



Getting the test results

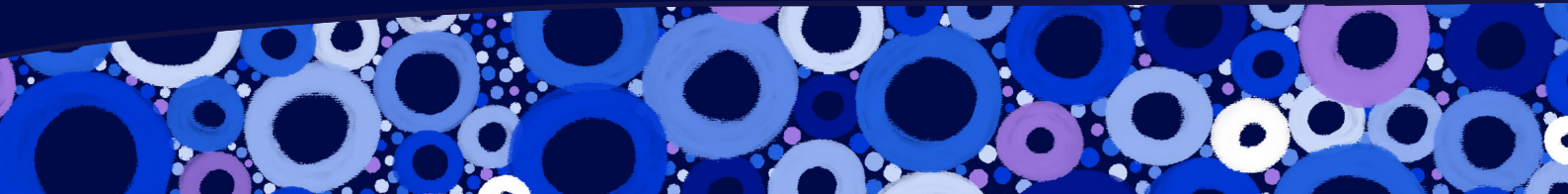
A booklet for Aboriginal and Torres Strait
Islander patients and their families

Book Two

Text & Illustrations by Simone Thomason
Cover artwork by Navada Currie

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The author sincerely acknowledges and pays respect to all Aboriginal and Torres Strait Islander Elders and Traditional Owners, past, present and emerging, on whose land these booklets have been developed and gives thanks for their on-going willingness to share their knowledge and wisdom.

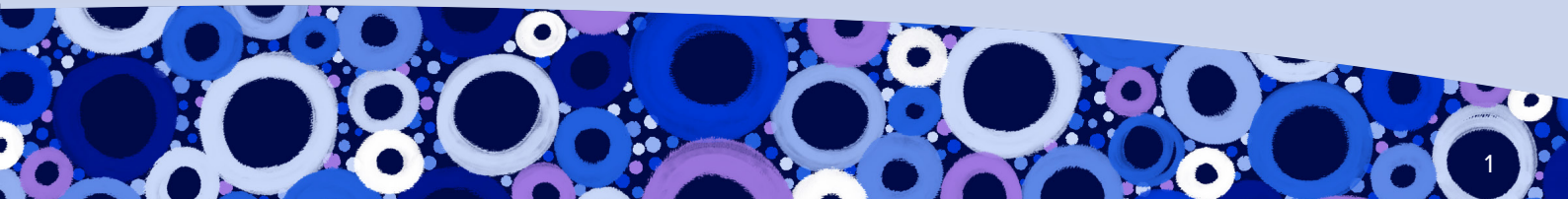


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Getting The Test Results, A Booklet for Aboriginal and Torres Strait Islander patients and their families, is book two in a series of five educational booklets. The booklets are primarily visual teaching tools, designed to meet the comprehension needs of Aboriginal and Torres Strait Islander patients, diagnosed with a blood cancer, and their families. This resource may also benefit all patients, including cultural and linguistically diverse people groups whose main language is not English.

Disclaimer: This booklet is not intended to provide or be a replacement for medical advice.

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Cover artwork © Navada Currie, 2022.

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The Leukaemia Foundation uses real-life stories to provide education, inspiration and hope. If you have an experience of blood cancer you'd like to share, please email storyhub@leukaemia.org.au

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Getting the test results

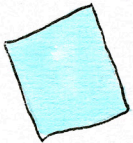
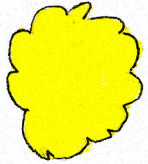
When the tests are back the doctors, blood nurse, Indigenous liaison officers and interpreters will explain the results to you and your family.

Your family and decision makers back home will be asked to come together in the community health clinic to talk over the TV link or phone.

The doctors can answer any questions you or your family may have about the results.



✓ Strong
Cells



✗ Weak
Cells



Blood sickness

When your blood cells have changed in a certain way, it is called a blood sickness or a blood cancer.

Cancer causes cells not to work right and will make you very sick.

