

Understanding Acute Leukaemia

A guide for people with cancer, their families and friends



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Check the publication date above to ensure this copy is up to date.

Editor: Nicole MacKee. Designer: Eleonora Pelosi. Printer: IVE Group.

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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 information provided in this booklet.

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



Cancer Council NSW 153 Dowling Street, Woolloomooloo NSW 2011 ABN 51 116 463 846

Telephone 02 9334 1900 **Email** feedback@nswcc.org.au **Website** cancercouncil.com.au

About this booklet

This booklet has been prepared to help you understand more about the 2 main types of acute leukaemia: acute myeloid leukaemia (AML) and acute lymphoblastic leukaemia (ALL).

Many people feel shocked and upset when told they have acute leukaemia. We hope this booklet will help you, your family and friends understand how AML and ALL are diagnosed and treated. We 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.¹⁻³



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

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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story

What is blood cancer?

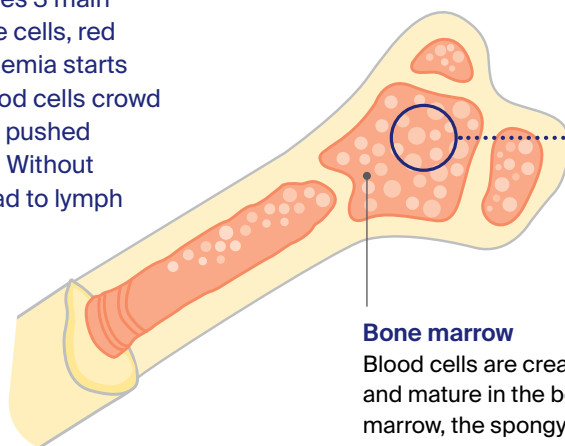
Cancer is a disease of the cells, which are the body's basic building blocks - they make up blood, tissues and organs. The body is constantly making new cells to help us grow, replace worn-out tissue and heal injuries.

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

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

How leukaemia starts

The bone marrow produces 3 main types of blood cells: white cells, red cells and platelets. Leukaemia starts when abnormal white blood cells crowd the bone marrow and are pushed out into the bloodstream. Without treatment, they can spread to lymph nodes and some organs.

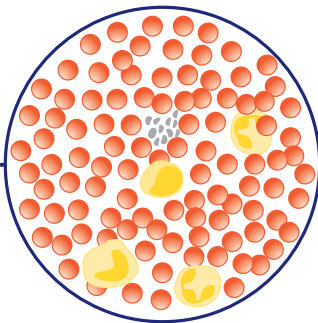


Bone marrow
Blood cells are created and mature in the bone marrow, the spongy part in the centre of the bone.

In leukaemia, white blood cells grow abnormally and multiply in such a way that they crowd the bone marrow. This can reduce the bone marrow's ability to produce normal levels of other blood cells, which affects the way that the rest of the body works. The abnormal cells then move from the bone marrow into the bloodstream.

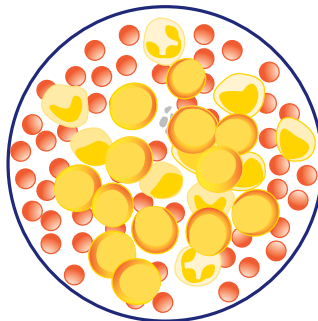
As leukaemia progresses, the bone marrow produces more abnormal white blood cells and fewer normal blood cells. As the abnormal white blood cells build up, they can spread from the blood to the lymph nodes, spleen, liver, lungs and kidneys. Without treatment, many of the ways the body works will be increasingly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

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



White blood cells



**Leukaemia cells
(abnormal cells)**



Red blood cells






Platelets

The blood

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

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

Bone marrow contains blood stem cells. These are unspecialised cells that usually grow into one of the 3 main types of blood cells: white blood cells, red blood cells or platelets. Each type of blood cell has a specific job to do (see below).

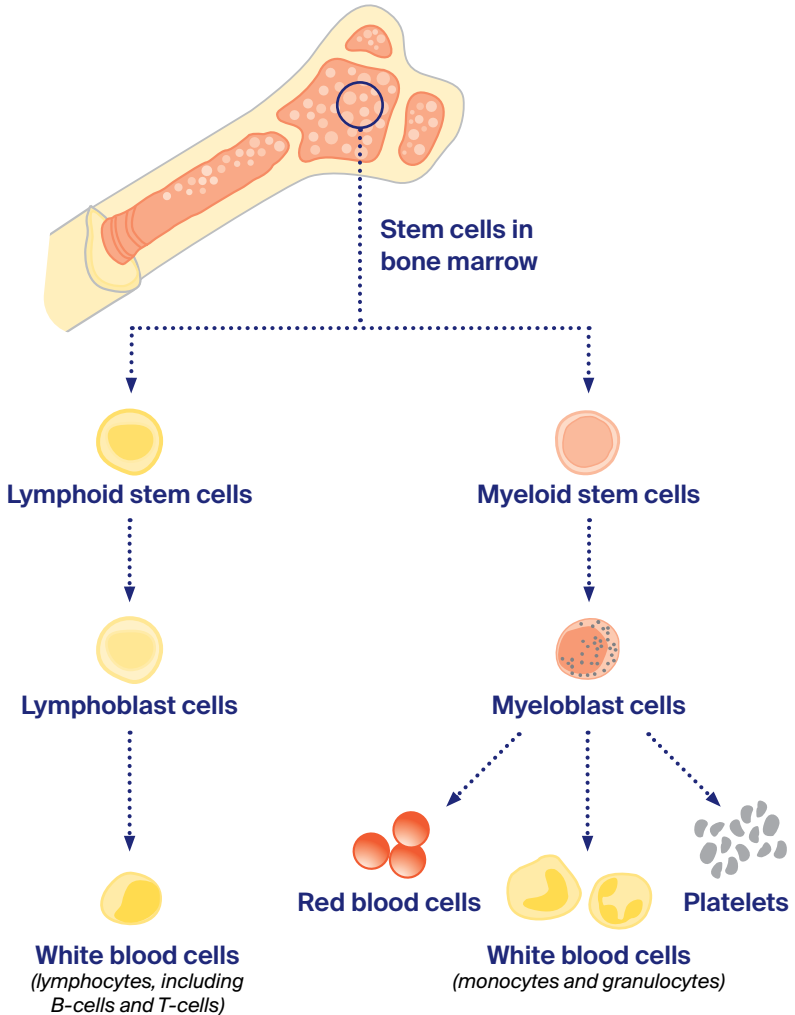
White blood cells	Red blood cells	Platelets
 fight infection	 carry oxygen around the body	 help the blood clot

There are 2 families of blood stem cells: lymphoid and myeloid (see diagram opposite). These develop into different types of white blood cells that can be affected by different types of leukaemia.

When myeloid stem cells grow abnormally, this is called acute myeloid leukaemia (AML); when lymphoid stem cells grow abnormally, this is called acute lymphoblastic leukaemia (ALL).

