

My Haematology Diary

Leukaemia Foundation

Leukaemia
Foundation®

Navigating the Health System

The Australian health system may seem large, complicated and stressful, especially when you are also living with a blood cancer. Knowing a bit about how our health system works and who are key people in your care can make navigating the system much easier.

Phone numbers

Emergency:

Outpatients:

Day patients:

Inpatients:

Social/welfare worker:

Pharmacist:

• **Name:**

• **Number:**

GP/ medical centre:

• **Name:**

• **Number:**

Who do I contact if...

(include contact name, email or phone number)

I have further questions?

I feel unwell?

I feel unwell after hours?

My details

Name:

Date of Birth:

Hospital Number:

Phone Number:

Name of my condition:

My consultant is:

Treatment centre:

Treatment protocol/clinical trial name:

Allergies:

Next of kin name:

Next of kin phone number:

Other health conditions:

Attach hospital sticker here

Notes

A series of 20 horizontal light blue lines for writing notes.

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Introduction

You have probably received a lot of information since your diagnosis of a blood cancer. Sometimes it is difficult to know when and how to deal with everything you have been told. Having a diagnosis of a blood cancer can affect all aspects of your life. All this can be very confusing. Talk to your treatment team if you have any questions about the treatment.

This booklet can be used as your personal diary to record your progress and to note any changes during and after your treatment. There is space for recording side effects of chemotherapy, temperatures and blood results. It can be helpful to have this information written down to make discussing any issues you may have with your treatment team easier.

The booklet also contains resources that will make your experience a little easier to deal with. Please do not hesitate to contact the Leukaemia Foundation on **1800 620 420**.

**** The information in this booklet does not constitute medical advice. All medical advice should be received from your treating doctor and treatment team.***

Blood Cancers

In this section of our booklet, we provide a brief overview of blood and how cells are made. It is important to point out that the information provided here is of a general nature. Blood cancers occur in cells that originate in the bone marrow and are defined by the uncontrolled growth of faulty cells. To best understand blood cancer, we need to understand the bone marrow, blood and lymphatic system.

Getting to know your bone marrow, stem cells and blood

What is blood?

Blood travels to all parts of the body, carrying oxygen and nutrients and removing waste products. It's made up of cells and plasma. Plasma is the straw-coloured liquid part of the blood that carries blood cells and other substances around your body.

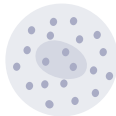
The main types of blood cells are red and white. Platelets are talked about like blood cells, but they are *fragments* of blood cells.

Platelets
Support blood clotting
to stop bleeding



Red Blood Cells

Carry oxygen for the body to produce energy



White Blood Cells

Form part of the immune system

Red blood cells

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives blood its red colour and carries oxygen from the lungs to all parts of the body.

Most blood cells in your total blood volume (40-45%) are red blood cells.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs.

Although they make up only a small part (1%) of the blood, white blood cells protect us against and fight off infection. While all of them are important, you will hear the most about neutrophils and lymphocytes. Neutrophils fight bacteria and are especially important in recovering from chemotherapy.

Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They help your blood clot or stick together; a process called *coagulation*.

Where and how is blood made?

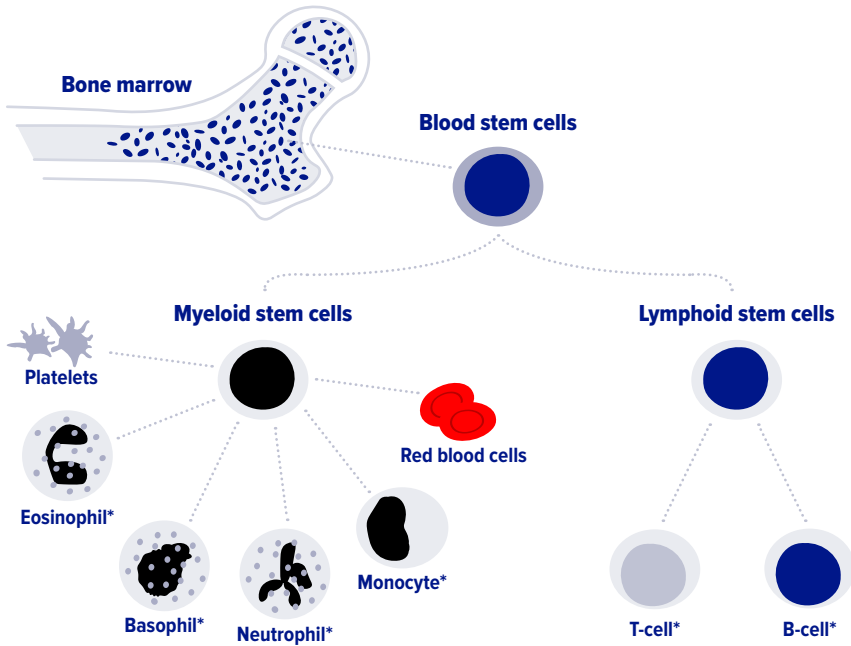
Bone marrow

Bone marrow is spongy tissue in the middle of certain bones. Most blood cells are made in your bone marrow. This process is called *haematopoiesis*.

