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FOUNDATION



Epworth

Epworth Centre for Immunotherapies  
& Snowdome Laboratories

Welcome to the Epworth Centre for  
Immunotherapies and Snowdome Laboratories

# Patient guide



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The Epworth Centre for Immunotherapies and Snowdome Laboratories aims to support you and your family through each step of blood cancer care. You can expect personalised care as you navigate diagnosis, management and treatment.

Our haematologists have extensive experience in treating lymphoma, leukaemia and myeloma. Their expertise includes cancers which have returned (relapsed) or aren't responding to treatment (refractory).

This guide shares what you can expect when receiving blood cancer care at the Epworth Centre for Immunotherapies and Snowdome Laboratories.

Our vision

A Centre of Excellence in blood cancer patient treatment and care



### Contact us

Your Centre haematology nurse coordinator and haematologist are here for your questions and concerns.

### Important numbers to note

**Epworth Centre for Immunotherapies and Snowdome Laboratories reception**  
Phone 03 9426 0555

**In an emergency, always call 000 for an ambulance first.**

## About the Centre

The Epworth Centre for Immunotherapies and Snowdome Laboratories is a private specialist centre launched in 2021. We focus on innovative treatments to bring hope to more Victorians with blood cancers.

Our Centre is unique in the way it combines world-class research with clinical excellence and exceptional patient care. With research, we hope to constantly improve how the world understands blood cancers. Our dedicated researchers work to accelerate new treatment options for these complex cancers.



*Epworth Medical Foundation and Snowdome Foundation, proudly supporting research into blood cancer at Epworth HealthCare.*



### What is blood cancer?

Blood cancer happens when abnormal blood cells grow out of control in the body. These abnormal cells form cancer cells. Cancer cells spread and replace healthy cells and interrupt how your body works.

Lymphoma, leukaemia and myeloma are blood cancers. There are more than 100 sub-types of blood cancers. Haematological malignancy is the medical term used to describe blood cancers. Haematology is the study of blood and blood disorders. Malignancy means cancerous (an uncontrolled growth of cells).

### What are immunotherapies?

Immunotherapies are any treatments that boost or use your immune system. Your body's immune system works to protect you from viruses and diseases, such as cancer.

There are many forms of immunotherapy. It may come as:

- > medication in a tablet, injection under the skin or infusion into a vein
- > immune cells modified to find and kill cancer cells
- > vaccinations against certain cancers.

## What to expect at the Centre

### Compassion

A blood cancer diagnosis is often a very challenging time. We're here to help you and your family through this difficult experience. Our team is always happy to answer your questions and concerns — or listen when you need support.

### Excellent care

Your safety and wellbeing always comes first. You will be closely monitored and have access to emergency care, imaging and allied health across Victoria's largest not-for-profit private hospital group.

### Innovation

Our haematologists are involved in trials and research to accelerate new treatments for blood cancers. We are passionate and connected to the latest knowledge in Australia and overseas.

### Personalised treatment

At Epworth, our priority is to give the very best care to patients as individuals. Blood cancers are unique from person to person. This is why a personalised approach to treatment is so important.

We can use genomics to learn about your individual cancer and guide treatment. Read more about genomics on page 14.



## Your treatment

### What is a treatment plan?

Your personalised treatment plan is a careful map that guides your cancer care at Epworth. It shares details of your treatment, including dates and medications.

At the Centre, you're involved in the decision-making process for your plan so it matches your goals and what matters most to you.

Your haematologist will help you understand your cancer and the types of treatments available. They will explain the potential risks and benefits of each treatment. They consult with a multidisciplinary team (other health professionals) as recommended for best-practice cancer care.

It's important to us that you understand your options and give informed consent during your time at Epworth.



### What is informed consent?

- > You agree or decide on treatment voluntarily (without pressure).
- > You receive enough information about the treatment and other options.
- > You understand the possible risks and benefits.

As someone accessing health services, you have a right to safety, information and partnership. Please ask us about the [Australian Charter of Healthcare Rights](#) or scan this QR code to learn more.