Blood stem cell families

Stem cells divide into 2 families (lymphoid or myeloid), then become immature cells (lymphoblast or myeloblast cells). If cells are normal, they develop into different kinds of mature blood cells.



Key questions

Q: What is acute leukaemia?

A: Acute leukaemia is a blood cancer that appears suddenly and grows quickly. It starts when undeveloped white blood cells – called blast cells – become cancerous. These abnormal blast cells are known as leukaemia cells. They multiply quickly and continue to divide but never mature into normal cells.

Because the leukaemia cells are undeveloped and abnormal, they don't carry out the usual infection-fighting role 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 also little room for normal red blood cells and platelets. This can cause fatigue, bleeding problems and other health issues.

Q: Is it different from chronic leukaemia?

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

Acute leukaemia usually affects undeveloped cells, occurs suddenly and grows quickly. Chronic leukaemia usually affects mature or partly developed cells, appears gradually and grows slowly over months to years.

▶ See our *Understanding Chronic Leukaemia* booklet.

Q: What are AML and ALL?

A: AML and ALL are the 2 main types of acute leukaemia. The difference between them is the type of white blood cell affected.

Acute myeloid leukaemia (AML) – Develops from myeloid cells. There are more than 20 subtypes of AML, including a subtype known as acute promyelocytic leukaemia (APML) that develops from immature myeloid cells called promyelocytes. APML is treated differently (see page 22). AML risk factors and symptoms are explained on pages 10–11. For information about how AML is diagnosed and treated, see pages 16–29.

Acute lymphoblastic leukaemia (ALL) – ALL can develop from different types of lymphocytes, including B-cells or T-cells.

T-cell ALL is very similar to T-cell lymphoblastic lymphoma, and the 2 conditions are often treated the same way. In T-cell ALL, the abnormal lymphocytes are mainly in the blood and bone marrow, while in T-cell lymphoblastic lymphoma, the abnormal lymphocytes are in the lymph nodes. ALL risk factors and symptoms are explained on pages 10–11. For information about how ALL is diagnosed and treated, see pages 30–44.

Some people have a type of leukaemia called mixed-phenotype acute leukaemia (MPAL). This means the disease has features of both ALL and AML. MPAL may also be called biphenotypic acute leukaemia.



For an overview of what to expect during all stages of your cancer care for AML, visit cancer.org.au/cancercareguides/acute-myeloid-leukaemia. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Q: What are the risk factors?

- A:** The exact causes of acute leukaemia are not yet understood. Things known to increase the chance of developing the disease include:
- 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
 - smoking and/or obesity
 - particular blood disorders, such as myelodysplasia (for AML)
 - some viruses, such as Epstein-Barr virus (for ALL), but this is rare.

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. Usually, people with acute leukaemia find that some of the following symptoms appear quickly over a few weeks.

Anaemia – Low levels of red blood cells (anaemia) can cause tiredness (fatigue), weakness, a pale complexion and breathlessness.

Increased bruising and bleeding – Low platelet levels can cause bruising without a bump or fall, nosebleeds, bleeding gums, heavy periods, and small red or purple spots on the skin or mouth (called petechiae).

Repeated or persistent infections – A lack of normal white blood cells can cause mouth sores or ulcers, sore throats, fevers, sweats, coughing, boils, infected cuts or scratches, and frequent and painful passing of urine. A low white blood cell level can also lead to more serious infections.

Enlarged spleen and lymph nodes – When leukaemia causes a build-up of abnormal white blood cells, the lymph nodes and spleen can become swollen (see next page). An enlarged spleen can cause pain or discomfort in the abdomen or back.

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

Q: How common is acute leukaemia?

A: About 5200 people are diagnosed with a form of leukaemia in Australia each year. About 1500 of these cases are acute leukaemia.⁴

AML is the most common type of acute leukaemia in adults, with about 1100 people diagnosed each year. It becomes more common with age and mostly occurs after 60.

About 410 people are diagnosed with ALL each year. Of these, more than half are children and adolescents aged under 20, although ALL can occur at any age.

Children with acute leukaemia

This booklet is for adults diagnosed with acute leukaemia. As children and adults with acute leukaemia have similar tests, treatments and side effects, much of the information in this booklet will also apply to

children. However, no 2 cases of acute leukaemia are the same, so it is important to discuss your child's case in detail with their doctors. For more information about children with acute leukaemia, see page 58.

The lymphatic system and leukaemia

The lymphatic system is part of the immune system, which protects the body against disease and infection. It is a network of vessels, tissues and organs, including:

- **Lymph vessels** – These thin tubes are found throughout the body. They carry lymph fluid.
- **Lymph fluid** – This clear fluid travels to and from the tissues in the body, carrying nutrients and taking away bacteria, viruses, abnormal cells and cell debris.
- **Lymph nodes** – These are small, bean-like structures in the neck,

underarms, chest, abdomen and groin. Lymph nodes filter toxins, help fight infections, and produce some blood cells. They may also be called lymph glands.

- **Spleen** – This is an organ in the abdomen. It clears out old or damaged blood cells.

Sometimes leukaemia cells build up in the lymph nodes or spleen. When this happens, it can stop the lymphatic system from working properly and increase the risk of infections.

Q: Which health professionals will I see?

A: Your general practitioner (GP) will often arrange the first tests to assess your symptoms. If these tests do not rule out leukaemia, you will usually be referred to another 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 a range of health professionals who specialise in different aspects of your care.

Health professionals you may see

haematologist*	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy, targeted therapy and immunotherapy (systemic treatment); oversees stem cell transplants
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
cancer care coordinator	coordinates care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
haematology nurse	administers chemotherapy and other drugs and provides care, support and information throughout treatment
clinical trials nurse	coordinates recruitment to clinical trials and acts as a link between you and the team if you join a clinical trial
pharmacist	dispenses medicines and gives advice about dosage and side effects
dietitian	helps with nutrition concerns and recommends changes to diet during treatment and recovery
clinical psychologist, social worker	help with emotional issues and link you to support services
physiotherapist, occupational therapist	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment
palliative care specialists* and nurses	work closely with the GP and cancer team to help control symptoms and maintain 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 what time you can before making a decision.

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

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

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 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.

► 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. For general information about AML, including its risk factors and symptoms, see the *Key questions* chapter on pages 8–13. For information about managing the common side effects of treatment, see pages 45–49.

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 and whether the levels of the different types of blood cells are different from what would be expected in a healthy person.

Blood tests will also check for:

- lactate dehydrogenase (LDH), an enzyme that is released into the blood when cells are damaged or destroyed. LDH levels are usually raised in people with AML
- infections, such as HIV (human immunodeficiency virus) or hepatitis.

Bone marrow tests

Blood cells develop in your bone marrow, so your doctor will check your bone marrow for signs of leukaemia. Samples of bone marrow are usually collected by either aspiration or biopsy.

