

# Chronic lymphocytic leukaemia (CLL)

Your guide to best cancer care



## About this guide

Being told you have or could have chronic lymphocytic leukaemia (CLL) 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 CLL, visit the Leukaemia Foundation website [www.leukaemia.org.au/CLL](http://www.leukaemia.org.au/CLL).

**Cancer Council:** For information and support, call **13 11 20** to talk to an experienced health professional or visit [www.cancer.org.au](http://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](http://www.leukaemia.org.au). The team can also help with practical concerns such as accommodation close to treatment, transport to appointments and financial assistance.

**Lymphoma Australia:** For education, support and advocacy for lymphoma and CLL call **1800 953 081** or visit [www.lymphoma.org.au](http://www.lymphoma.org.au). Lymphoma Australia nurses can help patients and their families understand their diagnosis and treatment options, navigate the lymphoma journey and connect patients with other support networks.

More information is available in the 'Resource' section of the optimal care pathway for CLL [www.cancer.org.au/OCP](http://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](http://www.tisnational.gov.au).

## Initial tests and referrals

### Symptoms

CLL is often picked up during routine blood tests by your general practitioner (GP) or other primary care physician for unrelated conditions; most people don't have any symptoms when they are diagnosed. When present, symptoms can include painless swelling of lymph nodes (often around the neck), unexplained weight loss, feeling extremely tired to the point where you can't do your normal everyday activities, frequent infections or shingles.

Your GP should do a check-up to see if they can find the reason for abnormal blood test results or symptoms you might have.

### Initial tests you may have

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

**Physical examination.** This is to check for signs and symptoms of CLL including a check of your lymph nodes to see if they are swollen and your abdomen to see if your spleen and liver are enlarged.

### Referrals

If your GP thinks you may have CLL, you 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 your doctor know what is most important to you in a specialist (e.g. that they specialise in CLL, cost, location, bedside manner, expertise).**



### Timeframes

Your specialist appointment should usually happen within about **two weeks**. If your GP finds that you have severely low platelets (severe bleeding), severely low red blood cells (severe anaemia), or your lymph nodes are very large, you should be referred to a haematologist **within 72 hours**.

**If you can't get an appointment within this timeframe, follow up with your GP.**



**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 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

- 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?



**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 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, staging and treatment planning

Your haematologist/specialist will do more tests to see if you have CLL, see how advanced it is and help determine whether treatment is needed, and if so, the best treatment for you.

You may have one or a combination of these treatments:

- **Bone marrow biopsy.** A small sample of bone marrow is taken from the back of your hip/pelvic bone under local anaesthetic and, in some cases, light sedation. The samples are sent to a laboratory for examination to see if there is any cancer detectable and in some instances for further specialised testing.
- **CT scan.** Computers and x-rays are used to make a detailed picture of the body. This may be recommended if you have specific symptoms, there is concern about very large lymph nodes causing internal problems, or your specialist is considering the need to start treatment.



### Timeframes

You should generally have results back **within two weeks**.



### Questions you might want to ask

- What is CLL and where can I find more information about it?
- What tests will I need and why?
- Will my follow-up appointments be face-to-face or by tele/videohealth or a combination?
- What's my prognosis?
- How much will appointments and tests cost and how much will I have to pay myself?
- Can I choose where I have treatment?
- Will I need to start treatment straightaway?
- How long will 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

CLL is usually slow growing, so unless you have symptoms or there is evidence that your CLL is getting significantly worse, your specialist will generally recommend a 'watch and wait' approach rather than immediately starting treatment. This will involve monitoring your CLL with regular blood tests. Watch and wait is recommended as starting treatment before there are symptoms or signs that the disease is worsening does not improve how long you live or your quality of life.

If and when you need treatment, your specialist will talk to you about your options. You may 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 or a combination of these treatments:

- **Chemotherapy.** Drugs are used to kill cancer cells and stop the cancer growing.
- **Targeted therapy.** This uses drugs to attack specific features of cancer cells to stop the cancer growing.
- **Immunotherapy.** This is a type of cancer treatment that helps the body's immune system fight the cancer.

- **Allogeneic bone marrow 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 and put into your bloodstream through a drip into a vein. This is only used in rare cases and will not be the first treatment used.
- **Radiation therapy.** This uses x-rays to kill cancer cells and stop the cancer growing. This may be used to treat large/obstructive lymph nodes or enlargement of the spleen.

For more information visit <https://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 for CLL is rarely urgent and may be managed by a period of close observation without active treatment. This is known as 'watch and wait'. By keeping an eye on your symptoms and test results, your specialist will determine when active treatment may be needed. Once the decision for active treatment is made, it should generally start **between two to four weeks**.

### 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](http://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](http://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 and complementary therapies might not work well with your treatment.

## 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](http://www.leukaemia.org.au) and type 'Relationships and sex' in the search bar.



**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/exercise will help 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?
- 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 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 affect your ability to work.

For more information about costs, call the Cancer Council on **13 11 20** or visit [www.cancer.org.au/support-and-services/practical-and-financial-assistance](http://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](http://www.leukaemia.org.au/how-we-can-help/practical-support-services).

## Transitioning from active treatment

Blood cancer treatment can cause physical and emotional changes.

### Survivorship care plan

Your specialist and 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 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 overall health and wellbeing
- what healthcare and community support services are available to you and how to access them.

For more information visit [www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment](http://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?
- Where can I get more help?

## Living with relapsed or progressive disease

### If CLL returns or progresses

In most cases CLL will eventually come back or start growing again after treatment, but it is usually gradual, and you may not develop symptoms. This is known as relapsed or progressive disease. It's important to know that developing relapsed disease does not necessarily mean you will need immediate treatment. If you don't have symptoms, your doctor may recommend 'watch and wait' instead.

If you do need treatment, options will depend on the features of the disease, how it was managed before and your current preferences.

Options may include one or more of:

- targeted therapy
- chemoimmunotherapy
- taking part in a clinical trial where you may try a new treatment
- an allogeneic stem cell transplant.



### Questions you might want to ask

- How advanced is the blood cancer?
- What are my 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

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 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](http://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](http://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](http://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?

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, Leukemia 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 chronic lymphocytic leukaemia (1st edition), available at [www.cancer.org.au/OCP](http://www.cancer.org.au/OCP).