### Treatment intent

Your treatment plan includes the treatment intent. This describes the goal or aim of the treatment plan.

This can be:

- > **curative** – to treat the cancer with the aim of cure. Cure means the cancer never returns.
- > **anti-cancer** – to limit cancer growth or spread, to live longer with quality.
- > **palliative** – to help relieve the symptoms of cancer to provide the best possible quality of life.



### Making treatment decisions

You may like to keep these questions with you to ask at your appointments. Please let us know if you need more information about any part of your care.

- > What is my blood cancer sub-type?
- > What stage is my blood cancer?
- > What test/s do you recommend?
- > What treatment/s do you recommend and why?
- > What is the aim of this treatment?
- > What changes might this treatment have for my life, work, family life etc?
- > What are the risks and side effects of this treatment?
- > Where can I get more information and support?

You are welcome to bring a person with you to your appointments for support or to take notes. We will let you know if there are visitor restrictions at the time of your appointment. In this case, you may like to phone your support person so they can listen in.



## Testing

### A short overview of tests and scans related to lymphoma, leukaemia and myeloma.

Testing helps to diagnose and track how your cancer is responding to treatment (monitoring). The specific tests you have depend on the blood cancer sub-type.

Please note, your treatment may not involve every test below. Your treating doctor will explain any tests they recommend in detail.

- › Physical examination
- › Discussion of your symptoms
- › Blood tests
- › Bone marrow biopsy
- › Lymph node biopsy (tissue biopsy)
- › Imaging
- › Assessment for stem cell transplant eligibility (to see if you are suitable)
- › Other less common tests, such as lumbar puncture (spinal tap).

### Biopsy

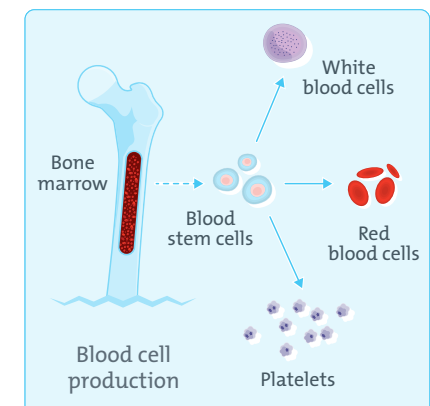
These procedures collect cells from areas with suspected cancer. This allows us to analyse cancer cells under the microscope for accurate diagnosis and monitoring.

You have local anaesthetic to numb the test area.

- › **Bone marrow biopsy** — a needle is inserted into the bone at the back of the pelvis to take out small samples of bone marrow.

#### What is bone marrow?

Blood cells are created and live in the bone marrow. Bone marrow is inside of different bones in the body. It is mostly in the area of the pelvis and spine.

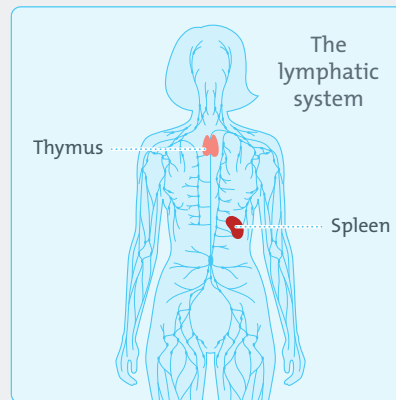


- > **Lymph node removal, or partial removal** — all or some of a lymph node is taken out for testing. This is also known as an excisional or incisional lymph node biopsy. It is commonly performed with local anaesthetic but depending on the location of your lymph node you may need surgery with general anaesthetic (where you are unconscious).
- > **Lymph node core needle biopsy** — a needle is inserted into a lymph node to take out a sample of the lymph tissue and cells.

### What are lymph nodes?

Lymph nodes are a part of the lymphatic system. This system is a network of lymph nodes, blood vessels and organs. It allows white blood cells to travel around the body and if needed, defend the body from infection. The spleen, the tonsils and thymus are part of the lymphatic system.