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, usually from the hipbone.

You will be given a local anaesthetic to numb the area. To help you relax, you may be offered a light sedation that you inhale (a mild pain reliever known as “the green whistle”) or is injected through a small plastic tube inserted into a vein (cannula). You may feel drowsy after the procedure, so ask someone to drive you home. It takes up to 30 minutes to prepare for a biopsy, but the actual procedure takes only a few minutes.

The bone marrow samples are sent to a laboratory where they will be tested to work out the subtype of AML and any gene changes that may have occurred. Tests may include:

Immunophenotyping – This test looks for certain markers that are on the surface of leukaemia cells. Looking at the patterns of these markers can help your doctor confirm that the leukaemia is AML (and not ALL) and to work out the subtype.

Genetic tests (cytogenetic and molecular tests) – Cancer changes the genes of affected cells. These gene changes are not the same as genes passed through families. The fault is only in the leukaemia cells. Tests looking for changes in the genes involved in leukaemia are becoming more standard. They help doctors decide on suitable treatment options and work out the chance of the AML coming back (recurring) after a period of improvement (remission).

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

Further tests

You may have other tests to find out more about the AML, your general health and how well your organs are working. Imaging tests may include a chest x-ray, a computerised tomography (CT) scan, ultrasound and a magnetic resonance imaging (MRI) scan. Other tests may include:

HLA typing – If a stem cell transplant is a treatment option (see pages 24–25), a blood or bone marrow sample will be tested for human leukocyte antigen (HLA). HLA is found on most cells in your body – it helps your immune system recognise which cells belong in your body. Usually, a stem cell transplant can only go ahead if the donor is a close match to your HLA type. This is why your close relatives may also have an HLA test to see if they are a match.

Gated heart pool scan – This scan shows how well the heart is working and may be used to check that you are fit enough for chemotherapy. A small amount of your blood is taken, mixed with some radioactive material and injected back into your body. A special camera takes pictures of the blood being pumped by your heart. The scan usually takes about an hour.



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast (dye) during previous scans. You should also let them know if you have diabetes or kidney disease, or if you are pregnant or breastfeeding.

Classification

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

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

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 likely outcomes for people with your type of AML.

To work out your prognosis, your doctor will consider test results, how fast the leukaemia cells are growing or spreading, the subtype, how well the leukaemia responds to treatment, and other factors such as your age, fitness and medical history.

For many people, treatment can reduce the signs and symptoms of acute leukaemia for years. This is known as remission.

Acute leukaemia sometimes becomes active again (relapses) after a period of remission because a small number of leukaemia cells have remained in the body. Those remaining cells are known as minimal residual disease (MRD). Doctors may measure a person's MRD to work out the risk of relapse and if there is a need for more treatment. Immunophenotyping and PCR tests (see pages 17–18) are used to measure MRD.

Treatment for AML

Treatment will depend on the subtype, the genetic make-up of the AML, and your overall health and age. In most cases, your doctor will need the results of genetic tests and immunophenotyping (see page 17) to work out the best treatment for you. It may take up to 2 weeks for these results to come through.

For younger people, chemotherapy is the main treatment (see below). Older people are generally treated with a lower intensity therapy, including an oral drug called venetoclax (see page 27). You may have other treatments depending on the subtype and how the AML responds to the drugs you are given.

Chemotherapy

Chemotherapy uses drugs to kill leukaemia cells or slow their growth. Treatment protocols set out which drugs to have, how much and how often. You can find information about protocols at eviq.org.au, although your haematologist may need to tailor the drugs to your individual situation. For AML, there are usually 2 phases of high-dose chemotherapy (see opposite page). Chemotherapy drugs are most commonly given as a liquid through a drip inserted into a vein (intravenous infusion). Some drugs can be given as tablets you swallow.

Side effects – As well as killing leukaemia cells, the drugs may also damage healthy fast-growing cells, such as new blood cells or the cells in the mouth, stomach, hair and bowel. This can cause side effects such as hair loss, high risk of infection, mouth sores, body aches, nausea, vomiting, constipation or diarrhoea, skin and nail changes, memory and concentration problems, and tiredness (fatigue).

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

Phases of high-dose chemotherapy for AML

Chemotherapy for AML is usually given in 2 phases: induction and consolidation.

Induction chemotherapy

- Aims to bring about remission (when the signs and symptoms of cancer reduce or disappear).
- You'll have an intensive course of 2–4 drugs given over a week.
- The drugs are often given through a central venous access device (CVAD) inserted into a vein in your upper arm or chest. The CVAD will be inserted under a general or local anaesthetic, and then left in place throughout the induction phase.
- 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 medicine and intravenous fluids.
- You will usually stay in hospital for 4–5 weeks to be monitored for complications of chemotherapy. Your doctor will discuss this with you in detail before starting treatment.
- You'll have a bone marrow biopsy (see pages 16–17) to check 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 stop AML returning (relapsing).
- Over several days, you will have 2–4 chemotherapy sessions (called cycles) with rest periods in between.
- You may be given a similar combination of drugs to those used in induction, at the same or a higher dose.
- 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.

Treatment for APML

Treatment for the subtype of AML known as acute promyelocytic leukaemia (APML) is different from most other AML treatments.

Induction phase – A drug called all-trans retinoic acid (ATRA) is the main type of induction treatment. ATRA is not a chemotherapy drug, but it may be given with chemotherapy.

ATRA makes immature promyelocyte cells mature, so they are no longer leukaemia cells. It is taken as a tablet (orally).

People with APML are also treated with arsenic trioxide. This is given daily, through a drip into a vein or through a central venous access device (CVAD).

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 your full blood count and the levels of minerals in the blood.

In most people with APML, treatment with ATRA and arsenic trioxide leads to remission.

Some people with high white blood cell counts may also need to have intravenous chemotherapy.

Samples of your bone marrow (see pages 17–18) will be tested for a gene 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 (relapsing).

Side effects – Side effects of ATRA and arsenic trioxide may include headaches, bleeding and clotting problems, and nausea (feeling sick). During the induction phase, 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.

Stem cell transplant

After high-dose chemotherapy (see pages 20–21), some people may be offered a stem cell transplant. 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 (a donor). This is called an allogeneic transplant. A suitably matched donor could be a relative or an unrelated person found through the Australian Bone Marrow Donor Registry. It can sometimes be hard to find a suitable donor. In this case, an overseas donor, a partially matched donor or a cord blood transplant may be considered. Half-matched family donors are increasingly being used (a haploidentical transplant).

A transplant that uses stem cells collected from your own body (called an autologous transplant) is rarely used to treat AML in Australia.

Although a stem cell transplant can help some people, it is not suitable for everyone. The chemotherapy that is given before the transplant can have a lot of side effects. The main steps in an allogeneic stem cell transplant are described on the next 2 pages.

