



When I have Chemo

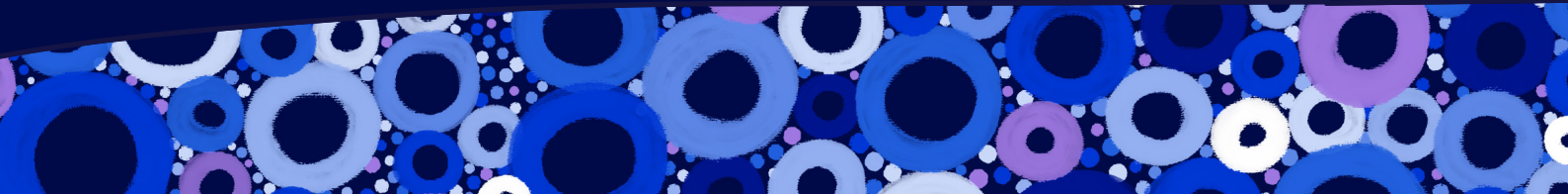
A booklet for Aboriginal and Torres Strait
Islander patients and their families

Book Three

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.

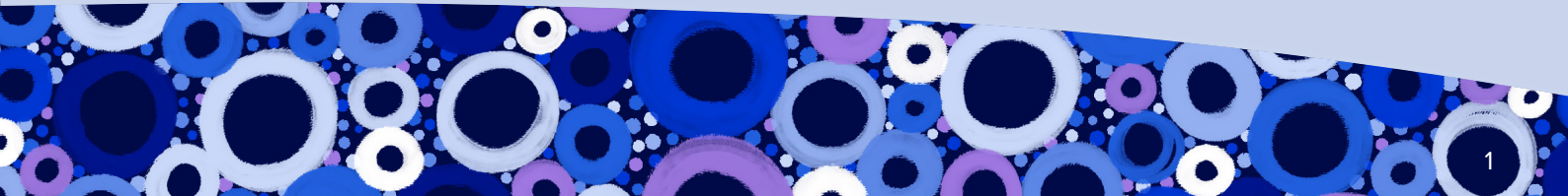


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When I have Chemo, A Booklet for Aboriginal and Torres Strait Islander patients and their families, is book three in a series of five educational booklets. The booklets are primarily visual teaching tools, designed to meet the comprehension needs of 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

Contents

Chemotherapy treatments for blood cancer	4
Chemotherapy “chemo” explained	8 - 9
Things you can do to keep yourself strong	13 - 28
Half way through – what’s next?	33 - 34
Common questions	37
Abbreviations and references	38 - 39

