

Acute leukaemia in children, adolescents and young adults

A guide to best cancer care



About this guide

Being told that you or your child has, or could have, acute leukaemia can be overwhelming. A lot can happen quickly, and you might have many questions. This resource can help to guide you, your family and friends through this experience.

Information and support

For more information about leukaemia, visit the Leukaemia Foundation website www.leukaemia.org.au/leukaemia.

Cancer Council: For information and support, call **13 11 20** to talk to an experienced health professional or visit www.cancer.org.au.

Leukaemia Foundation: To speak with an experienced health professional who can provide you with disease-specific information, answer questions, talk through concerns and connect you to blood cancer support groups call **1800 620 420** or visit www.leukaemia.org.au. The team can also help with practical concerns such as accommodation close to treatment, transport to appointments and financial assistance.

Canteen: Call **1800 835 932** for information, individual case management, counselling, therapeutic programs and education and career support for adolescents and young adults (12–25 years) who have been affected by their own or a family member's cancer diagnosis. Canteen also provides support to the parents of these young people. You can also visit www.canteen.org.au.

Redkite: Call **1800 592 410** for free practical, emotional and financial support for all members of families with a child with cancer (aged 18 or younger). Support includes counselling for all members of the family (including children), peer support groups, financial assistance and help to connect with other relevant support services. You can also visit www.redkite.org.au.

More information is available in the 'Resource' section of the optimal care pathway for acute leukaemia in children, adolescents and young adults www.cancer.org.au/OCP.

Translating and Interpreting Service (TIS): If you need a translator, call TIS on **13 14 50** or visit www.tisnational.gov.au.

Initial tests and referrals

Symptoms

Your / your child's general practitioner (GP) or other primary care physician will do a check-up to see if they can find what is making you / your child unwell. They will ask about any symptoms such as persistent unexplained fever or bruising, extreme fatigue, recurring infections, bone pain with no obvious cause, inability/refusal to walk and/or pale appearance.

Initial tests you may have

Physical examination. To check for signs and symptoms of acute leukaemia, this may include an examination of the abdomen.

Blood test. A sample of blood is collected and sent to a laboratory for testing.

Referrals

If the GP suspects acute leukaemia, you / your child will be referred to a haematologist or medical oncologist (specialist) at a public hospital or in private practice for more tests. Haematologists are doctors highly trained in conditions that affect the blood and bone marrow.



It can help to have a family member, carer or friend attend appointments with you.



Let the doctor know what is most important to you / your child in a specialist (e.g. that they specialise in leukaemia, cost, location, bedside manner, expertise).



Timeframes

If acute leukaemia is suspected or confirmed, referral to a specialist should happen **immediately**. This may be done by telephone.



Ask the GP to recommend trusted sources of information and support – these can be shared with family and friends too.



Talk to the GP/specialist about how to manage other health conditions during your cancer treatment and let them know if you have any concerns.



Questions you might want to ask

- Can I / my child choose the specialist?
- What emotional and mental health support services are available? How can they be accessed?
- Can I choose between a public or private hospital?
- What are the differences of being treated in the public versus private system?
- Will siblings be at a higher risk of developing an acute leukaemia?



It's a good idea to keep a written diary or digital record of treatment details and appointments with the GP and specialists. You can ask permission to record appointments. It's also helpful to bring a list of questions and ask for a written treatment plan. This can be an important source of information for later in life.



Don't ignore new signs and symptoms. Alert the GP or specialist. Trust yourself. It's OKAY to be persistent.

Travel to access tests, treatment and care

You may have to travel to see a specialist, undergo tests or access treatment, especially if you live in a rural or regional area. In some cases you may have to leave home for an extended period of time. Accommodation and transportation support services are available and it is encouraged to have family support with you whilst you undergo treatment.

