

Acute lymphoblastic leukaemia

Your guide to best cancer care



About this guide

Being told you have or could have acute lymphoblastic leukaemia (ALL) can be overwhelming. A lot can happen quickly, and you might have many questions. There are two types of ALL depending on which young (immature) white blood cells (lymphocytes) are affected and are rapidly growing and dividing out of control; these are B-cell ALL and T-cell ALL. This resource can help to guide you, your family, and friends through this experience.

Information and support

For more information about ALL, visit the Leukaemia Foundation website www.leukaemia.org.au/blood-cancer/leukaemia/acute-lymphoblastic-leukaemia/.

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

Leukaemia Foundation: To speak with an experienced healthcare professional who can provide you with disease-specific information, answer your questions, talk through your 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.

More information is available in the 'Resources' section of the optimal care pathway for acute lymphoblastic leukaemia 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 general practitioner (GP) or other primary care physician will do a check-up to see if they can find out what is making you unwell. They will ask you about any symptoms you might be having such as fatigue, weakness, dizziness, pale appearance, chest pain when exercising, nose bleeds, easy bruising, fevers with severe and/or recurrent infections, bone and/or joint pain, or heavy menstrual bleeding. Pain management for symptoms such as bone and joint pain may be necessary at time of diagnosis.

Initial tests you may have

Physical exam. Your doctor will check to see the cause of symptoms such as those noted above.

Blood tests. A sample of your blood is collected and sent for a full blood examination and may include a liver function test.

Referrals

If your GP thinks you may have ALL, you will be **immediately** referred to a specialist cancer centre.



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



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



Timeframes

Your general practitioner should begin investigations **immediately** if ALL is suspected. If you are clinically unwell, **immediate** referral to an emergency facility is recommended without waiting for blood results. ALL is always a medical emergency as it progresses quickly, and treatment will need to begin soon after diagnosis.

ALL is always a medical emergency, and you will be immediately referred to an emergency facility to begin treatment.



Ask your GP to recommend trusted sources of information and support – you can share these with your family and friends too.



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



Questions you might want to ask your doctor

- Are there any symptoms that I should watch out for while I am waiting for my appointment to see a specialist?
- Can I choose the specialist I see?
- What emotional and mental health support services are available and how do I access them?
- Can I choose whether I go to a public or private hospital?
- What are the differences of being treated in the public versus private system?
- Are there any extra tests we can do now to eliminate some other possibilities?



It's a good idea to keep a written diary or digital record of treatment details and appointments with your GP and specialists. You can ask permission to record your appointments. It's also helpful to bring a list of questions and ask for a written treatment plan.



Don't ignore new signs and symptoms. Alert your 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 all cases, you will have to leave home, and it may be for an extended period of time as ALL requires intensive inpatient hospital treatment in the initial stages. It is likely you will stay in hospital for your first cycle of treatment.

Accommodation and transportation support services are available, and it is encouraged to have family support with you whilst you undergo treatment. See further information on Leukaemia Foundation's accommodation and transport support by visiting the following websites www.leukaemia.org.au/how-we-can-help/accommodation-services/ and www.leukaemia.org.au/how-we-can-help/transport-services/

Mental health and emotional wellbeing

A blood cancer diagnosis can affect your mental and emotional wellbeing. Many people being treated for a blood cancer experience a range of feelings and it is not uncommon to feel low, depressed, or anxious. Patient support organisations such as the Leukaemia Foundation or Cancer Council, your GP, or another health professional such as a psychologist or social worker can help you develop strategies to cope. They can help you access a mental health treatment plan if required.

Diagnosis, staging and treatment planning

The haematologist/specialist will do more tests to see if you have ALL, to check how advanced it is, and to help determine the best treatment for you.