Chemo treatment for blood cancers

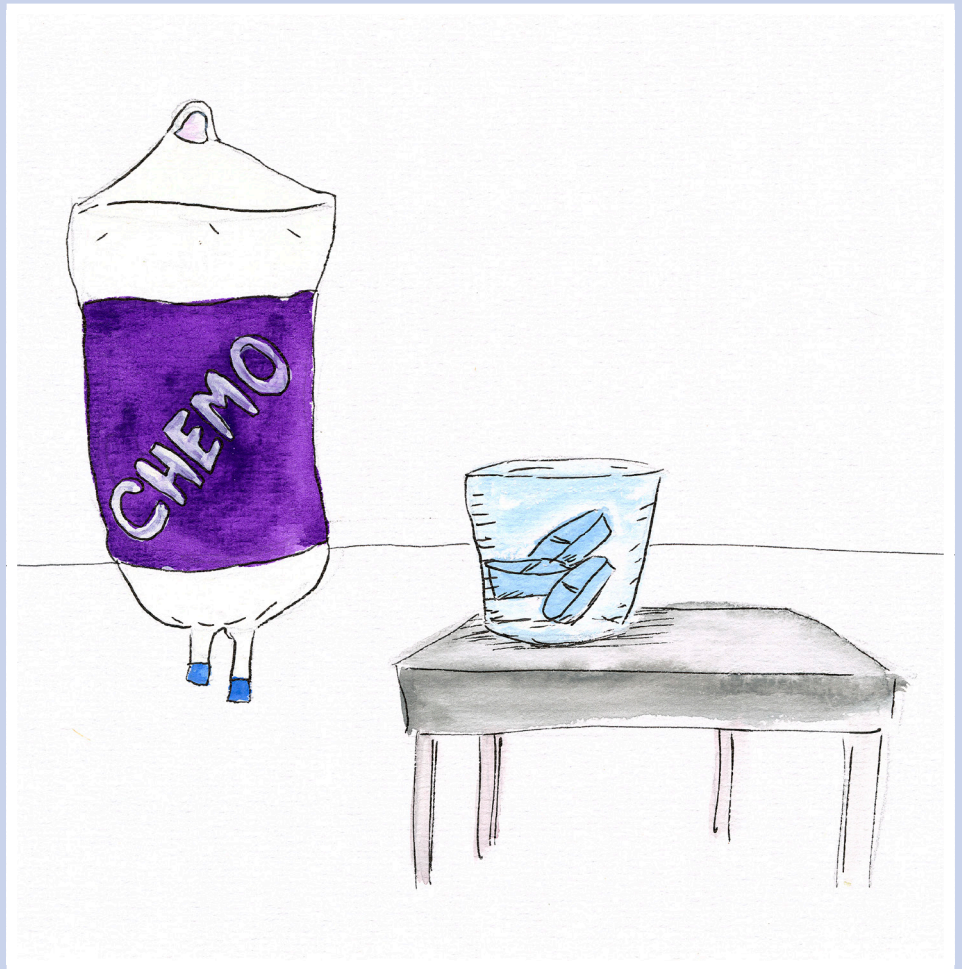
Special medicine called chemotherapy or “chemo” heals your body and gets rid of the blood cancer cells and allows healthy blood cells to grow again.

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

You may have a few different types of chemo’s and some maybe different colours

Chemo can also be tablets.

You will need to be away from country to have the chemo as it needs to be given in the city hospital by special trained staff.





How long will you have chemo for?

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

Chemo is usually given over 6 to 12 months, the same time as a dry season or a wet season. Or 6 or more full moons.

You won't be able to go back to country whilst you are having the chemo, as you can get infections and get very sick back home.

Having chemo in the hospital

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.

During chemo you will need to stay in your hospital room, so you don't get germs from other patients.





The chemo day unit

You may 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.

You won't be able to go back to country whilst you are having 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.