Blood cancers – what they look like

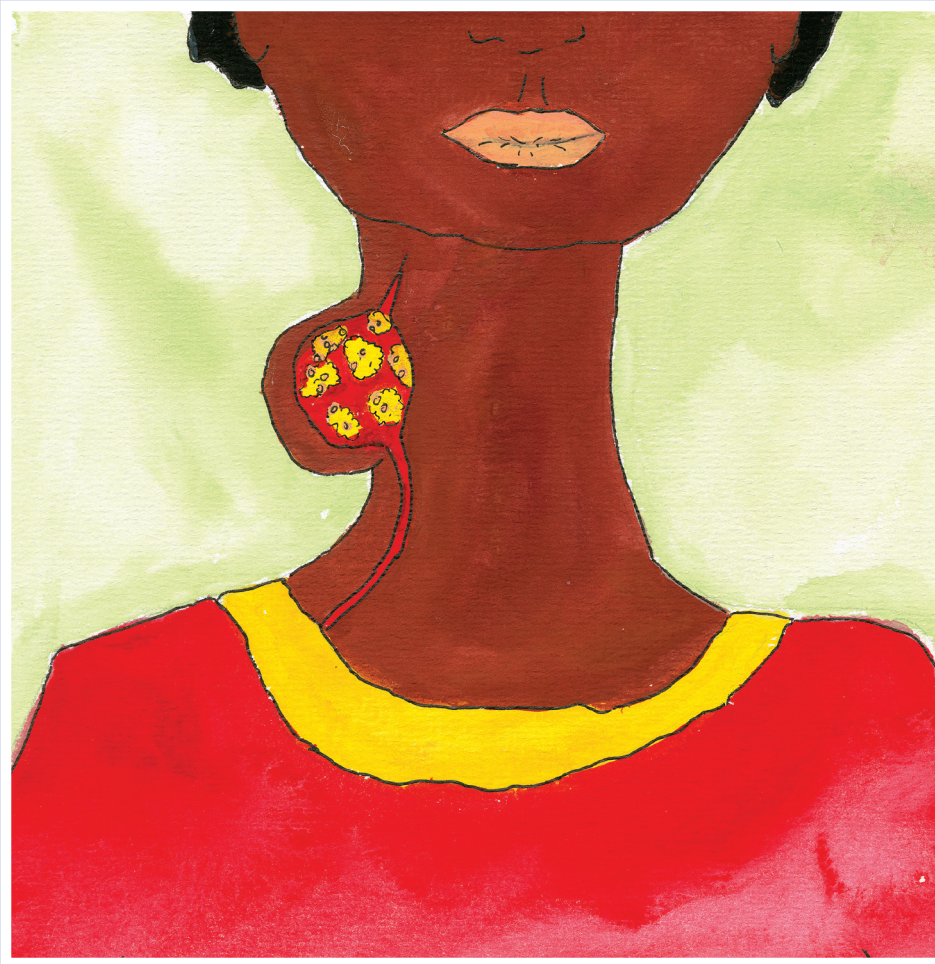
When you have a blood cancer your blood can look like this picture.

This picture shows blood inside two veins:

The top one is healthy blood:
with strong healthy blood cells
and the right number of cells.

**The second one is a weak
blood that has a blood cancer:**
The cells have changed shape
and there are too many cells,
which crowd the blood.





Lumps

Some people have special lumps in their bodies caused by the blood cancer.

These lumps are swollen lymph glands, full of blood cancer cells.

To get rid of these lumps special medicine is given to you.

These lumps are different to other cancer lumps of the breast, lung or gut, which can be cut out of the body.

Types of blood cancers

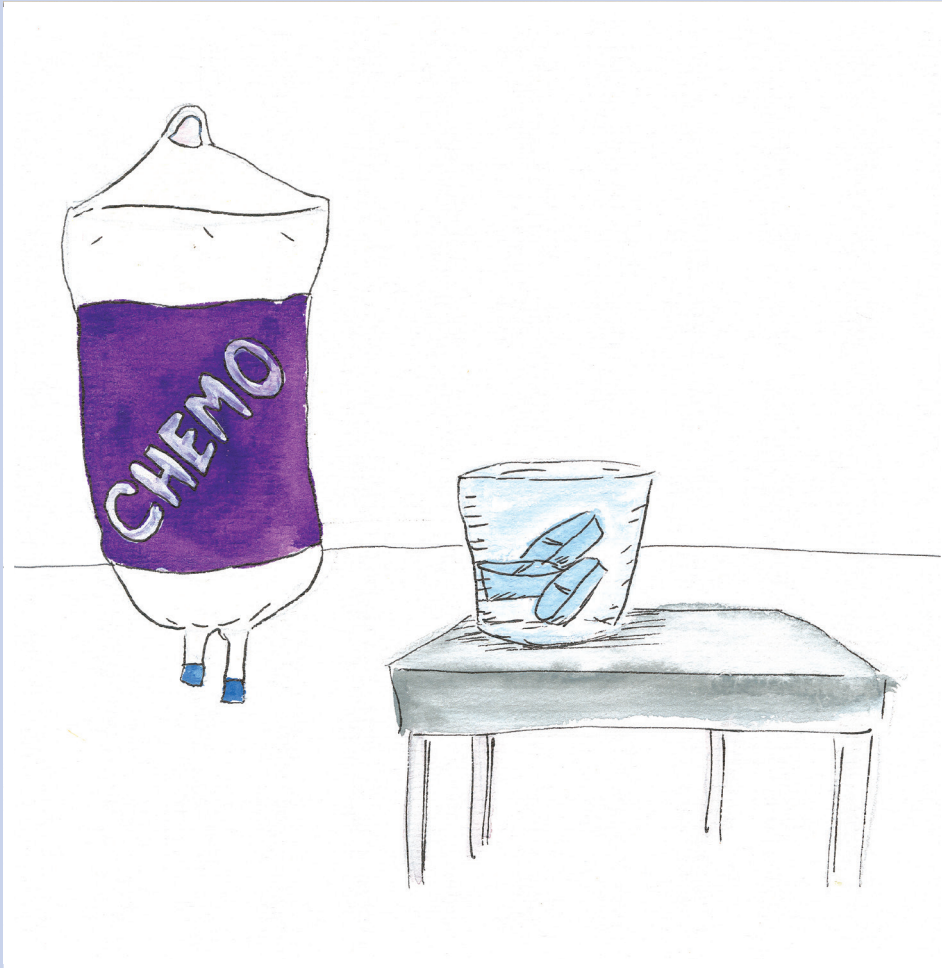
There are different types of blood cancers, with special names, such as:

Leukaemia

Lymphoma

Myeloma

The doctor will tell you and your family what type of blood cancer you have.



How to heal your body of the cancer

Special medicine called chemotherapy or “chemo” gets rid of the blood cancer cells and allows healthy blood cells to grow again.

Chemo can come in a bag and go into your PICC line or through a drip into your blood.

Chemo can also be tablets.

Chemo is given over a few days followed by weeks off for your body to recover.

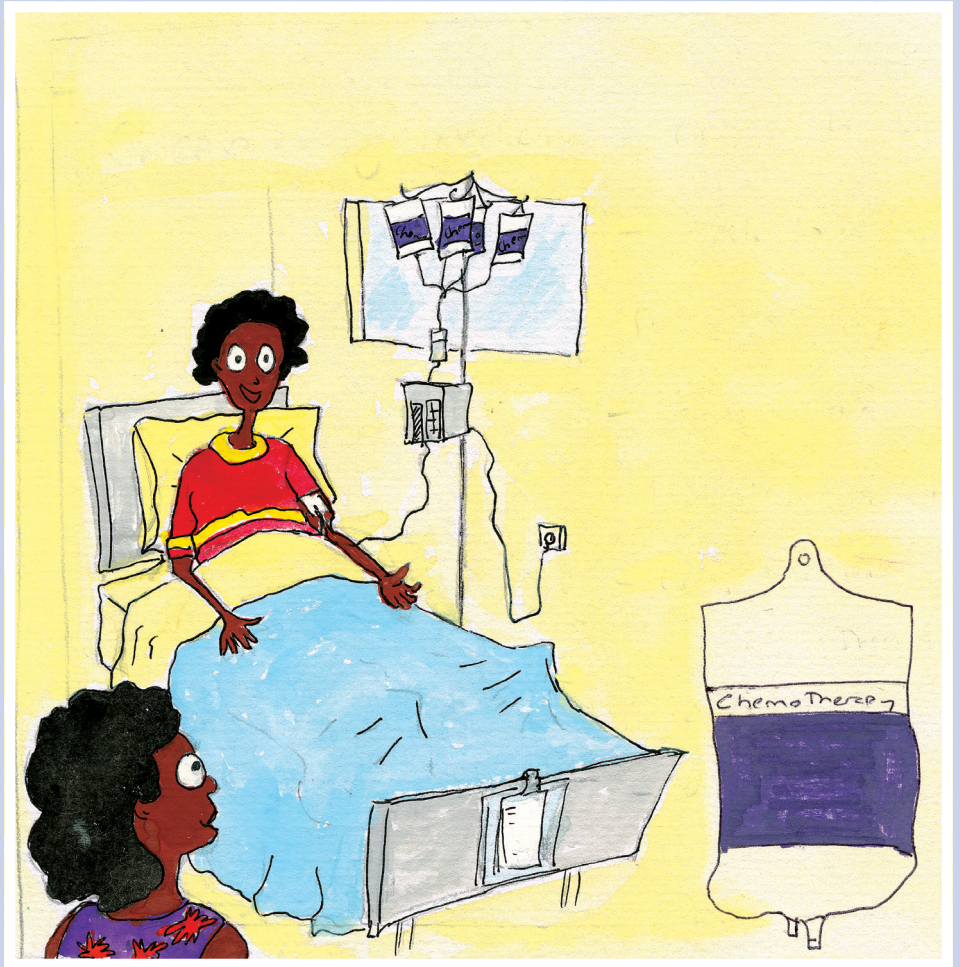
To heal you, chemo needs to be given many times over many months, this can be as long as a dry season and a wet season or 6 or more full moons.