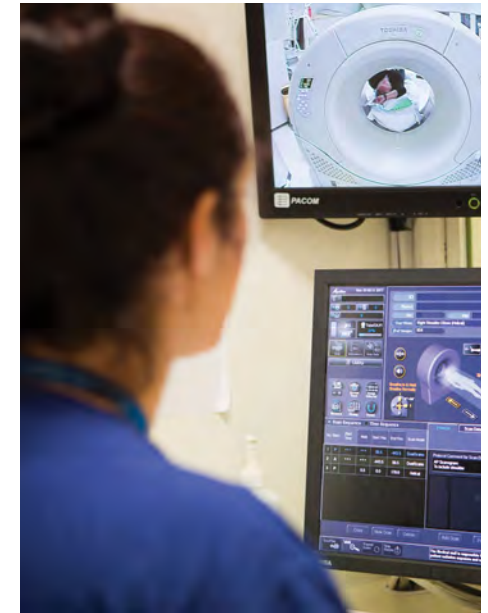
Lymph nodes are all around the body, mostly in the neck, armpits, abdomen (tummy) and groin.



### Imaging

Imaging technology allows us to see what is happening inside the body. Imaging may look at your chest, heart health, and other areas to see the effects of blood cancer.

- > Ultrasound
- > Chest X-ray
- > PET (positron emission tomography) scan
- > CT (computerised tomography) scan
- > PET-CT scan
- > MRI (magnetic resonance imaging) scan



## Genomic testing

Genomic testing looks closely at cancer DNA to see if there are mutations. Mutations are a change to the DNA (instructions for the body).

Your doctor may recommend genomic testing to look for mutations and personalise treatment.

Some mutations help predict how a person's cancer may respond to different types of treatment. Your doctor will explain your results and the treatment approach they recommend.

Genomic testing returns one of three results:

- > no mutations
- > mutations with unknown significance. This result means there is a mutation but it isn't clear whether it relates to the cancer diagnosis and treatment.
- > actionable mutations. These may affect your treatment.

You won't usually need an extra procedure for genomic testing. Tests can run from biopsy and blood samples already taken for diagnosis. We coordinate this testing and deliver the results to you in a personalised way.



## Treatments

### A short overview of treatment options for lymphoma, leukaemia and myeloma.

Your treating doctor will speak to you about their recommendations in more detail. They will explain the:

- > benefits of treatment
- > treatment process
- > short and long term risks and side effects of the various possible treatments.

Not all treatments are suitable for every stage and sub-type of blood cancer.

### Watch and wait

*Also known as active surveillance, monitoring, observation*

Watch and wait means you do not require treatment. Your disease is monitored. During this time, you are always in the care of your treating doctor with regular appointments and checks.

Your treating doctor will explain why they recommend this approach. This approach is more common if you don't have symptoms.

Watch and wait is mostly used for slower-growing blood cancer types such as indolent lymphomas and chronic leukaemias.

### Chemotherapy

Chemotherapy is a common first treatment for blood cancers. It is often combined with other treatments such as radiotherapy, immunotherapy and targeted therapies.

Chemotherapy is a type of medication that works to stop the growth or spread of cancer cells. However, chemotherapy can affect and damage the body's non-cancer cells too.

There are different types of chemotherapy medications.

Your doctor will recommend a specific chemotherapy plan for you. This includes:

- > the type/s (which specific medication)
- > the dose (amount)
- > the duration (how long you will have this treatment)
- > how many times you have this treatment (number of cycles)
- > the aim of chemotherapy.

Your plan depends on factors including your cancer sub-type, your age and other conditions.



You can receive chemotherapy through:

- > a slow infusion into a vein (drip/IV to the bloodstream)
- > a tablet to take orally (by mouth)
- > an injection under the skin (subcutaneously).

Epworth Day Oncology Units are a relaxed and supportive environment where you can receive chemotherapy.

*Your treating doctor will speak to you about chemotherapy side effects. Each chemotherapy medication has specific side effects. General side effects of chemotherapy may include:*

- > reduced number of blood cells, so you are at greater risk of infections
- > hair loss
- > nausea and vomiting
- > fertility issues
- > fatigue (tiredness)
- > weight loss
- > stomach and digestion issues such as constipation
- > pain where the cancer is
- > skin issues such as peeling hands and rash.