“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...found 2 male donors in Germany and they were both 10 out of 10 matches.” SUE

Steps in an allogeneic stem cell transplant

This is a general outline of a transplant using stem cells collected from another person, but the process may vary from hospital to hospital. Your transplant team

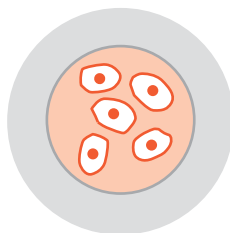
1. Stem cells stimulated



A suitably matched donor is found. They may be a close relative, or an unrelated donor found through 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 4–7 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 by a process called apheresis. A thin plastic tube called a cannula is inserted into a vein in each arm. Blood is taken from the donor, passed through a machine to remove the stem cells and then returned to the donor's body. This takes 3–4 hours and is usually done during a day visit to the hospital.

Less often, stem cells may be collected from the bone marrow. The donor is given a general anaesthetic and then a needle is inserted into their pelvic bone to remove the marrow.

3. Stem cells preserved

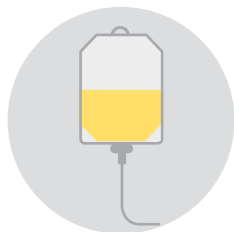


The stem cells from the donor are processed. They may be given to you on the same day they are collected or frozen using liquid nitrogen (cryopreservation).

If the stem cells are 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 (viable) for transplant.

will let you know what to expect. More detailed information about stem cell transplants is available at leukaemia.org.au.

4. Conditioning treatment

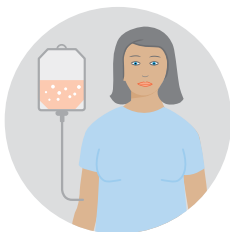


You may have high-dose chemotherapy and/or total body irradiation (radiation therapy to the whole body) before the transplant. These treatments aim to destroy any remaining leukaemia cells. They will also destroy the stem cells in your bone marrow, making room for new stem cells to grow.

Some people will have reduced intensity conditioning (RIC). This means lower doses of chemotherapy and radiation therapy are used before the transplant, which is easier for the body to tolerate.

For ways to manage some common side effects of high-dose chemotherapy, see pages 45–49.

5. Stem cells transplanted



A day or so after the conditioning treatment, the donor's stem cells are put into your body (infused) through a cannula or intravenous drip. This is similar to a blood transfusion and takes about an hour.

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

6. Engraftment



Over the next couple of weeks, the donated 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 stem cells attacking your body (graft-versus-host disease or GVHD).

You will usually stay in hospital for 3–4 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 weekly check-ups for the first few months. These will usually become less frequent over time.



Sharon's story

In late November, I visited my GP as I was feeling tired and had some strange bruises. After some blood tests I went home and didn't think any more about it. Just hours later, the GP phoned me and said I had to go to hospital immediately as she believed I had leukaemia.

Later that night, the hospital confirmed that I had an aggressive form of acute myeloid leukaemia. I couldn't go home and had to begin treatment immediately. Within 12 hours I went from being completely normal to facing the possibility of not surviving until Christmas. It was a harrowing time.

My journey with cancer was a difficult one. I found it hard to deal with the chemotherapy treatment and my weight dropped significantly. As a result, I had to be tube fed for a time. I also had severe rashes, painful ulcers and felt very weak.

The cancer proved hard to beat and I had to undergo multiple rounds of chemotherapy.

It was only the use of trial drugs that paved the way for me to undergo a bone marrow transplant.

Finding a suitable bone marrow donor also proved difficult as there was no match on any of the global donor databases. The doctors decided to use my brother's bone marrow. Although he wasn't a perfect match, he was the best and only option available.

Fortunately, the bone marrow transplant was successful, and I am now in remission.

Five years on I still have some ongoing issues with GVHD (graft-versus-host-disease) but otherwise I am healthy.

My brush with leukaemia has refocused my efforts on living a full and meaningful life. I treasure time with my family and friends, I volunteer at several charities and I visit leukaemia patients to give them support.

Targeted therapy

Targeted therapy uses drugs that attack specific features of leukaemia cells to stop them growing and spreading. Venetoclax is a type of targeted therapy drug that may be used for people with certain subtypes of AML and those who are not able to have high-dose chemotherapy.

Venetoclax blocks the action of BCL-2, a protein that helps leukaemia cells survive. It is taken as a tablet in combination with a chemotherapy drug called azacitidine. Some people may need to stay in hospital for the first 3-4 days of treatment while the dose is adjusted. Your doctor will advise you to drink plenty of water during the first few weeks of treatment. This helps to prevent tumour lysis syndrome (TLS). TLS may occur when leukaemia cells die and release a chemical called uric acid. A build-up of uric acid can damage the kidneys.

Side effects – Other possible side effects include: increased risk of infection; breathing problems; fatigue (tiredness); and diarrhoea, nausea and/or vomiting. Speak to your treatment team if you experience any side effects, as they can often be treated with medicines.

Other targeted therapy drugs

AML may be treated with other targeted therapy drugs such as midostaurin and gemtuzumab ozogamicin (which are both used in combination with chemotherapy). People with relapsed AML may be offered a drug called gilteritinib.

► See our *Understanding Targeted Therapy* fact sheet.



Immunotherapy uses the body's own immune system to fight cancer. This is more commonly used for ALL, but it may be used in some clinical trials for AML (see page 15). Ask your doctor if there are any trials that might be suitable for you.

Radiation therapy

Also known as radiotherapy, radiation therapy uses targeted radiation to kill or damage leukaemia cells 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, but it may be recommended for AML that has spread, or is likely to spread, to the spine and brain. It is also sometimes given to the whole body (total body irradiation) before a stem cell transplant (see pages 24-25).

Side effects – These may include: skin changes; nausea (feeling sick); fatigue (tiredness); diarrhoea; hair loss; or a dry mouth.

► 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 aims to meet your physical, emotional, cultural, social and spiritual needs. The team also provides support to families and carers.

► See our *Understanding Palliative Care* booklet.

“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

Key points about acute myeloid leukaemia

What it is

- Acute myeloid leukaemia (AML) is a blood cancer that affects white blood cells from the myeloid family.
- Symptoms can include anaemia, bruising and bleeding, persistent infections, and pain in the abdomen or back.

Tests

To diagnose AML, you may have a:

- blood test – to check the levels of the different blood cells and to check for leukaemia cells
- bone marrow aspiration and biopsy – samples of fluid or bone and marrow are removed from your hipbone with a needle and checked for leukaemia cells
- genetic test – to identify changes in genes associated with leukaemia.

Main treatment

For younger people, the main treatment for AML is chemotherapy. There are usually 2 treatment phases (induction and consolidation).

For older people, a lower intensity therapy is used, including a drug called venetoclax.

A subtype of AML called acute promyelocytic leukaemia (APML) is treated differently, using 2 drugs called all-trans retinoic acid (ATRA) and arsenic trioxide.

Other treatments

- Some people have a stem cell transplant or radiation therapy.
- People with advanced AML can have palliative treatment to improve their quality of life.