Where you will have the chemo

Chemo needs to be given in the city hospital by special trained staff. You will need to be away from country for this chemo.

You may need to stay in hospital for the chemo, as you will need special water and other medicines to help you get over the chemo.

You won't be able to go back to country in between the chemo, because if you get an infection back home, you will get sick very quickly and you will be too far from the city hospital to help you.





The chemo day unit

You may be able to have your chemo in the hospital day unit.

You will stay in a hostel in the city with a family member and travel into the day unit by bus.

Chemo is given over a few hours, every few weeks.

You will have chemo over 6 months or more, same time as a dry season or a wet season.

Talking with family and decision makers about chemo

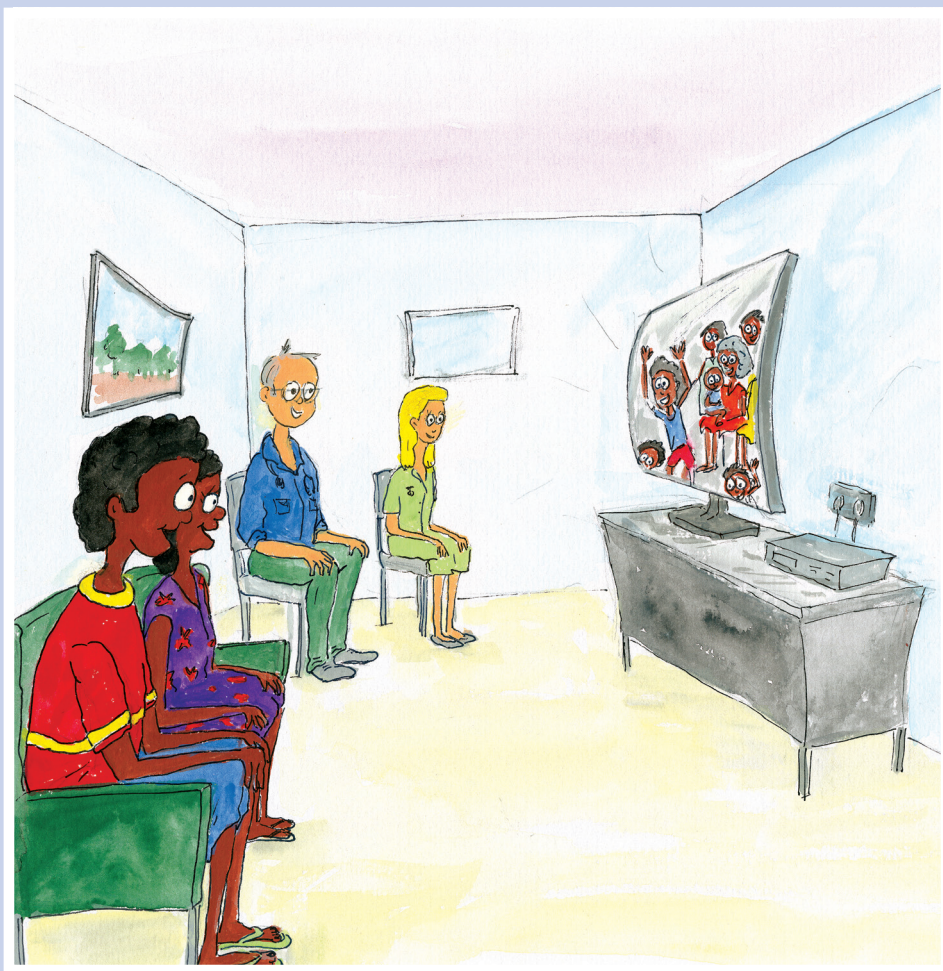
The hospital team will talk with you and your family – over the TV link or phone and explain about the chemo.