Our team will check in with you to help you manage chemotherapy side effects.

## Radiotherapy (radiation therapy)

Radiotherapy targets a specific area of the body where the cancer is. It points X-ray energy that can kill cancer cells to this specific area. Like chemotherapy, radiotherapy can damage non-cancer cells.

External beam radiotherapy is the most common type of radiotherapy. A radiation machine from outside your body sends the energy to inside your body.

A radiation oncologist is a specialist doctor in this type of cancer treatment.

*Your radiation oncologist will speak to you about radiotherapy side effects. These may include:*

- > swelling and skin problems at the radiation area
- > fatigue (tiredness).

The side effects of radiation are different depending on the location and how strong the dose is.



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## Targeted therapies and antibody therapies

Targeted and antibody therapies work differently to chemotherapy. They aim to target the cells responsible for cancer growth or spread without damaging your non-cancer cells.

- › **Targeted therapies** are medications (drugs) made to work for specific cancers. Your doctor may recommend genomic testing to check if you are a match for a targeted therapy.

Your treatment may involve different types of targeted therapies together. You may have a combination of targeted therapy and chemotherapy.

- › **Antibody therapies** are medications that bind onto the blood cancer cells. They behave like the antibodies our body makes to fight viruses and bacteria.

You may have a combination of antibody therapy and chemotherapy.

Each therapy has its own side effects. It's important to speak with your treating doctor about these.



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## Stem cell transplants

Stem cell transplants transfer healthy stem cells through an infusion into your bloodstream. This process is also known as a bone marrow transplant.

### What are stem cells?

Blood stem cells are immature cells that live in the bone marrow. These stem cells grow to make all your blood cells. The three types of blood cells are:

- › **white blood cells** that form part of your immune system and help your body fight infections
- › **red blood cells** for carrying oxygen
- › **platelets** for clotting your blood.

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## What is a stem cell transplant?

There are two types of transplant:

- › **Autologous** – uses your own cells (you are the donor). The aim of autologous transplant is to allow recovery from high dose chemotherapy.

The Epworth Autologous Transplant Service will open for patients in 2022.

- › **Allogeneic** – uses cells from someone else (a donor). The aim of allogeneic transplant is to replace your bone marrow with someone else's.

Epworth does not operate an allogeneic transplant service. In Victoria, allogeneic transplants are provided in the public health system.



## Understanding autologous stem cell transplant

*An autologous transplant allows you to have treatment with high dose (strong) chemotherapy.*

Autologous transplants are a treatment option for lymphoma and multiple myeloma. For people with multiple myeloma, the aim is to prolong myeloma remission (time without cancer). For people with lymphoma, the aim is a potential cure.

**Stem cell collection (apheresis)**  
> to collect your cells for later use

**High-dose chemotherapy**  
> to kill remaining cancer cells

**The transplant**  
> an infusion of your stem cells to recover the bone marrow

We collect your stem cells through a process called apheresis. These are stored safely until you are ready for your transplant.

The transplant involves high dose chemotherapy, followed by having your stored stem cells returned to you. This is the stem cell transplant. You receive both the chemotherapy and the stem cell transplant through an infusion.

High dose chemotherapy kills any remaining cancer cells left after previous treatment. Unfortunately, it also kills non-cancer (healthy) cells in your bone marrow. The stem cells in the transplant travel back to the empty bone marrow, their home environment. They start to make new blood cells (red, white and platelets).

An autologous stem cell transplant is an intensive treatment. Your treating doctor will discuss the benefit, risks and long term side effects if they recommend it for you.

Short term side effects from high dose chemotherapy may include:

- > infection
- > mouth issues including pain and sores
- > nausea and vomiting
- > diarrhoea
- > hair loss
- > fatigue (tiredness)
- > effects on other organs such as kidneys and liver.

All autologous stem cell transplant patients are closely monitored and treated for side effects during their hospital stay.