Acute lymphoblastic leukaemia (ALL)

This chapter explains how acute lymphoblastic leukaemia (ALL) is diagnosed, monitored and treated. For general information about ALL, including its risk factors and symptoms, see the *Key questions* chapter on pages 8–13. For information about common side effects of treatment, see pages 45–49.

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

The blood tests will also check for infections such as HIV (human immunodeficiency virus) or hepatitis.

Bone marrow tests

If the blood test shows abnormalities in the number or appearance of the white blood cells, your doctor will want to check a sample of your bone marrow for signs of leukaemia. This is because blood cells develop in your bone marrow. Samples of bone marrow are usually collected from the hipbone (pelvic bone) and there are 2 different ways to collect these samples.

- **Bone marrow aspiration** – The doctor uses a thin needle to remove a small amount of fluid (aspirate) from the bone marrow.
- **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. To help you relax, you may be offered a light sedation that you inhale (a mild pain reliever known as “the green whistle”) or is injected through a small plastic tube inserted into a vein (cannula). This 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 samples are sent to a laboratory. A specialist called a pathologist will do tests on the samples to work out the subtype of ALL. These tests may include:

Immunophenotyping – This test looks for certain markers that are found on the surface of leukaemia cells. Looking at the patterns of these markers can help your doctor to confirm that the leukaemia is ALL (and not AML) and to work out the subtype and the type of lymphocyte (B-cell or T-cell) affected. B-cell ALL is the most common type of ALL in adults.

Genetic tests (cytogenetic and molecular tests) – Cancer changes the genes of affected cells. These types of gene changes are not the same as genes passed through families. The fault is only in the structure of the leukaemia cells, not in normal cells.

A test called FISH (fluorescence in situ hybridisation) looks for abnormal chromosomes (including the Philadelphia chromosome, see page 34).

A test called PCR (polymerase chain reaction) looks for other common gene changes in ALL. These tests are used to work out suitable treatment options and assess the chance of ALL coming back after a period of improvement.

Further tests

You may have other tests to find out more about the ALL, your general health and how well your organs are working. This may include a chest x-ray, a computerised tomography (CT) scan, ultrasound and a magnetic resonance imaging (MRI) scan. Other tests may include:

HLA typing – If a stem cell transplant may be an option (see page 37), a blood or bone marrow sample will be tested for human leukocyte antigen (HLA). HLA is found on most cells in your body – it helps your immune system recognise which cells belong in your body. A stem cell transplant can usually only go ahead if the donor is a close match to your HLA type. This is why your close relatives may also have an HLA test.

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

Lumbar puncture – Once you have been diagnosed with ALL you will have a lumbar puncture. This test shows if any leukaemia cells have



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you have diabetes or kidney disease, or if you are pregnant or breastfeeding.

travelled to the fluid around your spine and brain. This fluid is called cerebrospinal fluid. A sample of cerebrospinal fluid is removed with a thin needle from a space between 2 bones in the lower back. This takes only a few minutes, but it can be uncomfortable, so your doctor will use a local anaesthetic to numb the area.

A lumbar puncture may be done under x-ray guidance if your doctor thinks the lumbar puncture may be difficult.

In some people, the back of the legs may tingle when the needle is inserted – this is harmless and doesn't last long. You may get a headache after a lumbar puncture, but this usually improves with a few hours of bed rest. You can ask your doctor for pain relief if the headache is ongoing.

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

Classification

Working out the specific type of ALL is called classification. It is an important step because it helps doctors to work out the prognosis and suggest the most suitable treatment.

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 (see next page) is present. The tests described in this chapter look for these changes.

Philadelphia chromosome

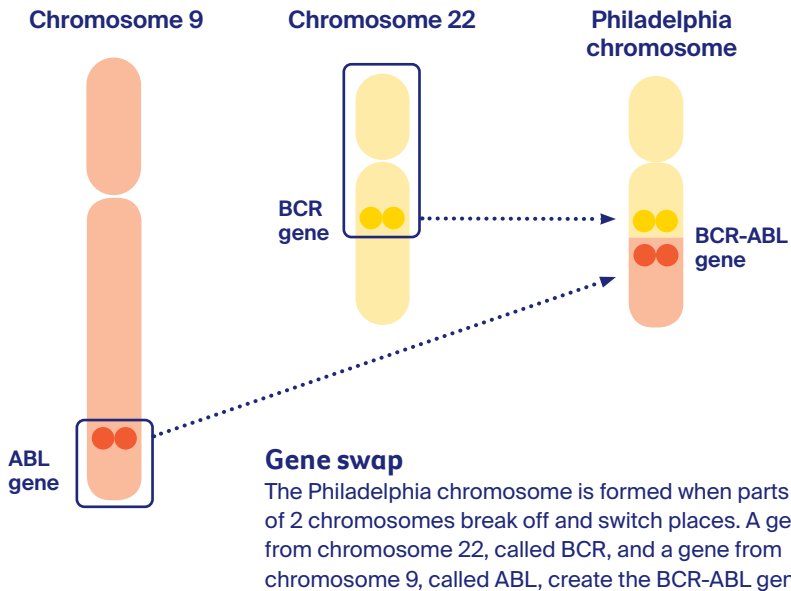
Most cells in the human body have 23 pairs of chromosomes. Chromosomes are threadlike structures that contain sets of instructions known as genes.

Chromosome 22 is abnormal in about 1 in 4 adults with ALL. This is known as the Philadelphia chromosome.

The Philadelphia chromosome is not inherited and cannot be passed on to your children – it is a gene change that happens to some people during

their lifetime. This chromosome contains the BCR-ABL gene (see diagram below).

BCR-ABL is considered a cancer gene because it is present only in developing leukaemia cells. It tells the body to produce an abnormal type of protein called tyrosine kinase, which tells leukaemia cells to grow and multiply. Drugs are sometimes used to block tyrosine kinase (see page 41).



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 likely outcomes for people with your type of ALL.

To work out your prognosis, your doctor will consider 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 your age, fitness and medical history. 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. The longer the remission lasts, the lower the risk of relapse. In some cases, however, ALL becomes active again (relapses) because a small number of leukaemia cells remained in the body. Those remaining cells are known as minimal residual disease (MRD).

Doctors may measure a person's MRD to work out the risk of relapse and if more treatment is needed. Immunophenotyping and PCR tests (for information on these tests, see pages 31–32) are used to measure a person's MRD.



Acute leukaemia treatment can cause temporary or permanent infertility. If you may want to have children in the future, ask your doctor for a referral to a fertility specialist before treatment starts. You may be able to store eggs, embryos, ovarian tissue or sperm for later use. While there have been significant advances, preserving fertility is not guaranteed. See page 49.

Treatment for ALL

Treatment will depend on the type of ALL you have, your age and fitness levels, and will usually begin as soon as a diagnosis is made. Chemotherapy is the main treatment, but you may also have other treatments depending on how the ALL responds to chemotherapy.