In children, haematopoiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae) and hips, ribs, skull, and breastbone (sternum). You may have a bone marrow biopsy taken at the back of your hip (the iliac crest).

Think of blood production as a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

There are two types of progenitor cells that split the family tree: lymphoid cells and myeloid cells. Progenitor cells form blast cells.



Growth factors

All normal blood cells live a short time: red blood cells for 80-100 days, neutrophils 8-14 days, and platelets 4-5 days. They then die off and are replaced by new cells from the bone marrow. This means that your bone marrow remains very busy throughout your life.

Chemicals in your blood, called *growth factors*, control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

Some growth factors can be made in the laboratory (synthesised) and given to people to help treat blood disorders.

The Leukaemia Foundation has a range of booklets to help with your questions about specific blood cancers:



leukaemia.org.au/how-we-can-help/information-and-education-services/download-information-booklets/

Question Builder

Below is a list of questions which you may find helpful to ask:

At diagnosis

- What is the name of my condition?
- Do I need further tests?
- What does that involve?
- What treatment is recommended?
- How long will my overall treatment take?
- Who do I call if I become unwell and what should I do?
- Where will I have this treatment – as an inpatient, outpatient, at home?
- What side effects may I experience?
- Will I need to take time off work/school or organise childcare?
- Are there any other treatment options?
- How do they differ from my recommended treatment?
- Would I have to pay for these or move to another treatment centre?
- Am I eligible for clinical trials here or at another nearby treating centre?
- Will I lose my hair?
- How will it affect my physical ability?
- Will my fertility be affected?
- Who else is available to help manage my care and how do I access them?
 - Physio
 - Occupational Therapist
 - Dietitian
 - Social Worker/Welfare officer
 - Chaplain
 - Counsellor/Psychologist

- Do you have any dietary recommendations?
- Can I use complimentary therapies?
- If I can't work, am I eligible for financial assistance?
- Can you provide me with information about the Leukaemia Foundation?
- Are there any other support organisations that I may benefit from?

At routine appointments

- Are there any changes to my treatment schedule?
- Where will this treatment take place?
- How long will this treatment take?
- What are the side effects?
- When am I due for my next investigation? (e.g. CT scan)
- Do I need a prescription/discharge medication?
- When is my next appointment?

Remember to tell your doctor or nurse about any symptoms or side effects you are experiencing



Things to consider

- Do I (or my carer) need a sick form?
- Do I need any Centrelink forms completed?
- Am I entitled to a hospital carpark discount?
- Am I entitled to any government rebates for transport or accommodation?
- How do I access this in my state?
- Do I need forms completed for insurance?

Chemotherapy and infections

Chemotherapy works by killing cells in the body that are dividing. The more frequently particular cells divide, the more they are affected by chemotherapy. Blood stem cells divide rapidly and are destroyed by chemotherapy, temporarily leaving a person with low blood counts and more susceptible to potentially life-threatening infections.

Even when you are at home, you are still at risk of infection. Because your white blood cells may not yet be at normal levels, it is harder to fight infections. This is when you are neutropenic due to low neutrophil counts.

These things will help you prevent infections when you are neutropenic:

- Wash your hands well with soap and water before preparing food, eating meals, taking medications and after going to the toilet
- Make sure you brush your teeth with a soft toothbrush at least four times a day (after meals and before bed at night)
- Avoid people with colds, flu or viruses; especially people with measles, shingles or chicken pox
- Avoid crowds of people where possible - without being obsessive about it
- Try to have little contact with animals. Wash your hands after touching pets. Try not to touch animal litter. Take extra care if handling reptiles or poultry
- Try not to do things that disturb dust, for example vacuuming, dusting, cleaning, gardening, home maintenance or visiting building sites
- Make sure that food is prepared and washed well
- Wear gloves and shoes in the garden. You should not touch mulch or work with dirt/potting mix or wood chips



Check with your treatment team:

- before you take medicine or other remedies that were not prescribed
- which vaccinations you should have

A fever or temperature is one of the first symptoms of infection. That's why, during chemotherapy, it's important to check your temperature at least twice daily at home and at any time that you do not feel well. You need to do this between treatment cycles and for 6-8 weeks after your treatment has finished. You might need to go back to hospital if you have a fever or infection. This is quite common after chemotherapy and is part of the recovery process.