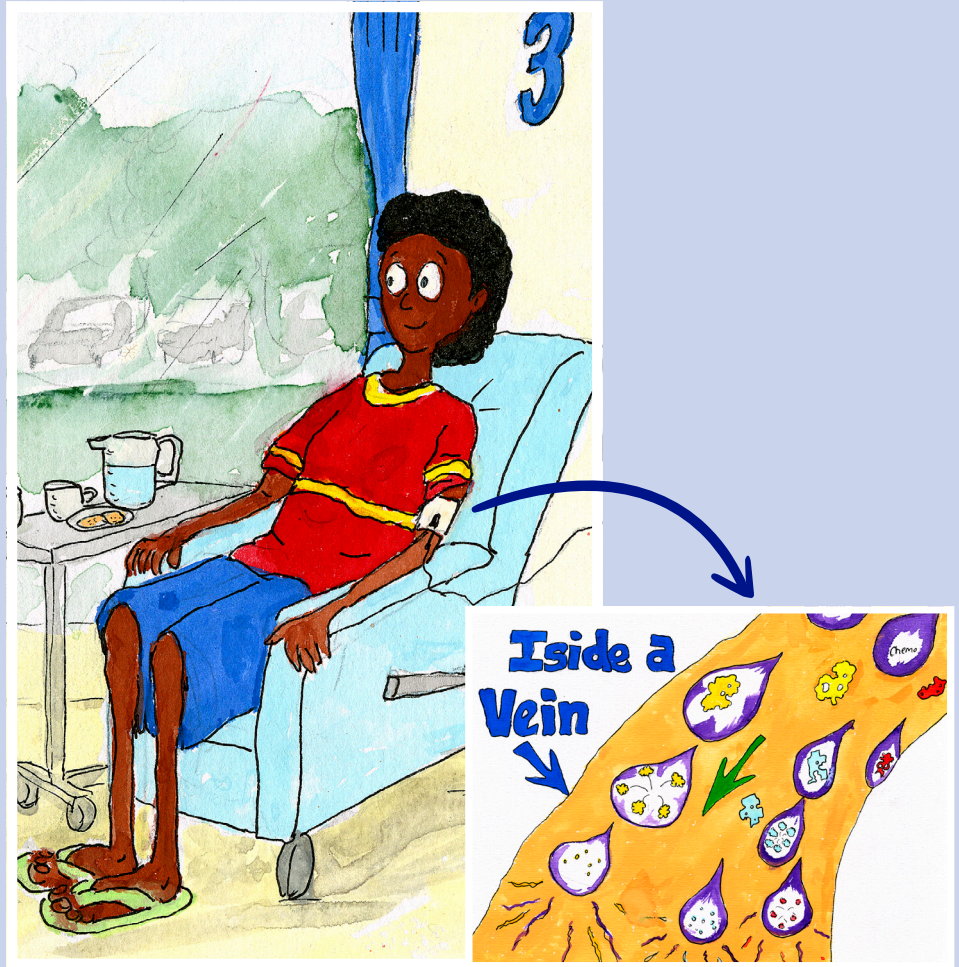
How chemo works in your body

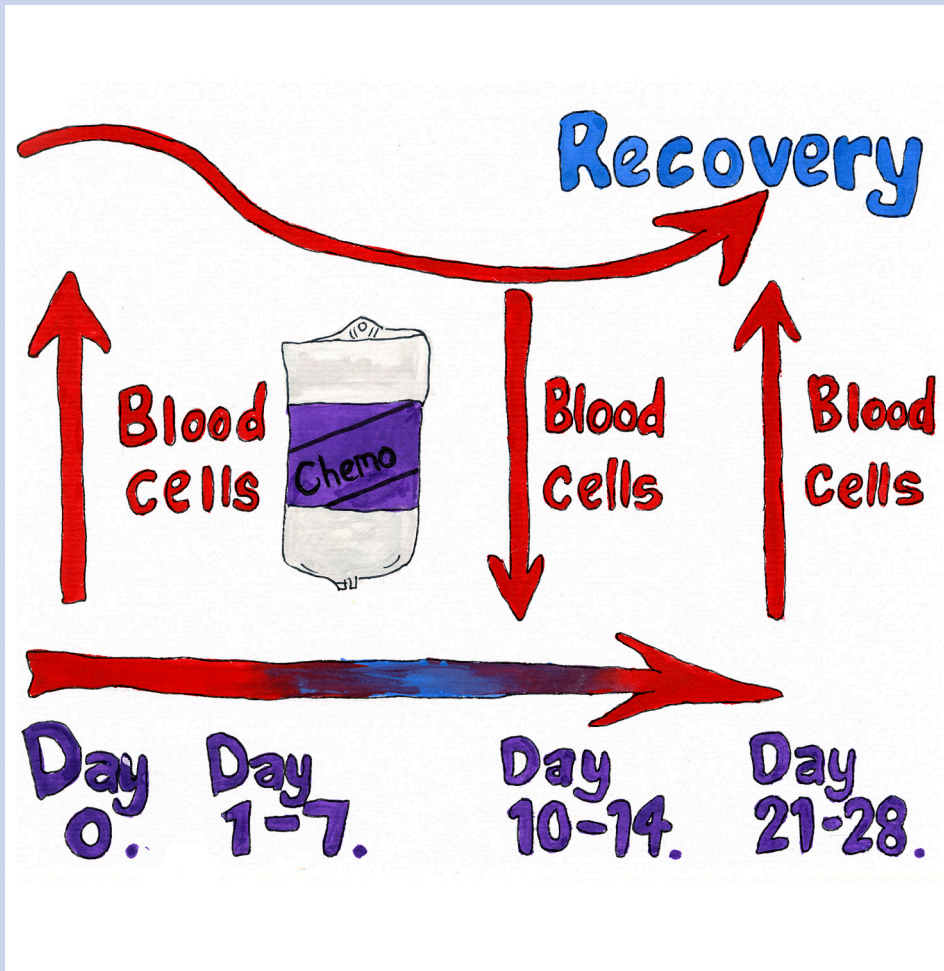
When chemo goes into your blood through the drip, it travels around your body to kill the cancer cells.