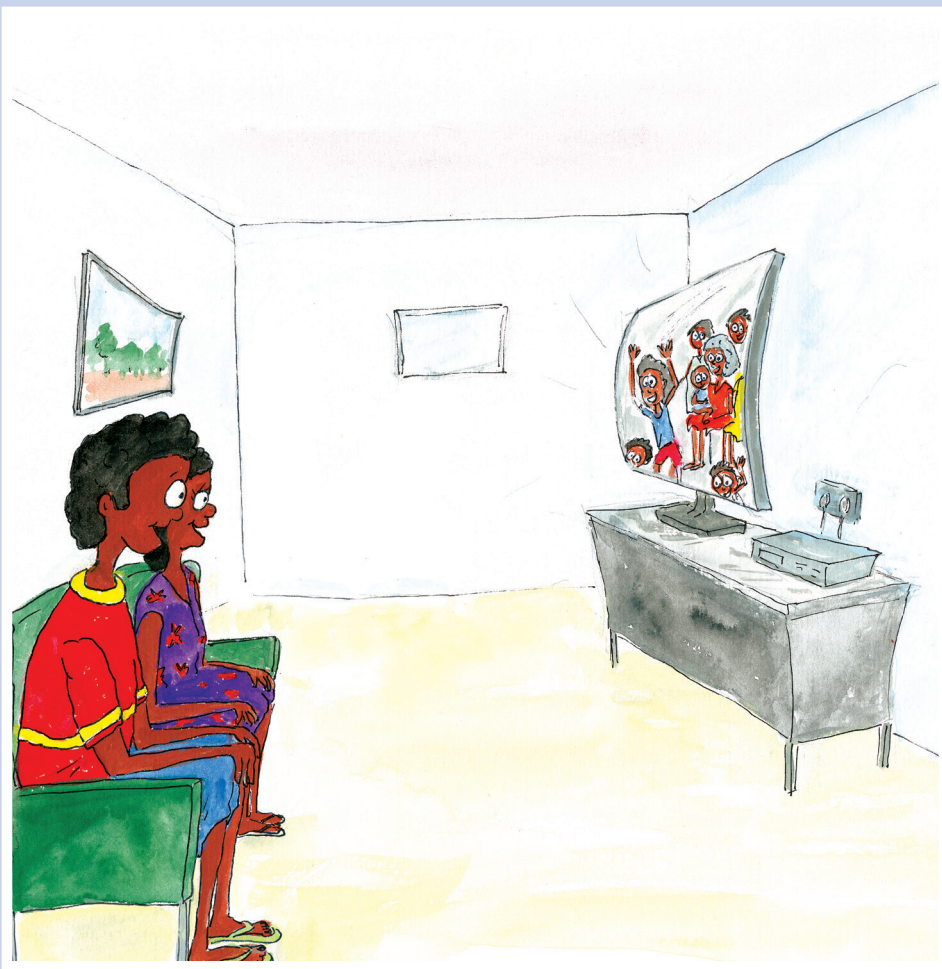
Chemo is the way to heal your body from this cancer.

Decision Makers:

If an Elder or someone from your family are the decision makers for you, then the doctors will ask them to decide for you if you can have the chemo.

Or the doctors will ask you to decide about having chemo.





Talk to your family

You will need to talk with your family about staying for the chemo.

The chemo will need to start very soon as your blood cells are changing quickly, and your body will get sick soon without the chemo.

Decisions

If you and your family decide not to have chemo.

You and your family will need to know that this blood cancer is a strong sickness. Without the chemo it will cause you to pass away or 'finish up' over the next weeks to months.

If you have no chemo, the doctors will arrange for you and your family to return back home to country.

What you can expect to happen in the next weeks and months:

You will feel changes in your body.

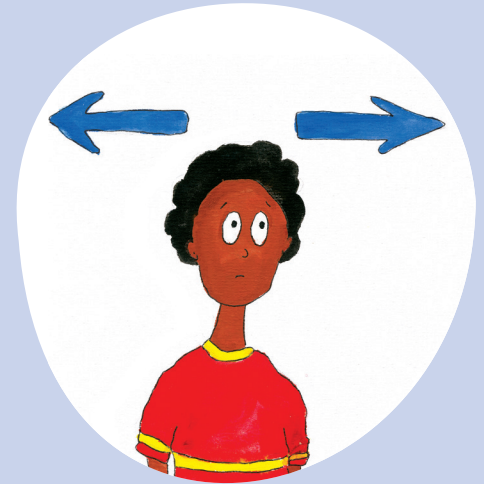
You will get more tired, short of wind and weak, you may also get some pain or bleeding.

The community nurses and doctors on country, can give you medicines, to help you feel no pain and be comfortable during this time.

The Palliative Care Team:

Before you leave hospital you will meet a new team of doctors and nurses called The Palliative Care Team.

They will help you and your family and the nurses and doctors in your community to care for you at home, until you pass away or finish up.