## CAR T-cell therapy

CAR T-cell therapy aims to re-engineer cells from your immune system so they can better target cancer. CAR T-cell therapy is short for chimeric antigen receptor T-cell therapy.

### How CAR T-cell therapy works

T-cells are a type of white blood cell and part of your immune system. T-cells sometimes fail to recognise or effectively destroy cancer cells.

Scientists can genetically modify (change) your T-cells in the lab to give them chimeric antigen receptors. This makes modified CAR T-cells that can recognise and destroy cancer cells. Scientists also multiply the CAR T-cells to make more of them.

You receive the modified CAR T-cells through an infusion into your vein. In the body, they continue to multiply and look for cancer cells to destroy.

CAR T-cell therapy is a new and intensive treatment. Your treating doctor will discuss its risks if they recommend it for you.

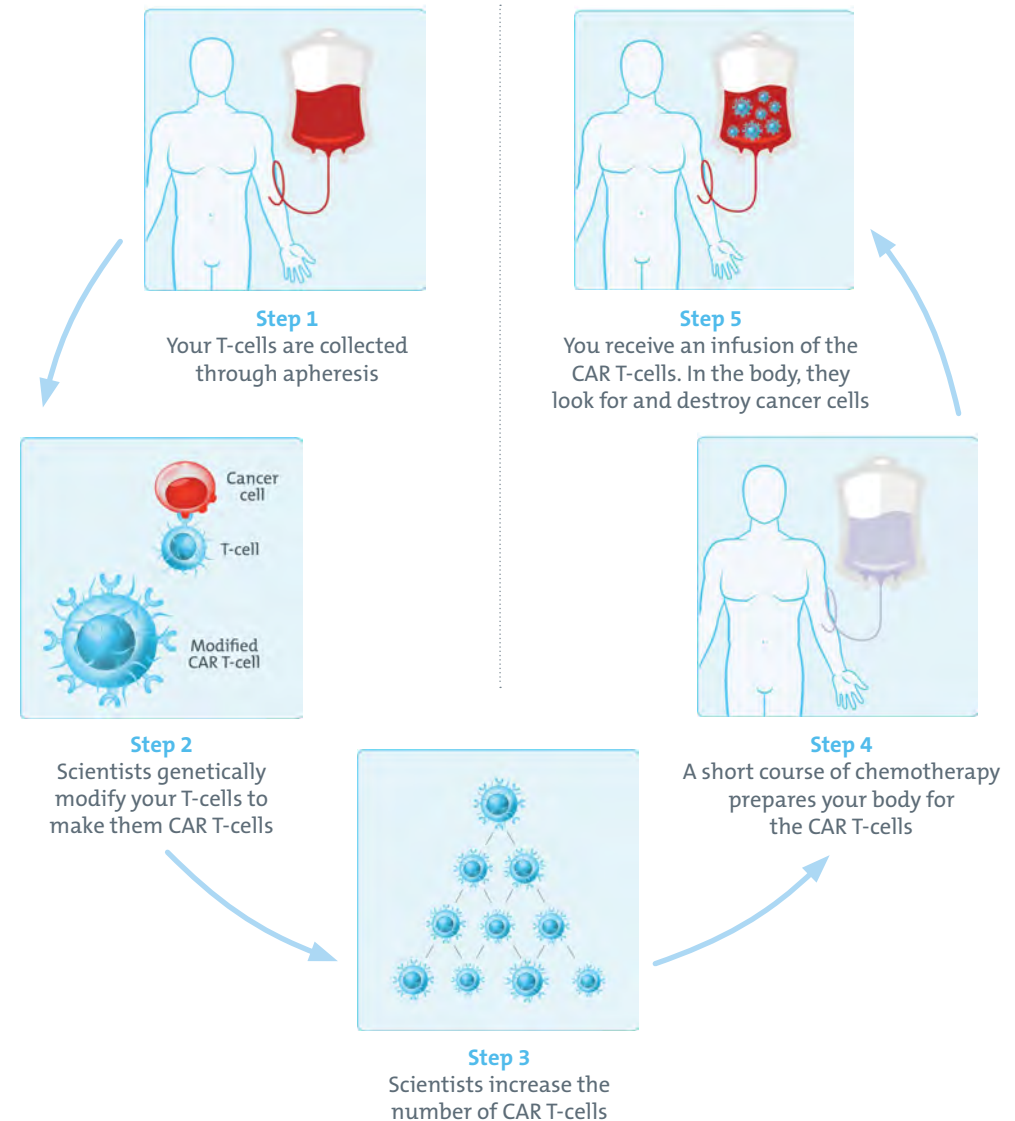
CAR T-cell therapy side effects may include:

- > cytokine release syndrome (CRS), where the immune system becomes overactive. CRS can be mild to serious (grade 1 to 4) and involve fever, breathlessness and low blood pressure.
- > immune-effector cell-associated neurological syndrome (ICANS), an adverse neurological (brain) reaction. ICANS can be mild to serious (grade 1 to 4) and involve changes such as difficulty speaking or writing, confusion and seizures.
- > infections.

Currently in Victoria, CAR T-cell therapy is available at two public hospitals. If recommended, your treating doctor and the Centre can support you to access CAR-T.

**We plan to offer CAR T-cell therapy at Epworth through the Haematology Clinical Trials Unit in 2022/3.**

## The CAR T-cell therapy process



## Our research

### Clinical trials

Clinical trials allow researchers to test new and emerging treatments. Through trials, we hope to improve blood cancer treatments into the future.

Clinical trials can offer patients access to treatments which aren't yet available to the public. Your doctor will discuss if trials are an alternative option for you.

Clinical trials may look at:

- > treatment safety, performance and side effects
- > if an existing treatment can treat another condition
- > if the new treatment works better than existing treatments.



### Types of clinical trials

Our Centre leads interventional clinical trials, which means they test an intervention. An intervention is an action that aims to improve health. For example, prescribing a medication is an intervention.

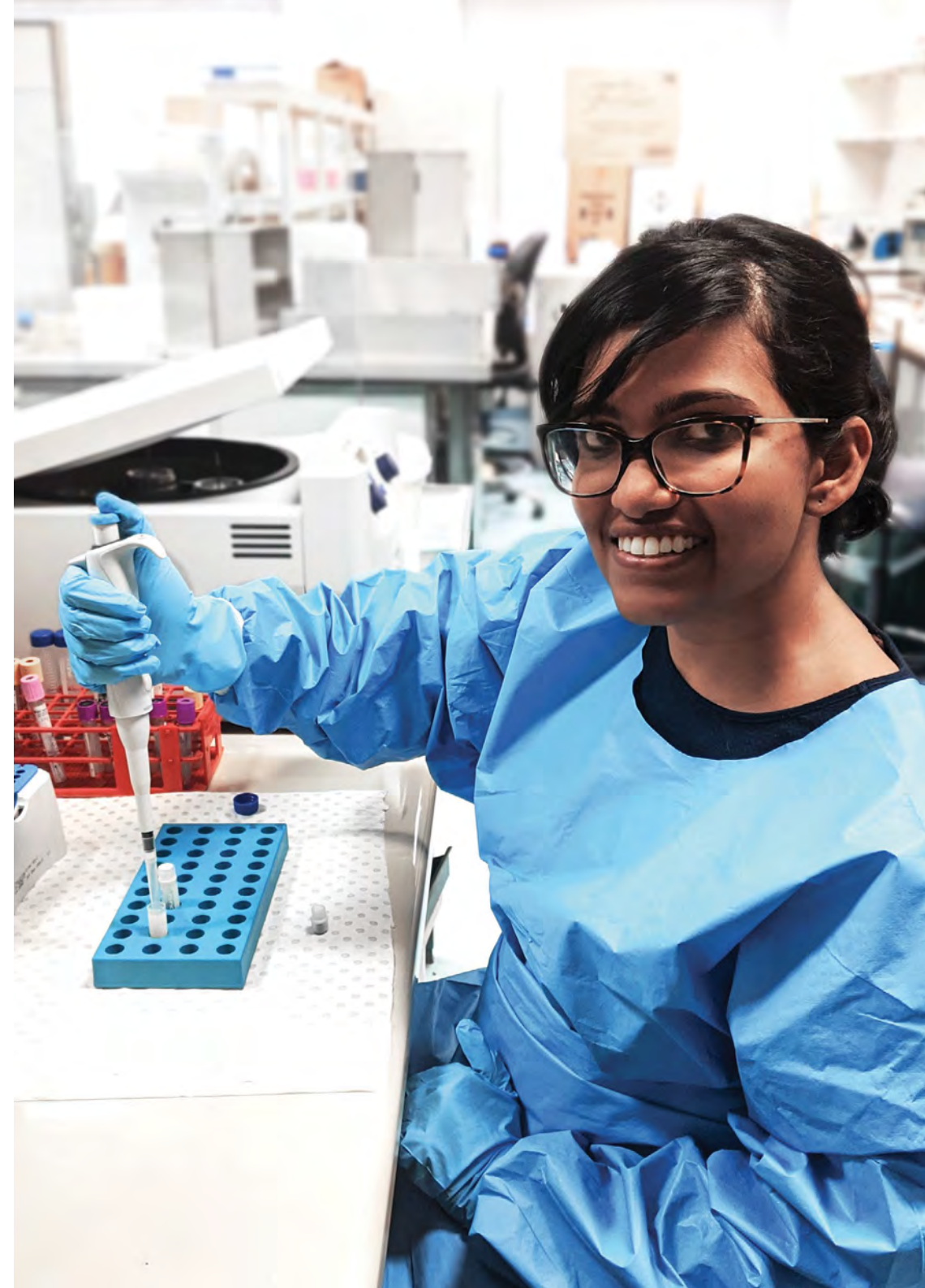
There are two types of clinical trials:

- > **Investigator-led trials** start from an academic (clinician-scientist). They investigate an area they believe will improve clinical care.
- > **Industry-led trials** start from a pharmaceutical company or sponsor. The company partners with a hospital or institution to test a commercial treatment to strict standards. These often involve the testing of new medications (drugs).

At the Centre, we work on both investigator-led and industry-led trials.

*“We see the Centre as a place where blood cancer patients can find hope through the best possible holistic, personalised care.”*

*Dr Costas Yannakou, Haematologist  
Director, Haematology Clinical Trials Unit*



## Clinical trial FAQs (frequently asked questions)

### Will my information be confidential?

Yes, all patient information and samples are strictly confidential. All patients are assigned a patient trial number so their personal details are kept private. The trial sponsor (company) receives all information under that patient number only.

### What does my participation involve?

This is different across trials. Your doctor can help you understand the requirements for your specific trial.

First, you meet with your treating doctor to speak about the trial. You receive a patient information and consent form. Your doctor uses this form to explain the tests, appointments and procedures for the trial. You can sign the consent form to continue.

Then you will enter a screening phase. This is to check if you are suitable to join the trial (fit the eligibility criteria). After a successful screening, treatment starts.

### What happens if I do not wish to continue with the trial?

You are free to stop taking part in the trial at any time. Please tell your treating doctor and trial team if you wish to stop the trial and withdraw consent.

### What will I have to pay for if I take part in the trial?

Provided to you at no cost:

- > the trial medication (drug)
- > procedures such as blood tests, imaging and medical consults if related to the trial.

The sponsor might not cover other procedures required for the trial if they are part of your regular medical care. These are billed according to your insurance arrangements.

Please note that Epworth is a private hospital group. If you don't have private health insurance, you will need to self-fund these parts of your care. The Patient Services Centre at your admitting hospital location can assist with more information.

### How is the trial managed?

Your treating doctor and assigned trial coordinator work as a team to manage your activities. Both are here to help you through the trial.

Your treating doctor is available for all medical questions. Your trial coordinator manages scheduling and can help with appointments and non-medical questions.