Some treatment centres use alert cards to let people know that you are potentially neutropenic. You should keep this on you at all times

Important advice while having chemotherapy

It is important to discuss all symptoms you may experience during treatment at your regular hospital appointments.

However, it is important that you contact your treatment team for advice immediately if you are feeling unwell or if you are experiencing any of the following:

- A **temperature** of 38°C or more, even if feeling well
- **Shakes, chills** or **sweating** with or without a temperature
- **Bleeding** or **bruising**, for example blood in your urine, bowel motions, coughing up blood, bleeding gums or persistent nose bleeds
- **Nausea** and **vomiting** that prevents you from eating or drinking or taking your normal medications
- **Diarrhoea** – more than four bowel actions per day
- **Constipation** – unable to open bowels for three days
- New/persistent **stomach cramps**
- **Pain** in urination/inability to control passing urine
- **Sore mouth/mouth ulcers** that prevent you from eating or drinking
- Persistent **coughing** or **shortness of breath**
- The presence of a new **rash, reddening of the skin, or itching**
- **Headaches** or **blurred vision**
- A new **severe pain** or persistent unexplained soreness.
- If you notice **pain, swelling, redness** or **pus** around your central venous catheter
- If you think you might have had contact with someone with an illness for example **chicken pox, measles, shingles** or **other viruses**.

Clinical trials

Clinical trials (also called research studies) test new treatments. They are compared against current treatments to see if the new treatment works better. They also check for the new treatment's side effects. Many clinical trials are randomised, which means some patients receive the new treatment and others receive the current standard of care treatment. Clinical trials provide important information about how treatments can be improved. Sometimes people on clinical trials (called 'participants') have access to expensive new treatments that aren't on Australia's Pharmaceutical Benefits Scheme (PBS). Your haematologist may suggest you join a clinical trial. Before you can start, you will need to give informed consent. This shows that you understand the risks and benefits of the trial treatment.

Clinical trials are run through hospitals and clinics, just like other treatments. You will have a clinical trial nurse as part of your treatment team. Clinical trial participation is purely voluntary. If you are offered a clinical trial, make sure you understand how that treatment will be different compared to what is generally given (standard of care treatments). Be sure to ask any questions you have before deciding whether to participate.

You can search current clinical trials at:

Australian Cancer Trials: australiancancertrials.gov.au

ANZ Clinical Trials Registry: anzctr.org.au

ClinTrial: clintrial.org.au





Second opinion

If you feel unsure about your diagnosis or treatment, you are entitled to seek a second opinion from an independent doctor. This may be at the same hospital or clinic, or at a different location. If you feel overwhelmed, then you might benefit from speaking with someone at the Leukaemia Foundation, your GP, or a counsellor for advice.

Complementary therapies

Complementary and alternative medicines (CAM), also known as integrated therapies, are not standard medical treatments. However, some people find that they help with side effects. These therapies should 'complement' or be done alongside medical treatment, after consultation with your treatment team. No complementary or alternative treatment on its own can treat blood cancer. It is important that you discuss any plans you have to try complementary therapies with your treatment team first.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue. It can be hard to describe to people who haven't felt it. It's more than being tired, it's different to normal everyday tiredness, and is often not resolved with sleep or rest. You will feel tired but you may also feel weak and be sleepy, drowsy, impatient, or confused. It's hard when you have no get-up-and-go, however, for most people fatigue should improve after you finish treatment.

Tips for managing fatigue

Fatigue is a side effect of your blood cancer or treatment so managing fatigue is an important part of your overall treatment and care. Make sure you talk to your treatment team about it; they may suggest referral to someone who specialises in sleep management. It's very important to explain how you feel to your carers and support people, and to let them know your priorities and discuss how they can help. A positive sleep routine, pre-sleep relaxation techniques, napping if tired during the day for an hour or less, regular moderate exercise or movement, eating well, drinking plenty of water, and avoiding use of electronic equipment such as computers late at night can be very helpful in improving sleep and reducing fatigue.

While you're managing your fatigue, you can jot down what time of day you have most energy and when you feel most tired. That will help you get into a routine and prioritise your energy. Play games, listen to or play music, read, catch up with friends and family; these things might seem difficult, but they will help distract you from the fatigue. For more tips to manage fatigue with exercise, please refer to our advice on exercise and physical activity.

Exercise/physical activity

With any blood cancer treatment, it is common to experience deconditioning; a physical and/or psychological drop in function. Having cancer doesn't mean you can't be physically active. People with blood cancer should attempt to avoid inactivity and sedentary behaviour as much as possible and return to normal daily activities as soon as possible following diagnosis.