Chemotherapy

Chemotherapy uses drugs to kill leukaemia cells or slow their growth. Treatment protocols set out which drugs to have, how much and how often (see eviq.org.au for more information). However, your haematologist may need to tailor the drugs to your individual situation.

For ALL, chemotherapy is usually given in 3 main phases over 1–3 years. The first 2 phases (induction and consolidation) involve high-dose chemotherapy, so most people need to stay in hospital for several weeks. The process is described on pages 38–39.

You may have a bone marrow biopsy or lumbar puncture during chemotherapy to see how you are responding to the treatment.

Side effects – As well as killing leukaemia cells, the drugs may also damage healthy fast-growing cells, such as hair follicles, blood cells, and cells inside the mouth or bowel. This can cause hair loss, high risk of infection, mouth ulcers, nausea, vomiting, constipation or diarrhoea.

► See the *Managing side effects* chapter on pages 46–49 and our *Understanding Chemotherapy* booklet.

Intrathecal chemotherapy

Some people with ALL have leukaemia cells in the fluid around the brain and spinal cord (cerebrospinal fluid) at the time of diagnosis. Leukaemia cells may also spread to the cerebrospinal fluid after remission.

Chemotherapy drugs given into a vein 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 pages 32–33). This is called intrathecal chemotherapy.

After the procedure, you may have to lie on your back for a short time to help prevent a headache. Your doctor will discuss other possible side effects with you before the procedure.

Stem cell transplant

Some people may be offered a stem cell transplant after consolidation chemotherapy (see pages 38–39). 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).

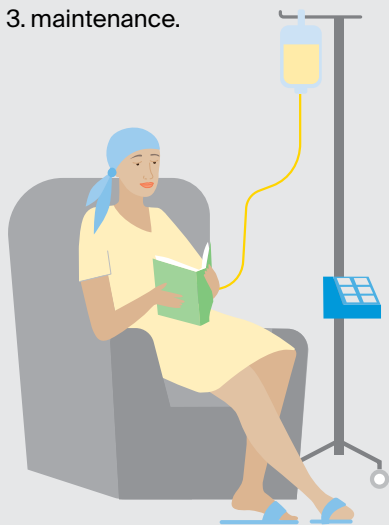
For ALL, stem cells are usually collected from another person. This is known as an allogeneic transplant. A suitably matched donor could be a relative or an unrelated person found through the Australian Bone Marrow Donor Registry.

It can sometimes be hard to find a suitable donor. In this case, an overseas donor, a partially matched donor or a cord blood transplant may be considered. Half-matched family donors are increasingly being used (a haploidentical transplant).

Phases of chemotherapy treatment for ALL

Chemotherapy for ALL is generally given in 3 phases:

1. induction
2. consolidation
3. maintenance.



Depending on the features of the leukaemia, you may have some or all of these phases of treatment.

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

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

1. Induction chemotherapy

- The aim of induction chemotherapy is to bring about (induce) remission. This means leukaemia cells are no longer found in bone marrow samples, the normal cells return, and blood counts become normal.
- You'll have an intensive course of 3–4 drugs given at frequent intervals over 1–4 weeks. You'll need to stay in hospital for 2–5 weeks.
- The drugs are often given through a central venous access device (CVAD) inserted into a vein in your upper arm or chest. The CVAD will be inserted under a general or local anaesthetic, and then left in place throughout the induction phase. 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 medicine and intravenous fluids.
- You will have a bone marrow biopsy (see pages 30–31) to check how well the treatment has worked. If no leukaemia cells are seen, this is called remission.
- If the biopsy shows leukaemia cells in the bone marrow, you may be given more chemotherapy, at similar or higher doses.

2. 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 induction chemotherapy and to stop ALL coming back and/or spreading to the central nervous system.
- You will have several cycles of high-dose chemotherapy over 6–12 months.
- The type of chemotherapy drugs you are offered will depend on your risk of relapse.
- 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 your chance of relapse is high, you may be offered further induction chemotherapy or a stem cell transplant (see page 37).

3. Maintenance chemotherapy

- Maintenance chemotherapy is commonly given after consolidation chemotherapy has finished. It will not be needed if you have a stem cell transplant (see page 37).
- The aim is to increase how long you are in 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.

CAR T-cell immunotherapy

Some young people with ALL may be offered a special type of immunotherapy called CAR (chimeric antigen receptor) T-cell therapy. T-cells are part of the immune system and their job is to hunt down and attack abnormal cells in the body. CAR T-cell immunotherapy modifies a person's own T-cells so they are better able to do this.

First, a small plastic tube (cannula) is inserted into a vein in each arm. Blood is taken from one arm and fed through a special machine that separates out the T-cells. The remaining blood is then returned to you through the cannula in the other arm.

Chimeric antigen receptor is added to the T-cells to make them into CAR T-cells. This happens in a laboratory and may take 2-3 weeks. The CAR T-cells are then injected back into your body to attack the leukaemia cells.

Currently, this treatment is only funded through the Medicare Benefits Schedule for some young people (aged 25 or younger) with a certain type of ALL. If you are suitable for CAR T-cell therapy, you may be referred to a specialist centre for treatment.

Side effects – These may include: a high temperature; fast heart rate; low blood pressure and dizziness; nausea and/or vomiting (feeling and/or being sick); muscle and joint pain; and breathing difficulties. These side effects usually occur in the first 10 days after treatment and can be managed, but it's important to let your doctor know about them.

In the 4-8 weeks after treatment, there may also be side effects in the brain, including headaches, loss of balance and confusion. These brain-related side effects usually get better in 1-2 weeks and can be managed.

Targeted therapy

Targeted therapy uses drugs that attack specific features of leukaemia cells to stop the leukaemia 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 34). They work by blocking a protein called tyrosine kinase, which tells the leukaemia cells to grow and multiply. Without this signal, the cells die.

TKIs such as imatinib, dasatinib and ponatinib are taken as tablets. You may have TKIs on their own or in combination with chemotherapy.

Side effects – These may include: fatigue; nausea and vomiting; diarrhoea; skin rashes; facial, hand or leg swelling; and anaemia, bruising or infections.

Monoclonal antibodies

Monoclonal antibodies are made in a laboratory but behave like natural antibodies that fight infection and disease. They lock onto specific proteins on the surface of leukaemia cells to interfere with how they grow and survive.

Monoclonal antibodies such as rituximab, blinatumomab and inotuzumab are sometimes used for particular types of ALL. These drugs are given through a drip into a vein (intravenously), either on their own or in combination with chemotherapy.

Side effects – These may include: flu-like symptoms; nausea and vomiting; increased risk of infections (see page 46); and fatigue.

▶ See our *Understanding Targeted Therapy* fact sheet.

Radiation therapy

Also known as radiotherapy, radiation therapy uses targeted radiation to kill or damage leukaemia 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
- whole body (total body irradiation) before a stem cell transplant.