Consent for chemo

If you and your family agree to have chemo you will need to sign your name on a special piece of paper, called a Consent Form.

This means you give your permission to the hospital staff to give you chemo.

A consent means, you understand what chemo is, how it can heal you and how it can also change your body for a short while, whilst you are being treated for the cancer.

Please see Book Three for more information on chemo.

A family member can stay in hospital with you, or in a hostel nearby and help keep you strong, when you have chemo.

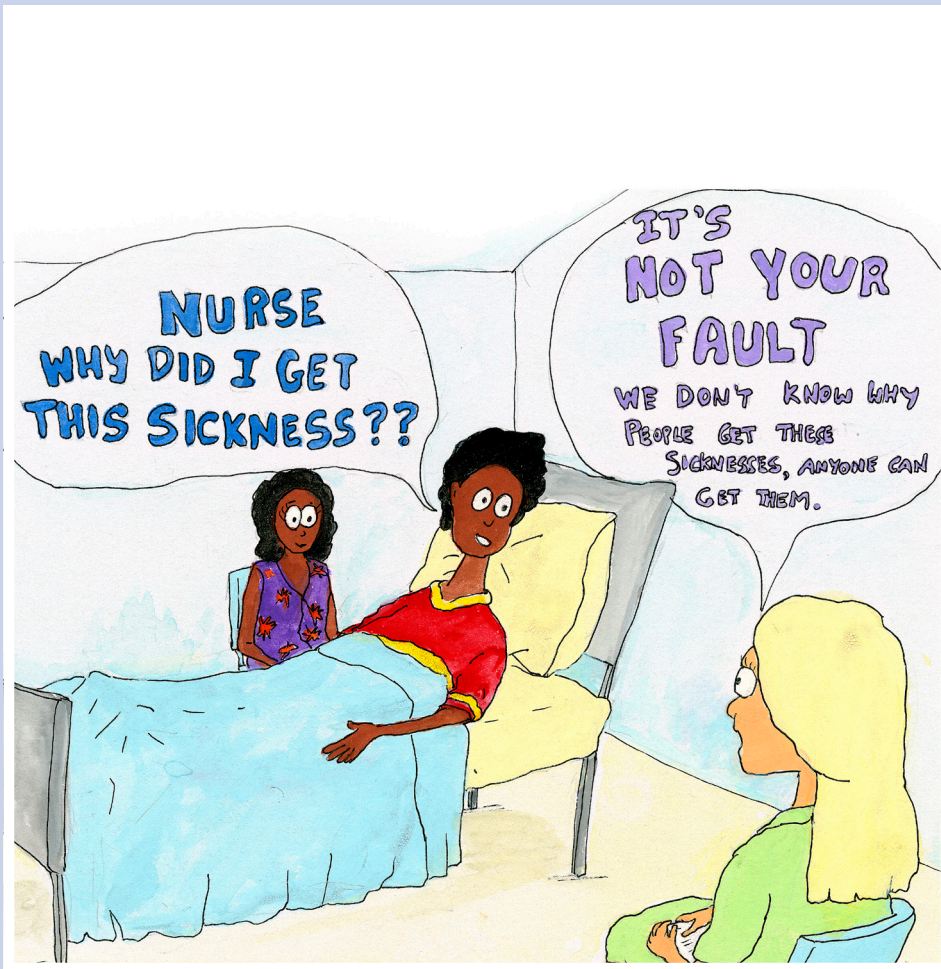


Your treating team is here for you

There will be many people who work in the hospital to help you and your family get through your chemo.

The team know it is not easy for you being away from your home and country.

Please tell us if you or your family have any worries, so we can help you best.



It is normal to ask “Why Me?”

It is normal to ask “why me?”

Anyone can get a blood cancer, you have done nothing wrong, do not feel shame.

The doctors and nurses do not know why you have got this cancer.