You may have one or a combination of these tests:

- **Blood tests.** A sample of your blood is collected and sent for a full blood examination.
- **CT, MRI, or PET scans** of the neck, head, chest, abdomen, and pelvis with a contrast dye as indicated by symptoms experienced.
- **Echocardiogram** or other cardiac imaging to check heart function.
- **Hepatic tests** including a liver span test to check the size and functioning of the liver.
- **Scrotal ultrasound** in all male patients.
- **Lumbar puncture.** A doctor will put a needle into your lower back and take out a small amount of fluid. This is usually done with a local anaesthetic and can be done under CT scan in some situations.
- **Lymph node biopsy.** A doctor will put a thin needle into your lymph node to remove a small sample of cells which will then be sent to a laboratory for examination.
- **Bone marrow testing.** A bone marrow sample is collected from the hip using a thin needle. You may have a bone marrow aspirate and/or a bone marrow biopsy. The fluid portion of the bone marrow will be sampled for a bone marrow aspirate and the solid portion will be sampled for a bone marrow biopsy. Samples are then sent to a laboratory for examination. This is usually done with a local anaesthetic.



Timeframes

You should have most critical results back within **48 hours** though some tests may take longer and may come back after treatment has already commenced.



Questions you might want to ask

- What is ALL and where can I find more information about it?
- What tests will I need and why?
- What's my prognosis?
- How am I going to be impacted financially and what financial support is available if needed?
- Can I choose where I have treatment?
- Will I need to start treatment straight away?
- How long will the treatment last?
- How will my disease be monitored?
- Is there information that I can share with my family or friends?
- What support services are available to me?

Treatment

Your specialist will talk to you about your treatment options for ALL. You may need more than one treatment type to get the best results, and you may require ongoing treatment to manage your ALL for the rest of your life.

You may have one or a combination of these treatments:

- **Chemotherapy.** Drugs that are used to kill cancer cells to stop the cancer growing. Treatment for newly diagnosed ALL generally consists of nine to 12 months of intensive chemotherapy, followed by three years of maintenance therapy. Chemotherapy for ALL can be delivered intravenously (through IV) or orally in pill form.
- **Allogeneic stem cell transplant (allo-SCT).** An allo-SCT is where stem cells are collected from the blood of a suitable donor and put into your blood stream through a drip into a vein.
- **Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. It can be considered as an emergency treatment.
- **Targeted therapy and immunotherapy** use drugs to attack specific features of cancer cells and 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 cancer experience) are also available, often delivered through a multidisciplinary team that may include nurses, pharmacists, psychologists, physiotherapists, and dietitians.



Timeframes

By evaluating your symptoms and test results, your specialist will determine when your treatment should start. For most people with ALL this will be **as soon as possible**. Radiation should be commenced **within 72 hours** where preserving the organs is the goal. There may be instances where your treatment could be delayed beyond this timeframe. If this occurs your specialist will discuss this with you.

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. Participation in a clinical trial is voluntary and you can choose not to participate in a clinical trial or withdraw from a clinical trial at any point if you wish.

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

Complementary therapies and other medications

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

Fertility and sexual health

Blood cancer and blood cancer treatment may cause fertility problems for both men and women. 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 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. Canteen Australia also provides some helpful information on fertility options after a cancer diagnosis www.canteen.org.au/young-people/with-cancer/fertility-options.



You can ask for more time to think about your treatment options.



You can ask your GP for a referral to another specialist for a second opinion.



Questions you might want to ask

- What treatment do you recommend and why?
- Are there alternatives?
- What will happen if I don't have treatment?
- How long will I need to be on treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercises are available to me during and after treatment?
- Is there any specific diet I should follow or foods or drink to avoid during treatment?
- How will the treatment affect my day-to-day life, and can I still work?
- Can people visit me in hospital?
- Who is in my treatment team and who is the main contact person if I have any questions or feel unwell?
- What side effects could I have from treatment and how should I manage them?
- Will treatment affect my ability to have children, and if yes, what options should I consider?



Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel, or parking.

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

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

- being bulk-billed or being treated in the public system
- help with accommodation and/or transport during treatment
- the possible financial impact of your treatment and financial support schemes you may be able to access
- how your treatment might impact your 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 or contact the Leukaemia Foundation on **1800 620 420** or visit www.leukaemia.org.au/how-we-can-help/practical-support-services/.

Care during treatment

ALL can often relapse, and this can affect your physical, psychological, nutritional, and general wellbeing. Comprehensive support and side effect management should be part of your routine ongoing care.