If you are having radiation therapy to the brain, you will be fitted for a special mask. This keeps your head still during treatment.

Side effects – Radiation therapy most commonly causes tiredness, dry or itchy skin, and hair loss from your body and head. These side effects are usually 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, see pages 35 and 49).

▶ 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. They 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 – Possible side effects include hyperactivity, difficulty sleeping, mood changes, heartburn and high blood glucose levels. You may also experience increased appetite, weight gain, high blood pressure and muscle weakness, as well as fluid retention that can cause puffy eyelids, face, hands, fingers and feet, and may blur your vision. If used for a long period, steroids may cause diabetes and contribute to thinning of the bones (osteoporosis).

Taking steroids in the morning with food or milk can reduce the risk of sleeplessness at night and stomach irritation. Tell your treatment team if you experience heartburn, as it can be relieved with medicines.

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 the National Diabetes Services Scheme (NDSS) Helpline on 1800 637 700.

Palliative treatment

Palliative treatment can be used at any stage of advanced ALL to improve quality of life. As well as slowing the spread of leukaemia, it can relieve pain, nausea and other symptoms. Many people think palliative treatment is for people at the end of their life; however, it can help people at any stage. Treatment may include chemotherapy and/or radiation therapy.

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

▶ See our *Understanding Palliative Care* booklet.

Key points about acute lymphoblastic leukaemia

What it is

- Acute lymphoblastic leukaemia (ALL) is a blood cancer that affects white blood cells from the lymphoid family.
- Symptoms can include anaemia, bruising and bleeding, persistent infections, and pain in the abdomen or back.

Tests

To diagnose ALL, you may have a:

- blood test – to check the different blood cell levels and to look for leukaemia cells
- bone marrow aspiration or biopsy – samples of fluid, bone and marrow are removed from your hipbone and checked for leukaemia cells
- lumbar puncture – a sample of cerebrospinal fluid (CSF) is taken from your lower spine
- genetic test – to identify changes in genes associated with leukaemia.

Main treatment

The main treatment for ALL is chemotherapy, which uses drugs to kill or damage leukaemia cells. There are usually 3 treatment phases:

- induction phase – intensive chemotherapy to bring about remission
- consolidation phase – chemotherapy to kill any remaining leukaemia cells
- maintenance phase – low doses of chemotherapy to prolong remission.

Other treatments

- Stem cell transplant may be an option after consolidation chemotherapy
 - CAR T-cell therapy – a type of immunotherapy that may be used to treat some young people with ALL
 - Targeted therapy or radiation therapy may also be used.
-

Managing side effects

Chemotherapy drugs affect fast-growing healthy cells as well as leukaemia cells. This can cause side effects such as nausea, hair loss and fatigue. Other leukaemia treatments, such as targeted therapy and radiation therapy, may also have side effects and your doctor will talk to you about the best way to prevent and manage these. This chapter focuses on the possible side effects of chemotherapy.

Most side effects are short term, but some may be permanent. Side effects tend to gradually improve once treatment stops and the normal, healthy cells recover. Side effects can usually be managed.

Some side effects from chemotherapy may not show up for months or years. These are called late effects. Before treatment starts, talk to your doctor about whether you are at risk of developing late effects from your treatment and what you can do to help prevent them. Once treatment has finished, it is important to see your GP for regular health checks.

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.



For more information on managing side effects, see our booklets on chemotherapy, nutrition and fertility, and our fact sheets on fatigue, hair loss, mouth health, peripheral neuropathy, 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.

Effects on the blood

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. You may also have nosebleeds or bleeding gums. If you usually have monthly periods (menstruate), you will be given drugs to stop periods and prevent 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 it harder for your body to fight infections. Viruses such as colds, flu and COVID-19 may be easier to catch and harder to shake off, and scratches or cuts may get infected more easily.

To speed up the production of new white blood cells, your doctor may give you injections of a growth factor drug called granulocyte-colony stimulating factor (G-CSF). The table on the opposite page lists some ways to reduce your risk of getting an infection.

Fatigue – Your red blood cell level may drop (anaemia), causing you to feel tired and breathless. This can be treated with blood transfusions.

Some people feel fatigued for weeks or months after leukaemia 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 for more ways to manage fatigue.

- ▶ See our *Exercise for People Living with Cancer* booklet and listen to our podcast episodes on fatigue and sleep.

Taking care with infections during chemotherapy

Ways to reduce your risk

To prevent the spread of infection:

- check your temperature daily and any time you feel unwell
- avoid touching your eyes, nose and mouth with your hands
- check with your doctor about having vaccines for COVID-19, flu and pneumococcal disease
- ask people close to you to consider having the COVID-19 and flu vaccines
- ask family and friends with a cold, flu, COVID-19 or other contagious infections (e.g. a cold sore) not to visit until the symptoms have gone away
- avoid shaking hands, hugging and kissing other people
- try to avoid crowded places, such as shopping centres; or, if you must visit a busy place, wear a mask
- 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 foods (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 (weeing)
- 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 heavy nosebleeds, blood in your urine (wee or pee) or black faeces (poo)
- prolonged faintness or dizziness and a rapid heartbeat
- any sudden deterioration in your health.

Other common side effects

Nausea – 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.

Appetite changes – Chemotherapy drugs may affect your appetite or change how food tastes. Try eating snacks frequently instead of large meals, and enriching drinks with powdered milk, yoghurt or honey. A dietitian at the treatment centre can help you work out an eating plan.

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 health care team may recommend that you use mouthwashes and have regular dental check-ups. Tell the dentist about the type of treatment you are having and talk to your haematologist before you have any dental work.

Changed bowel habits – Hard, dry bowel movements (constipation) or loose, watery movements (diarrhoea) can be caused by chemotherapy drugs and other medicines. Tell your doctor or nurse if your bowel habits have changed, as it is important to act early to prevent further problems. They may suggest changing what you eat or medicines.

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. It is usually a short-term issue, but for some people, it can last a long time or even be permanent. If you have 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 – This 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. Wearing some form of head covering will help keep you warm and protect your head from direct sunlight. Look Good Feel Better runs free workshops on managing appearance-related side effects – call 1800 650 960 or visit lgfb.org.au.

Thinking and memory changes – Some people have difficulty concentrating, focusing and remembering things after 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 return to work.

Infertility – If you have periods, they may become irregular during treatment, but return to normal when it finishes. For other people, periods stop permanently (menopause). After menopause, it is no longer possible to have a child naturally. Chemotherapy drugs may lower the number of sperm produced and reduce their ability to move. This can sometimes cause infertility, which may be temporary or permanent. Total body irradiation can also reduce sperm production. Speaking to your doctor or a counsellor about your feelings and individual situation can be helpful.

► See our *Fertility and Cancer* booklet.

Osteoporosis – Early menopause may cause bones to become weaker and break more easily. This is called osteoporosis. Talk to your doctor about having a bone density test or taking medicines to prevent your bones becoming weak. Healthy Bones Australia has more information on preventing osteoporosis. Call 1800 242 141 or visit healthybonesaustralia.org.au

Looking after yourself

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

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

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

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

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

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

▶ See our *Understanding Complementary Therapies* booklet.