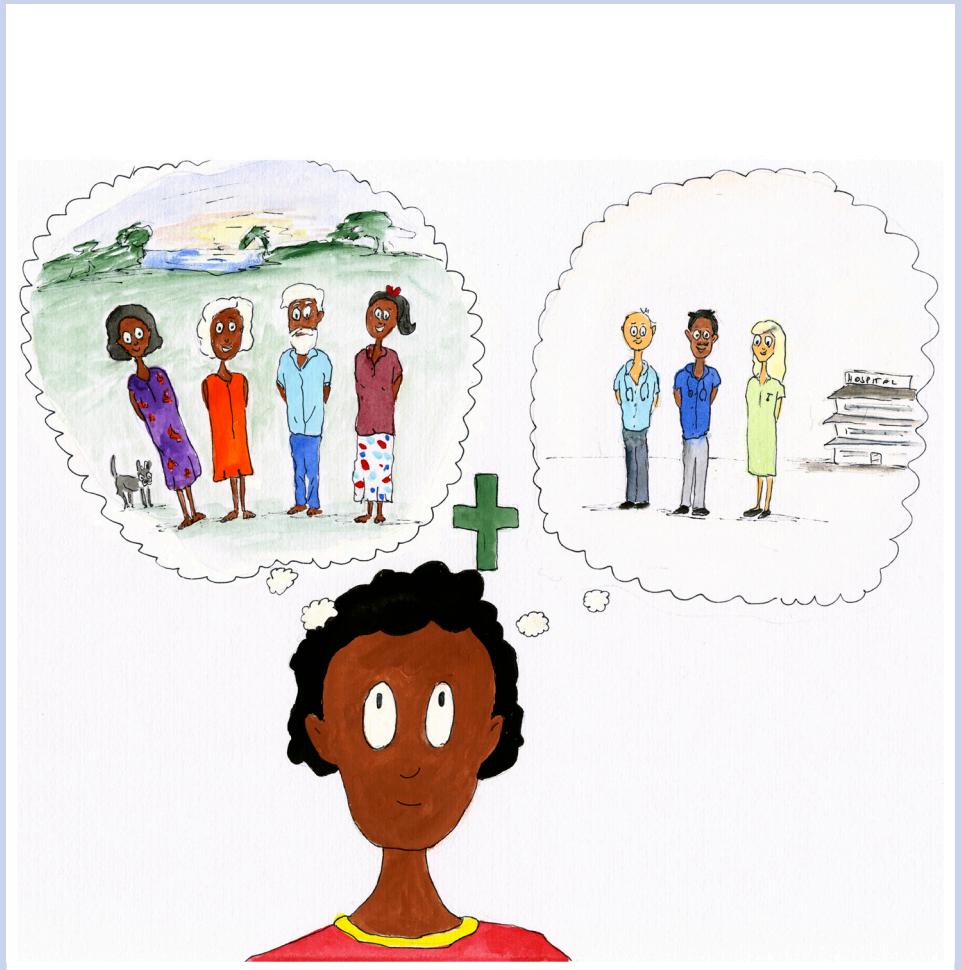
They do want to heal you so you can get well and return back home.

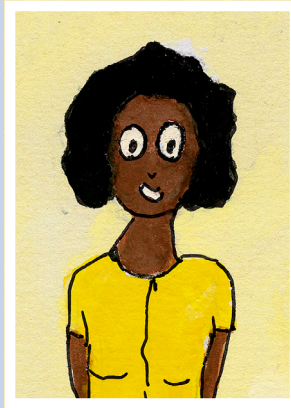
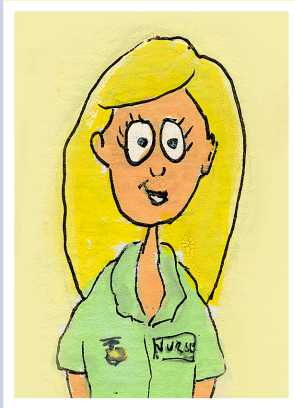
Two treatments - family and chemo

Getting you better is a big job.

The chemo is one way to get you better and make you strong.

Having family and friends visit or talk on the phone is the other way to help you heal and keep you strong.





Special business back home

When there are times of special ceremony or sorry business you will not be able to travel home. You will have to stay in or near the hospital. This will be hard for you.

If you travelled back home when you are weak you can get infections from germs making you so sick you could 'finish up'.

The doctors will ask you and your family to see if there is a way to excuse you from the ceremony.

You can talk to the:

Church Minister, Blood Nurse, Interpreter, Social Worker or ILO.

Please talk to the hospital workers if this is a worry for you.

A few more tests, before chemo

The chemo will lower your white blood cells which fight germs and infection and this can make your teeth sore.

You will need to see the hospital dentist for a check-up, before starting chemo.





Fertility or family planning doctor

Some chemo can make it hard for you to have children in the future.

To help you with this you may need to visit a family planning or fertility doctor before chemo.