Exercise can be tailored to the individual and often around activities of daily living. Before you commence any exercise program, it is important to speak with your treatment team to make sure it is safe to do so and to see who is best placed to help you.

Information on exercise in cancer can be found on the Clinical Oncology Society of Australia (COSA) website: [cosa.org.au](https://www.cosa.org.au)



Diet and nutrition

During treatment, nutritional goals are to prevent or reverse malnutrition, avoiding weight loss (preserving lean body mass/muscle) and minimise side effects. Common side effects are decreased appetite, nausea, diarrhoea, dry mouth, and taste changes.

To ensure your body is receiving enough nutrition, you can make an appointment to see a hospital dietitian as an outpatient or ask to see one if you are an inpatient.

Community dietitians are also available, and your GP can arrange this through a care plan if you don't have private health insurance or insurance that covers dietitians.



For more information on nutrition, read our 'Eating Well' booklet here:

leukaemia.org.au/wp-content/uploads/2022/08/Eating-Well_Leukaemia-Foundation_FINAL.pdf

Mental health and emotions

Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings and it is not uncommon to feel low, depressed, or anxious.

The Leukaemia Foundation Blood Cancer Support Coordinators can help you to work through what you are feeling and provide information on who might assist you in your local area.

Finances

People with blood cancer often report a negative impact on their financial situation during treatment. Monthly costs can increase and may be influenced by financial considerations such as travel, childcare, and taking time off work for appointments. Your household income may be reduced due to you or your carer having to stop work, or reduce hours permanently or temporarily, as a result of your diagnosis.

Do not hesitate to discuss your financial circumstances with your treatment centre social worker, blood cancer support coordinator or your private insurer. They may be able to assist with advice on deferring payments. Some of your household accounts may also have hardship support programs (including energy providers). It may be possible to access some money from your superannuation fund to help with emergency payments. Don't forget to check if your superannuation has income replacement insurance as one of its features. If you are not sure, give their helpline a call.

An Enduring Power of Attorney (EPOA) is a document that allows your trusted person the power to sign documents on your behalf, make personal, administrative and, if you choose, financial decisions.

An Enduring Guardian (EG) is another document where your trusted person can make decisions on your behalf regarding your health matters such as medical treatment, care, and protection, even if this decision overrides your wishes.



Advance Health Directive

This is a document you may complete to clearly indicate your wishes as to medical treatments you may or may not wish to receive in the event of a serious illness or accident. Although this is a lengthy document, it is simple to complete as it mainly consists of a series of optional questions. There are also sections where you make comments in your own words. While this form can be completed on your own, you may wish to discuss it with your family and you are also required to have a doctor sign the form to certify that you understand the contents of the document.

Useful websites

Leukaemia Foundation

leukaemia.org.au

Australian Bone Marrow Donor registry

abmdr.org.au

Cancer Australia

canceraustralia.gov.au

Cancer Council

cancer.org.au

Lymphoma Australia

lymphoma.org.au

Myeloma Australia

myeloma.org.au



My treatment

Date	Name	Drugs

Date	Name	Drugs

My medications

You have probably been given a number of medications since your diagnosis and may have received a list from the hospital pharmacist. It is important that you take your medications as directed and so it is important that you understand which medications you are taking and why you are taking them. Adhering to your medication regimen is important. Taking a “break” from treatment without the knowledge of your doctor can be harmful. Include your doctor in all your treatment decisions. As your medications and doses can change often, an updated pharmacy list is the best way to keep track.

If you are taking chemotherapy tablets at home, you must remember to wash your hands after taking your medication. If your carer is assisting you to take your medications they should wear gloves as chemotherapy medications can enter the body through the skin.



Date	Dose	Date started?	What's it for?	Side effects?

Date	Dose	Date started?	What's it for?	Side effects?

My appointments

Date	Time	Place	With	For

Date	Time	Place	With	For

Blood results

Monitoring your blood results is an important part of taking control of treatment and care. Use this section to record your progressive results. Please speak to your treatment team if you have any concerns or questions.

Date	Hb	WCC	Neut	Platelets	Other

Date	Hb	WCC	Neut	Platelets	Other

Date	Hb	WCC	Neut	Platelets	Other


Date	Hb	WCC	Neut	Platelets	Other

The Leukaemia Foundation gratefully acknowledges those who assisted in the development of this information: Leukaemia Foundation Blood Cancer Support Coordinators, nursing staff, clinical haematologists, and bone marrow transplant physicians representing the various states and territories of Australia.

The Leukaemia Foundation values feedback. If you would like to make suggestions or tell us about your experience in using this booklet, please contact us via email: info@leukaemia.org.au or phone us on **1800 620 420**.

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GPO BOX 9954, BRISBANE QLD 4001
1800 620 420
leukaemia.org.au

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