have had chemotherapy. This is called cancer-related cognitive impairment or, sometimes, “chemo brain” or “cancer fog”. These problems usually improve with time, although some people experience issues for years. Tell your doctor if this issue is affecting your day-to-day life or your return to work.

## Infertility

Some women’s periods become irregular during treatment, but return to normal when it finishes. For other women, chemotherapy or 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 the sperm’s ability to move. This can cause infertility, which may be temporary or permanent. Total body irradiation can also reduce sperm production. Before treatment starts, your doctor will talk to you about infertility and can refer you to a fertility specialist.



For more information on managing side effects, see our booklets on chemotherapy, nutrition and fertility, and our fact sheets on hair loss, mouth health, taste and smell changes, and thinking and memory changes. You can also listen to podcast episodes on fatigue, appetite loss and nausea, and brain fog at [cancercouncil.com.au/podcasts](https://cancercouncil.com.au/podcasts).



# Looking after yourself

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

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

▶ See our *Nutrition and Cancer* booklet.

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

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

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

▶ See our *Understanding Complementary Therapies* booklet.



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

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

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

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

➤ See our *Emotions and Cancer* booklet.

**Sexuality** – 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.

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

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

➤ See our *Fertility and Cancer* booklet.



# Life after treatment

For most people, the 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 that every ache and pain means the cancer is coming back.

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

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

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

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

## Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects and check that the leukaemia hasn't come back or spread. During these check-ups, you will usually have a physical examination and may have blood tests, x-rays or scans. You will also be able to discuss how you're feeling and mention any concerns you may have.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

## What if the leukaemia returns?

For some people, leukaemia does come back after treatment, which is known as a recurrence. It 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 the testicles. Having regular check-ups means tests may find 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 control the leukaemia and may lead to a second remission. You may be offered different chemotherapy drugs or a stem cell transplant.



## Seeking support

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

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

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

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

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

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



## Support from Cancer Council

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

### Cancer Council 13 11 20

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



### Information resources

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

### Practical help

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



### Legal and financial support

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

### Peer support services

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



## Useful websites

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

### Australian

Cancer Council NSW	<a href="http://cancercouncil.com.au">cancercouncil.com.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Cancer Institute NSW	<a href="http://cancer.nsw.gov.au">cancer.nsw.gov.au</a>
Department of Health	<a href="http://health.gov.au">health.gov.au</a>
Department of Human Services	<a href="http://humanservices.gov.au">humanservices.gov.au</a>
eviQ	<a href="http://eviq.org.au">eviq.org.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.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>
Leukaemia Foundation	<a href="http://leukaemia.org.au">leukaemia.org.au</a>

### International

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



# Caring for someone with cancer

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

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

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

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Association** – Carers NSW, a statewide organisation specifically for carers, can also provide support. Call 1800 242 636 or visit [carersnsw.org.au](http://carersnsw.org.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit [cancercouncil.com.au](http://cancercouncil.com.au) to find out more about carers' services.

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



One way to 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) to find out more.

## Children with acute leukaemia

If your child has been diagnosed with acute leukaemia, there are many sources of support during this difficult time:

- Hospital staff who specialise in working with children (paediatrics) can offer valuable advice and support. Some hospitals also employ child life therapists or play, music or art therapists.
- Organisations such as CanTeen ([canteen.org.au](http://canteen.org.au)), Camp Quality ([campquality.org.au](http://campquality.org.au)), Redkite ([redkite.org.au](http://redkite.org.au)) and the Leukaemia Foundation ([leukaemia.org.au](http://leukaemia.org.au)) offer information for children, support for families and children, and other services.

### 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. Cancer Council has resources that may be helpful at this time.

- See our *Talking to Kids About Cancer* booklet and listen to our podcast episode on “Explaining Cancer to Kids”.



# Question checklist

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

## Diagnosis

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

## Treatment

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

## Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- How long will I have to have off work or away from my normal activities?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

## After treatment

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



# Glossary

## **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. It makes up about 10% of all acute myeloid leukaemias and is treated differently to other types of AML.

## **allogeneic stem cell transplant**

A transplant where stem cells 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**

A protein made by the blood in response to an invader (antigen).

## **antigen**

Any substance that causes the immune system to respond.

## **autologous stem cell transplant**

A transplant where stem cells come from the person's own body.

## **B-cell**

A type of lymphocyte (white blood cell) that makes antibodies to fight infection.

## **biopsy**

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

## **blast cells**

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

## **bone marrow**

The soft, spongy material inside bones. Bone marrow produces stem cells that become 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 biopsy**

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

## **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 with other treatments.

## **chronic leukaemia**

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

## **classification**

Performing tests to work out the subtype of the leukaemia.

**cycle**

A period of chemotherapy treatment that is repeated on a regular schedule with periods of rest in between.

**cytogenetic test**

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

**full blood count (FBC)**

A test that measures the number, size and maturity of each type of cell in the blood.

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

A possible complication of allogeneic stem cell transplants. It happens when immune cells in the transplanted tissue (the graft) attack the cells of the person receiving the transplant (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.

**haematologist**

A doctor who specialises in blood, bone marrow and lymphatic system diseases.

**immunophenotyping**

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

**immunotherapy**

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

**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.

**lymphatic system**

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

**lymph nodes**

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

**lymphocyte**

A type of white blood cell that helps fight infection. Lymphocytes destroy bacteria, viruses and other harmful substances.

**lymphoid**

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

**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.

### **myelodysplasia**

A disease that affects the production of healthy blood cells in the bone marrow and sometimes develops into acute myeloid leukaemia.

### **myeloid**

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

### **neutropenia**

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

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

### **prognosis**

The expected outcome of a person's disease.

### **protocol**

A recommendation that sets out which chemotherapy drugs to use and their dosage and timing. Also called a regimen.

### **radiation therapy**

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

### **recurrence**

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

### **red blood cells**

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

### **relapse**

See recurrence.

### **remission**

When the signs and symptoms of the cancer reduce or disappear.

### **side effect**

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

### **spleen**

An organ in the lymphatic system that produces lymphocytes, filters the blood, and destroys old blood cells, abnormal cells and bacteria.

### **stem cells**

Unspecialised cells from which various types of mature cells develop. Stem cells are found in the bone marrow.



### stem cell transplant

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

### steroids

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

### targeted therapy

Drugs that attack specific particles within cells that allow cancer to grow.

### T-cell

A type of lymphocyte (white blood cell) that helps the body fight invaders (antigens) by killing them directly or by helping B-cells make antibodies.

### tissue

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

### tyrosine kinase

A protein that tells cells when to divide and grow.

### tyrosine kinase inhibitor (TKI)

A targeted therapy drug that blocks the protein tyrosine kinase.

### white blood cells

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

### Can't find a word here?

For more cancer-related words, visit [cancercouncil.com.au/words](http://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 other Pink events, or hold your own fundraiser or become a volunteer.

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

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


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

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



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

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