End of Book Two

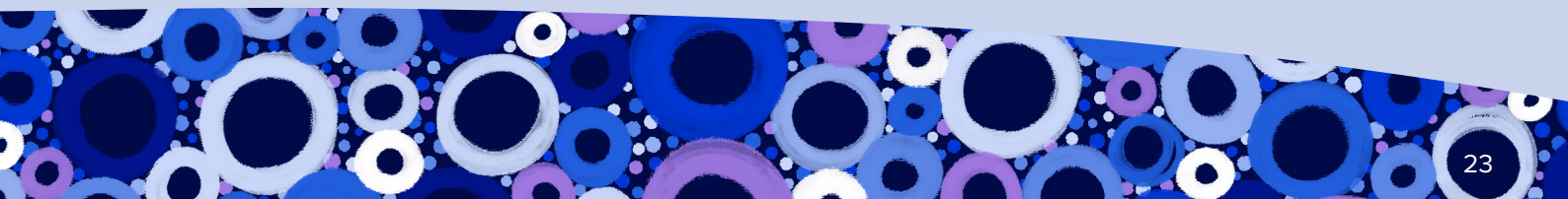
We hope this book has helped you and your family learn about:

- Your blood test results.
- What blood changes can mean.
- What blood cancers or blood sicknesses are.
- Medicine treatments – called chemotherapy or chemo.
- Where you will have chemo treatment.

Please look at book three, to learn more about having chemo for blood cancers.

Common questions

What are blood cancers or blood sicknesses?	5 - 6
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Abbreviations and references

Blood Nurse (Cancer Care Coordinator) – a member of the team who works with patients with blood changes and their families.

Chemotherapy/chemo – special medicine which gets rid of the blood cancer cells and allows you to heal and grow healthy cells again.

Consent/Consent form – when you agree to have a treatment and sign your name to a form.

Dietician – a member of the team who specialises in the right food for you to keep you well and strong.

Fertility Doctors – help with collecting sperm and eggs before chemo.

Finishing up – dying or passing away, passing on.

Haematologist – specialist blood doctor.

Leukaemia – blood cancer of the white blood cells.

Lymph System – is a network of tubes and glands in your body, which carry and clean excess fluid from the blood. The glands hold certain types of white cells whose job is to clean the fluid and fight infection.

Lymphoma – cancer of white cells usually found in the lymph system.

Myeloma – a cancer of plasma cells which is a type of white blood cell.

OT/Occupational Therapists – a member of the team who help patients recover and achieve everyday tasks.

Palliative Care Team – a team of doctors and nurses who help you and your family when you don't want chemo or when your cancer sickness cannot be healed, and you will finish up' from the sickness.

Pharmacist – a member of the team whom specialises in medicines and drugs.

PICC Line/Tube – (a Peripherally Inserted Central Catheter) are special tubes inserted into your upper arm, fluids and medicines can go into these tubes and blood samples can be taken from them without using needles.

Physio/Physiotherapist – a member of the team who gives you exercises to do so your body stays fit and strong.

Social Worker – a member of the team who helps with your physical, financial and social wellness.

Sorry Business – a funeral or a time for grieving and remembering people who have died

Special Business – are times of significance to strengthen peoples connection to the physical and spirit world.

References:

Cancer Institute of NSW (2020) Retrieved from www.eviq.org.au

Leukaemia Foundation (2020) Retrieved from www.leukaemia.org.au

Need to talk?

Contact us on 1800 620 420
leukaemia.org.au

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Helpful phone numbers and contacts

You might like to write down some of the contact details for the people you're talking with and make some notes about important stuff.

Emergency Ambulance: 000

Blood nurse (cancer care coordinator): _____

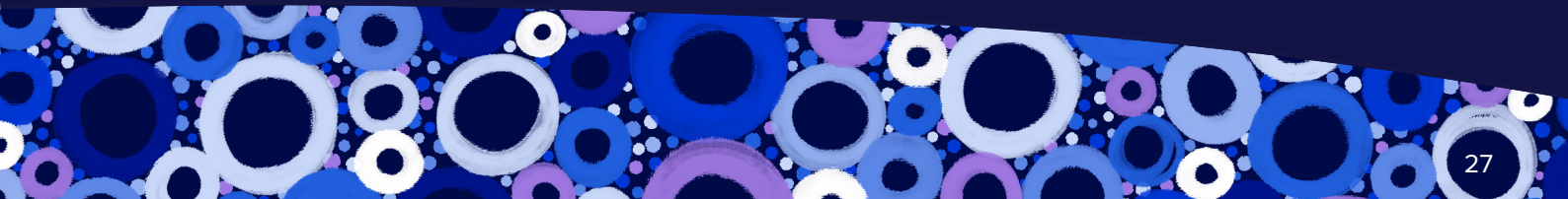
Cancer Council: _____

Health Worker: _____

ILO: _____

Cancer Day Unit: _____

Hospital number: _____





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