## Research studies

### Our research studies investigate blood cancers to better understand diagnosis and treatment.

Research studies are observational. This means you won't make any changes or receive a medication (like in interventional clinical trials).

They often collect or analyse patient information to find patterns. For example, a research study may look at the experiences of people with blood cancer over time.

A research study may ask you to:

- > complete a survey about your experience or feelings
- > give permission to record your treatment data (without personal details)
- > allow us to store your tissue or blood samples for future research (without personal details).

## Biobank studies

A biobank is a collection of patient samples and clinical information for use in future research. Our Centre runs the MOCI (Molecular Oncology and Cancer Immunology) Biobank Study. We also collaborate with other hospitals and research centres for related studies.

You can contribute to a biobank without any extra tests or collections. We use a small part of your sample already ordered for diagnosis or other tests. The samples are de-identified so that researchers won't see personal information such as your name.

Please note you won't experience a treatment benefit by joining a research study or biobank. These studies aim to enable blood cancer research for years to come and help people in the future.



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## Support organisations

Support organisations provide a range of free services to assist people affected by blood cancers. They can connect you with support groups, accommodation, financial help and transport.

### Leukaemia Foundation

Phone 1800 620 420  
leukaemia.org.au

### Lymphoma Australia

**Lymphoma Nurse Support Line:**  
Phone 1800 953 081  
lymphoma.org.au

### Myeloma Australia

**Telephone Support Line:**  
Phone 1800 MYELOMA (1800 693 566)  
myeloma.org.au

### Cancer Council Victoria

**Information and Support Line:**  
Phone 13 11 20  
cancervic.org.au



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## Other Epworth services

Blood cancer and treatment can affect many parts of your wellbeing. We have a comprehensive approach to cancer which values both your emotional and physical health.

We can link you in to access other Epworth services. Please ask our team about how to take part.

**Cancer rehabilitation** to support you before, during or after treatment.

The 8-week cancer program gives you the support of a multidisciplinary team focused on your wellbeing. The cancer rehabilitation program can help with:

- > fatigue
- > pain
- > loss of movement
- > strength and fitness
- > body image
- > self-esteem
- > work or family challenges
- > relationships
- > late treatment side effects.

*Available at Epworth Brighton, Epworth Camberwell, Epworth Hawthorn and Epworth Geelong.*

**Wig salon** to help you feel empowered and confident. Trained volunteers at the salon help you pick from wigs, scarves and headwear and learn how to style them. This free service is available thanks to the generosity of the Epworth Medical Foundation donor community.

*Available at Epworth Freemasons, Epworth Eastern and Epworth Geelong.*

**Allied health services** include support from dietitians, physiotherapists, social workers, speech therapists and psychologists. Epworth allied health professionals can help you with your goals across nutrition, exercise and mental health.

*These services are available when staying in hospital or at the Allied Health Clinic at Epworth Hawthorn.*

**Pastoral care** with religious and non-religious care workers in hospital. The qualified Pastoral Care Team is at Epworth to help you cope in times of anxiety and uncertainty.

*The pastoral care team supports patients as well as family members.*

*Note to reader:*

All care has been taken to ensure the accuracy of the information within this booklet at the time of its publication. Please remember that information pertaining to cancer is constantly being updated by healthcare professionals and the research community. This guide is intended as a brief introduction to blood cancers. This handbook is not intended as a replacement for medical or professional advice. You must always consult with your healthcare professionals about any medical symptoms, questions or concerns that you may have. The Epworth Medical Foundation and the Epworth Centre for Immunotherapies and Snowdome Laboratories exclude themselves from all liability for any injury, loss or damage incurred by the use of or reliance on the information provided in this booklet.







**Epworth**

[epworth.org.au](http://epworth.org.au)

[Contact us](#)

Epworth Centre for Immunotherapies  
and Snowdome Laboratories

**Phone** 03 9426 0555

**Email** [EHBloodCancer@epworth.org.au](mailto:EHBloodCancer@epworth.org.au)  
[epworth.org.au/BloodCancer](http://epworth.org.au/BloodCancer)

