# Chronic myeloid leukaemia (CML)

## Your guide to best cancer care

## About this guide

Being told you have or could have chronic myeloid leukaemia (CML) 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 CML, visit the Leukaemia Foundation website **www.leukaemia.org.au/CML**.

**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.

More information is available in the 'Resource' section of the optimal care pathway for CML **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 feeling very tired and weak, unexplained weight loss, bone pain, bruising or bleeding and night sweats. Some people experience symptoms, such as feeling very full after only eating a little/unable to finish meals or having abdominal discomfort, but it is common to have no symptoms at all.

### 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 CML.

**PCR test (polymerase chain reaction).** A blood test to check for a specific genetic abnormality found in patients with CML.

### Referrals

If your GP thinks you may have CML, 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 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 CML, cost, location, bedside manner, expertise).**

### Timeframes

The timing of your specialist appointment will depend on the initial results of tests performed by your GP. For a small number of patients an urgent appointment or hospital admission may be required, but for most people with no urgency, an appointment between **four to six weeks** is appropriate.

**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 in addition to 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, phases and treatment planning

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

You might have one test or a mix of tests:

- **Physical exam.** This is to check for signs and symptoms of CML.
- **Electrocardiogram.** This measures the rhythm of the heart.
- **Blood and urine tests.** These check how well your organs are functioning and whether you have certain infections.
- **X-ray.** A chest x-ray will be taken as part of a general assessment of your heart and lung function.
- **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, under light sedation. The samples are sent to a laboratory for examination to see if there is any blood cancer detectable and in some instances for further specialised testing.

CML has three phases called chronic, accelerated and blast. **More than 90 per cent of people who are diagnosed, and with ongoing (potentially life long) treatment, remain in chronic phase CML, which is the least advanced phase**.

### Timeframes

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

### Questions you might want to ask

- What is CML 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?
- Is there information that I can share with my family or friends?
- How will my disease be monitored?
- What support services are available to me?

## Treatment

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

You may have one or a combination of these treatments:

- **Targeted therapy.** This uses drugs that attack specific features of cancer cells and stop the cancer growing. The standard treatment for most people with CML is called a tyrosine kinase inhibitor (TKI). TKIs are oral medications that work by specifically blocking the signals CML cells need to divide and grow so the CML cells can't survive.
- **Chemotherapy.** Drugs are used to kill cancer cells and stop the cancer growing. Your doctor may recommend a mild form of chemotherapy before you start a TKI.
- **Supportive therapies.** These are treatments that support you through a cancer experience. These can help you manage side effects that you might experience while undergoing treatment.

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 this will generally be **within four weeks** of this decision being made. 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.

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 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 TKI 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** and type 'Relationships and sex' in the search bar.

**There are several types of TKI therapy so it is important you take the time to discuss your options with your specialist and understand the advantages and disadvantages of each drug before making a decision.**

**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 manage my treatment and its side effects?
- 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**. 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 during treatment

Lifelong TKI treatment for your CML may be required, 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.

### Survivorship care plan

Current therapies mean that most people with CML are expected to have a normal life expectancy. 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
- 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 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 with 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?
- Where can I get more help?

## Living with refractory or progressive disease

If your CML isn't responding well to treatment (refractory), or advances into the more aggressive accelerated or blast phases of disease (progressive), you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

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

Options may include one or more of:

- treatment with another TKI
- chemotherapy
- a clinical trial
- an allogeneic stem cell transplant.

### 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 this time?
- Is there a clinical trial available?
- What financial, practical or emotional support is available?
- What support services are available to me to help manage the ongoing nature of my blood cancer?

### 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**.

### 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?

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This resource is based on information from the optimal care pathway for people with chronic myeloid leukaemia (1st edition), available at www.cancer.org.au/OCP.