Mental health and emotional wellbeing

A blood cancer diagnosis can affect your mental and emotional wellbeing. Patient support organisations, your GP or another health professional (e.g. a psychologist or social worker) can help you process your diagnosis and develop strategies to cope. They can help you access a mental health treatment plan if required.

Diagnosis and treatment planning

The haematologist/specialist will do more tests to diagnose acute leukaemia and to help determine the best treatment.

You / your child might have one or a mix of tests:

- **Bone marrow biopsy.** A small sample of bone marrow is taken from the back of the hip/pelvic bone under local anaesthetic and, in some cases, light sedation. This is usually done with a general anaesthetic in children. The samples are sent to a laboratory for examination to see if there is any leukaemia detectable and in some instances for further specialised testing.
- **Lumbar puncture.** A needle is inserted between two lumbar bones (vertebrae) in the lower back to remove a sample of fluid from around the spinal cord (called cerebrospinal fluid). This is usually done with a general anaesthetic in children.



Timeframes

Tests are often performed **on the same day** you go to the specialist blood cancer service. However, after being assessed by the specialist, sometimes procedures are delayed to the nearest suitable day



Questions you might want to ask

- What is acute leukaemia and where can I find more information about it?
- What tests might be needed and why?
- Will follow-up appointments be face-to-face or by tele/videohealth, or a combination?
- What's my / my child's prognosis?
- How much will appointments and tests cost and how much will we have to pay ourselves?
- Can we choose where to have treatment?
- Will treatment need to start straightaway?
- How long will treatment last?
- Is there information that I can share with my family or friends?
- What support services are available to me or my child?

Treatment

Your specialist will discuss treatment options for acute leukaemia. This may involve a team of experts and require more than one treatment type to get the best results. The team will work with you and your family or carer to plan treatment.

Treatment may involve one or a combination of the following:

- **Chemotherapy.** Drugs are used to kill cancer cells and stop the cancer growing.
- **Radiation therapy.** This uses x-rays to kill cancer cells and stop the cancer growing.
- **Allogeneic stem cell transplant.** This replaces the blood-forming cells that have been destroyed during intensive chemotherapy or radiotherapy. Stem cells are collected from the blood of a suitable donor. These stem cells are cells that help the body grow new healthy blood cells. When your chemotherapy is finished, the stem cells that were collected are injected into your bloodstream through a drip into a vein.
- **Immunotherapy.** This is a type of cancer treatment that helps the body's immune system fight the cancer.
- **Targeted therapy.** This uses drugs to attack specific features of cancer cells to stop the cancer growing.

For more information visit www.cancer.org.au/cancer-information/treatment.

Supportive care (treatment or services that support you through a blood cancer experience) are also available, often delivered through a multidisciplinary team that may include nurses, pharmacists, psychologists, physiotherapists and dietitians.



Timeframes

Treatment should start **as soon as possible**.

Clinical trials

Your specialist may recommend participating in a clinical trial (or you can ask if you are eligible for any clinical trials). Clinical trials often provide access to promising new treatments that are not yet available to the general public. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit www.australiancancertrials.gov.au or <https://anzchog.org/clinical-trials-research/clinical-trial-initiatives/>, or search the Australian New Zealand Clinical Trials Registry www.anzctr.org.au.

Complementary therapies and other medications

Speak to the healthcare team about any dietary supplements, vitamins, herbal remedies and other medications that you / your child use or would like to use, including prescription and over-the-counter medicines (e.g. paracetamol or ibuprofen). Some medicines and complementary therapies might not work well with treatments.

Fertility and sexual health

Blood cancer and blood cancer treatment may cause fertility problems. This will depend on age, the type of blood cancer and the treatment received. If this is relevant, get advice from your treating team about contraception before, during and after treatment. Discuss having children whilst undergoing treatment and the need for a referral to a fertility specialist and options for fertility preservation before starting treatment. Diagnosis and treatment may affect your sex life or overall sexual health. For support and, if necessary, referral to counselling services, contact the Leukaemia Foundation on **1800 620 420** or visit www.leukaemia.org.au and type 'Relationships and sex' in the search bar.