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

Work and money – Leukaemia can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

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

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

▶ See our *Emotions and Cancer* booklet.

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

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

Contraception and fertility – If you have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor or nurse 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 leukaemia treatment can present its own challenges. You may have mixed feelings when treatment ends and worry that every ache and pain means the leukaemia is coming back.

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

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

► See our *Living Well After Cancer* booklet.

Dealing with feelings of sadness

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

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

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

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

Follow-up appointments

After your treatment, you will have regular appointments to monitor your health, manage any long-term side effects and check that the leukaemia hasn't come back or 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 relapse or 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. Leukaemia cells may also be found in the testicles. Having regular check-ups means tests may find a relapse before there are symptoms. Finding a relapse early offers the best chance for successful treatment.

If you have a relapse, further treatment may be able to control the leukaemia and lead to a second remission. You may be offered different chemotherapy drugs, targeted therapy drugs, or a stem cell transplant. It may also be possible to join a clinical trial (see page 15).

Seeking support

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

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

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

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

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



If you live in a rural or remote area, and have to travel a long way for treatment, talk to your hospital social worker or call 13 11 20 for information about assistance with accommodation, transport, finances and social support.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



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

Information resources



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

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.

Practical help



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

Peer support services



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

Useful websites

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

Australian

Cancer Council NSW	cancercouncil.com.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Arrow Bone Marrow Transplant Foundation	arrow.org.au
Australasian Leukaemia & Lymphoma Group	allg.org.au
Australian Bone Marrow Donor Registry	abmdr.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Institute NSW	cancer.nsw.gov.au
Department of Health and Aged Care	health.gov.au
eviQ Cancer Treatments Online	eviq.org.au
Healthdirect Australia	healthdirect.gov.au
Leukaemia Foundation	leukaemia.org.au
Services Australia (including Centrelink and Medicare)	servicesaustralia.gov.au

International

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

Caring for someone with leukaemia

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

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

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

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

“Caring for my mum was deeply emotional. It was difficult, but it gave me a tremendous sense of caring and giving.” SHARYN

Bone marrow and blood donations

You can offer indirect support to someone with acute leukaemia by becoming a bone marrow donor. Bone marrow donors are usually related to the person receiving the bone marrow, but sometimes donors are matched through the Australian

Bone Marrow Donor Registry. Visit abmdr.org.au to find out more.

Many people are eligible to donate blood at Australian Red Cross Lifeblood. Call 13 14 95 or visit lifeblood.com.au.

Children with acute leukaemia

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

- hospital staff who specialise in working with children. They can offer valuable advice and support. Some hospitals also have child life therapists or play, music or art therapists.
- organisations such as Canteen (canteen.org.au), Camp Quality (campquality.org.au), Redkite (redkite.org.au) and the Leukaemia Foundation (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 “Explaining Cancer to Kids” podcast episode.

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 fast is the leukaemia growing?
 - Are the latest tests and treatments for leukaemia available in this hospital?
 - Will a multidisciplinary team (MDT) 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 usual 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 enter the bloodstream.

acute lymphoblastic leukaemia (ALL)

A fast-growing leukaemia in which too many immature white blood cells from the lymphoid family are in the blood and bone marrow.

acute myeloid leukaemia (AML)

A fast-growing leukaemia in which too many immature white blood cells from the myeloid family 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 transplant

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

anaemia

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

anaesthetic

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes temporary loss of consciousness.

antibody

A protein made by the blood in response to an invader (antigen). Part of the body's immune system.

antigen

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

autologous transplant

A process that involves taking stem cells

or bone marrow from a person's own body and giving them back after high-dose chemotherapy.

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. 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 (trephine)

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

CAR T-cell immunotherapy

Treatment in which your own T-cells are modified so they are better able to find and attack abnormal cells in the body.

cells

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

central venous access device (CVAD)

A type of thin plastic tube inserted into a vein.

The CVAD gives access to a vein so fluid or chemotherapy can be given, and blood can be taken.

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.

CT scan

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

cycle

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

genes

The microscopic units that determine how the body's cells grow and behave.

genetic testing

Genetic testing aims to detect faulty genes that may increase the risk of developing certain cancers.

graft-versus-host disease (GVHD)

A possible complication of allogeneic stem cell transplants. GVHD 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 growth factor drug used to help the body make more stem cells so they can be collected for a transplant or to increase the number of white blood cells if they are low.

It is given either as an injection or through a drip into the bloodstream (intravenously).

immune system

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

immunophenotyping

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

immunotherapy

Drugs that use the body's own immune system to fight cancer.

intrathecal chemotherapy

Chemotherapy drugs that are delivered through 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 needle inserted into the base of the spine to collect fluid for testing or to inject drugs for treatment. Also called a spinal tap.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells.

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. 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.

molecular test

A test that looks for changes in the genes involved in cancer.

monoclonal antibodies

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

MRI scan

Magnetic resonance imaging scan. Uses magnetic fields and radio waves to take detailed, cross-sectional pictures of the body.

myelodysplasia

A disease that affects the production of healthy blood cells in the bone marrow. May develop into acute myeloid leukaemia.

myeloid

One of the two families of white blood cells. The myeloid family produces some types of white blood cells, all red blood cells and all 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 them manage pain and other physical and emotional symptoms. It is an important part of palliative care.

PET-CT

Positron emission tomography scan combined with a CT scan.

petechiae

Small red or purple spots on the skin or mouth. May be 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 tells leukaemia cells to grow and multiply.

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.

protein

Cells make proteins to carry out specific functions in the body.

protocol

A recommendation that sets out which chemotherapy drugs to use, their dosage and timing.

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.

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

The return of a disease after a period of improvement (remission). May also be called recurrence.

remission

When the signs and symptoms of the leukaemia 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 blood cells made in the bone marrow. They can grow into mature cells.

stem cell transplant

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

steroids

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

targeted therapy

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

T-cell

A type of lymphocyte (white blood cell) that helps the body fight invaders (antigens).

thrombocytopenia

A low level of platelets. It can be a side effect of chemotherapy and makes you more prone to bleeding and bruising.

tissue

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

total body irradiation (TBI)

A type of radiation therapy used to treat blood cancers; sometimes used with chemotherapy before a stem cell or bone marrow transplant.

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.

ultrasound

A scan that uses soundwaves to create a picture of part of the body.

white blood cells

One of the three main types of cells in the blood. They help fight infection.

Can't find a word here?

For more cancer-related words, visit: 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 Cancer Council NSW on 02 9334 1900.



Cancer Council

13 11 20

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

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

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

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



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



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

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

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

Visit our website: **cancercouncil.com.au**

*This booklet is funded through the generosity of the people of NSW.
To support Cancer Council, call 1300 780 113.*

