Acute myeloid leukaemia

Your guide to best cancer care

About this guide

Being told you have acute myeloid leukaemia (AML) or could have AML can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

Information and support

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

For more information about AML, look for Cancer Council's Understanding Acute Leukaemia booklet on your local Cancer Council website.

Leukaemia Foundation: For information and support from a healthcare professional call **1800 620 420** or visit **www.leukaemia.org.au.**

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 referral

Symptoms

Your general practitioner (GP) will do a check-up to see if they can find what is making you unwell. They will ask you about any symptoms you might be having such as feeling tired, unusual bleeding or bruising or a persistent infection.

Initial tests you may have

Blood test. A sample of your blood is collected and sent to a laboratory for examination under a microscope.

Referrals

If your GP has concerns, you will be referred to a haematologist (specialist) at a public hospital or in private practice for more tests. Haematologists are doctors who are highly trained in AML and other conditions that affect the blood.

You can bring a family member or friend with you to your appointments.

Timeframes

If your doctor thinks you might have AML you should be referred for an urgent assessment by a haematologist at an appropriate facility **within 24 hours.**

If you have fevers, bleeding or severe symptoms you should go straight to an emergency department without waiting for the results of laboratory tests **(same day)**.

Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the haematologist I see?
- How much will appointments cost me?

Australian Government
Cancer Australia

VICTORIA State Government

Cancer Council

Diagnosis and pre-treatment investigations

The haematologist will do some tests to confirm if you have AML (and acute promyelocytic leukaemia [APL] which is a special sub-set of AML). This process of working out if you have a medical problem is called making a **diagnosis**.

You might have one test or a mix of tests:

Physical examination. To check for signs and symptoms of AML.

Bone marrow tests. There are two main types of bone marrow tests – a bone marrow aspiration and a bone marrow trephine biopsy. These tests are usually done at the same time with a local anaesthetic, so you don't feel pain, and involve a long, thin needle being inserted into the hipbone.

For an aspiration, bone marrow cells are collected using a thin needle. For a trephine biopsy, a larger piece of bone marrow is removed using a slightly larger needle. The samples are sent to a laboratory for examination.

The haematologist may do more tests to see how well your organs are functioning. This helps to work out the best treatment for you. If you do have these tests, you might have one test or a mix tests:

Lumbar puncture or spinal tap. 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 so you don't feel pain.

Magnetic resonance imaging (MRI) brain. A scan where a powerful magnet and radio waves are used to make a detailed picture of the brain.

Positron emission tomography (PET)-computed tomography (CT) scan. Computers and x-rays are used to make a detailed picture of your body, and a small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

Echocardiogram. Soundwaves are used to make pictures of your heart and see how well it is working.

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

Human leukocyte antigen (HLA) typing. Your blood sample is tested for HLA. HLA is found on most cells in your body and it helps your immune system recognise which cells belong in your body.

Timeframes

Tests to see if you have APL should be done **immediately** and the results should be available as soon as possible.

If you have AML, other test results to help start your treatment should be available **within 72 hours** of your haematologist appointment.

Questions you might want to ask

- What is AML?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What support services are available to me?

Treatment

There are several ways to treat AML. Your haematologist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

Chemotherapy uses drugs to kill cancer cells and stop the cancer growing. Intensive chemotherapy is the most common treatment. For some people, very high doses of chemotherapy are needed to effectively treat their AML. The high dose might kill some of your bone marrow and stem cells. This is known as a side effect of treatment. You need these cells to make blood.

There are usually two stages in this treatment: the induction stage to kill the leukaemia cells (remission) and the consolidation stage to help prevent the leukaemia from reappearing.

Allogeneic stem cell transplant (allo-SCT). You might have an allo-SCT to get your bone marrow and stem cells back. 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 may be used with chemotherapy or before a stem cell transplant.

Targeted therapy uses 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.

Timeframes

Treatment should start **promptly** once a diagnosis is made and a treatment plan is confirmed.

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

Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. 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.**

Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.

Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?

Decisions about cost

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

Speak with your GP, haematologist 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 during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a healthcare professional about financial support.

For more information about costs, visit
www.cancer.org.au/support-and-services/practical-and-financial-assistance
and
www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment.

Recovery

Cancer treatment can cause physical and emotional changes.

Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. 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 side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your haematologist and healthcare team will talk with you about your needs and can refer you to other healthcare professionals and community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and 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 am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

Living with advanced cancer

If cancer returns

Sometimes AML can return after treatment. AML can come back in the same way as originally or in different ways.

If cancer returns, you may be referred to the haematologist or the hospital where you were first treated, or to a different haematologist.

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

Questions you might want to ask

- Where is the cancer and has it progressed?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your 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 healthcare 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.**

Palliative care

Your haematologist 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 cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or haematologist 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 may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit **www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment**.

Questions you might want to ask

- What can you do 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?

Published in September 2021.

This resource is based on information from the optimal care pathway for people with acute myeloid leukaemia (2nd edition), available at www.cancer.org.au/OCP.