Questions you might want to ask

- What treatment do you recommend and why?
- Are there alternatives?
- What will happen if I / my child decline treatment?
- How long will the treatment last?
- What will treatment cost and how much of the cost will we have to pay?
- What activities/exercise will help during and after treatment?
- Is there any specific diet to follow or foods or drink to avoid during treatment?
- How will the treatment affect day-to-day life and work/study?
- Who is in the treatment team and who is the main contact person for any questions?
- Will there be short-term or long-term side effects from the treatment? How can they be managed?
- Could the treatment affect fertility and, if yes, what options should be considered?



Decisions about cost

There may be costs for some appointments, tests, medications, accommodation, travel or parking.

Speak with the GP, specialist or private health insurer (if you have one) to understand what is covered and what out-of-pocket costs there may be.

If you have concerns about costs, talk to the healthcare team or a social worker about:

- being bulk-billed or treated in the public system
- help with accommodation and/or transport during treatment
- the possible financial impact of treatment and financial support schemes you may be able to access
- how the treatment might affect your / your child's ability to work.

For more information about financial and practical support call the Cancer Council on **13 11 20** or visit www.cancer.org.au/support-and-services/practical-and-financial-assistance. You can also contact the Leukaemia Foundation on **1800 620 420** or visit www.leukaemia.org.au/how-we-can-help/practical-support-services.

Care after initial treatment and recovery

Blood cancer treatment can cause physical and emotional changes. The ongoing care and support throughout and after treatment for acute leukaemia may vary depending on your / your child's age and the treatment received.

Survivorship care plan

The specialist and healthcare team will work with you and the GP to develop a written plan. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- understanding and dealing with the potential side effects of treatment
- how to get help quickly if you think the blood cancer has returned or is worse
- how to look after your / your child's overall health and wellbeing.

Many people worry that their blood cancer will return. The specialist and healthcare team will talk about your / your child's needs and can refer you to other health professionals and community support services. Other information you may get includes:

- signs and symptoms to look out for if the blood cancer returns
- side effects of treatment and the specialists you / your child may need to see
- how to make healthy lifestyle choices to give the best chance of recovery and staying well.

For more information visit <https://www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment>.



Questions you might want to ask

- Who should I contact if I / my child is feeling unwell?
- What can I / my child do to be as healthy as possible?
- Where can I / my child get more help?

Living with relapsed or refractory disease

Sometimes acute leukaemia can return after treatment (relapse) or doesn't respond to conventional treatment (refractory). Acute leukaemia can come back in the same way or in different ways.

If leukaemia returns, treatment will depend on when the leukaemia returned in relation to previous therapy, and what this therapy was. The treatment will be the best available therapy for the relapsed disease. In many cases relapsed leukaemia remains curable.



Questions you might want to ask

- What are the treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- What financial, practical or emotional support is available?

Advance care planning

The GP or healthcare team may talk with you, your family and carer about future treatment and medical needs.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and medical team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit www.advancecareplanning.org.au.

Symptom and palliative care management

Palliative care can help you / your child to live as well as possible including managing pain and symptoms, psychosocial support and assistance in identifying care goals. This care may be at home, in a hospital or at another location you choose. The specialist may provide a referral to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with blood cancer or if their blood cancer returns.

Speak to the GP or haematologist/specialist or visit www.palliativecare.org.au.

Making treatment decisions

You / your child may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You can always change your mind about treatment. Just talk to the specialist. For more information visit www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.



Questions you might want to ask

- What can be done to reduce the symptoms?
- What extra support can my family and friends get if they care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Is a referral to a community support service possible?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Leukaemia Foundation and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

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This resource is based on information from the optimal care pathway for children, adolescents and young adults with acute leukaemia (1st edition), available at www.cancer.org.au/OCP.