ALL survivors may experience inferior quality of life and cancer-related symptoms for up to five years after their diagnosis. Distress, fear of cancer recurrence, fatigue, obesity, and sedentary lifestyle are common symptoms reported by cancer survivors.

Survivorship care plan

You may need regular ongoing follow-up appointments and care, so your specialist and healthcare team will work with you to make a survivorship care plan for you and your GP. Your survivorship care plan may need to be updated over time if your needs change. 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 potential side effects of treatment
- how to get help quickly if you have an urgent problem
- how to look after your overall health and wellbeing
- what healthcare and community support services are available to you and how to access them.

Your specialist and healthcare team will talk to you about your needs and can refer you to other health professionals and community support services. Other information you get might be about:

- the side effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of staying well.

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



Questions you might want to ask

- Who should I contact if I'm feeling unwell?
- What can I do to be as healthy as possible?
- Will my follow-up appointments be face-to-face or by tele/video health or a combination?
- Where can I get more help?

Living with relapsed or progressive disease

The highest risk of relapse is within the first three years of starting therapy for ALL, but later relapse can occur. For immediate post-therapy follow-up, the frequency of these appointments will be determined by your specific needs and may range between several times a week and a follow-up every six weeks. Survivors of ALL generally require regular follow-up appointments for five or more years after cancer treatment finishes and will usually reduce over time for patients in remission. Follow-up of asymptomatic patients (experience no symptoms) should include regular monitoring of full blood counts and chemistry as well as a complete medical history and physical examinations.

Treatment will depend on how far the cancer has progressed, how fast-growing it might be, and the symptoms you are experiencing.

Options may include:

- Immunotherapies
- Chemotherapy
- Allogeneic stem cell transplant
- CAR-T cell therapy
- Supportive and/or palliative care.



Questions you might want to ask

- What is the phase of my disease?
- What are my treatment options?
- What are the chances that the treatment will work?
- How is this treatment different?
- Are there clinical trials available?
- What financial, practical, or emotional support is available?
- Are there any support services available that specialise in the psychological support of cancer patients?

Advance care planning

Your GP or healthcare team may talk with you, your family, and carer about future treatment and medical needs. It is important to have this conversation so that you can make your wishes and decisions about your treatment and care known to your doctors and family.

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. There are also sections in the document where you can make comments in your own words. For more information visit www.advancecareplanning.org.au.

Symptom and palliative care management

Palliative care can help you to live as well as you can 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. Your specialist may refer you 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 your GP or haematologist/specialist or visit www.palliativecare.org.au.

Making treatment decisions

You 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 your treatment. Just talk to your 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 my symptoms?
- What extra support can I get if my family and friends 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?
- Can I be referred to a community support service?
- What support services are available to me to help manage the ongoing nature of my blood cancer?

Survivorship

Many people are living longer with cancer, and it is important that people receive ongoing care and support in finding a 'new normal', managing general health, the effects of the cancer and/or treatment, and coping with the emotional impact of cancer and fear of recurrence.

Life is not exactly the same as it was before a blood cancer diagnosis. A 'new normal' is about living with your blood cancer or living in remission, and creating and maintaining your 'new normal' to live as good a life as possible while facing changes such as, but not limited to:

- physical/mental/spiritual
- emotional/relationships/identity/sexuality
- financial, ability to work/return to productivity.

Seeking information, tools, and support, and accepting help to manage challenges that arise throughout a person's cancer experience is very important. Having this support can enable individuals to have a high quality of life and it is important to remember that everyone handles it and is affected differently when diagnosed and treated for a blood cancer.

Helpful links

- Leukaemia Foundation Emotional Support Services: www.leukaemia.org.au/how-we-can-help/emotional-support-services/.
- Leukaemia Foundation Health and Wellbeing Services: www.leukaemia.org.au/how-we-can-help/health-and-wellbeing-support-services/.
- Leukaemia Foundation Support Groups and Webinars: www.leukaemia.org.au/get-involved/events/.

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 people with acute lymphoblastic leukaemia (1st edition), available at www.cancer.org.au/OCP.