You do not feel the chemo doing this. It does not hurt you.

This picture shows the chemo as purple droplets in your blood dissolving the blood cancer cells.

Chemo will also kill some of your healthy blood cells too.





Chemo works in your blood over a month

Day 0: Before chemo starts your blood is crowded with many cells.

Week 1 (Days 1-7): Chemo works in your blood and gets rid of many cells.

Week 2 (Days 10-14): the number of blood cells drops low, especially the white cells that fight germs and infections.

This means you can get fevers, coughs, and colds. You will also feel more tired at this time.

The last few weeks (Days 21-28+): healthy blood cells start to grow back in your body.

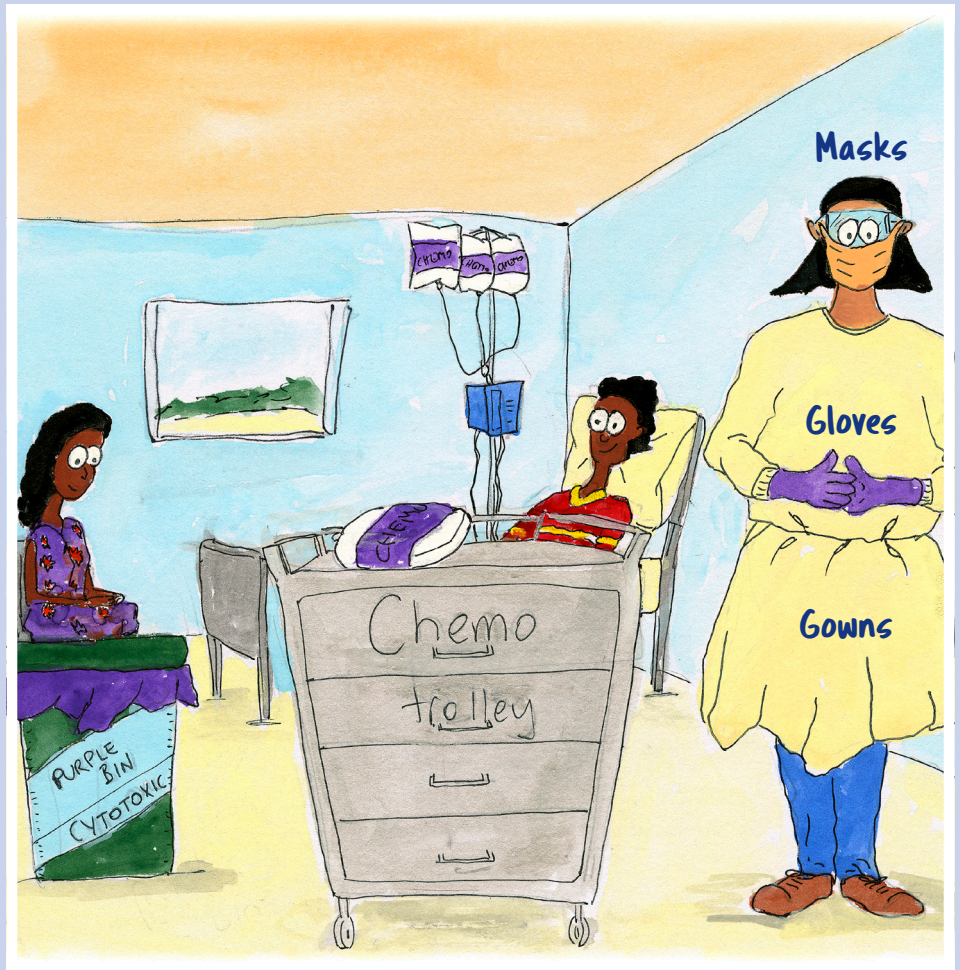
When you have chemo

When the nurses give you chemo they will put on masks, gloves, gowns and goggles.

Nurses wear these things when they open or finish with the chemo bags and tablets to keep everyone safe.

When chemo goes into your PICC line or drip you do not feel it. If you do feel any pain, you need to tell the nurses straight away.

If your chemo tubes leak or become loose, you need to tell the nurses straight away.





Chemo will make some changes in your body

As the chemo is working in your body, it will cause some changes in your body for a while.

The rest of this book tells you about these changes and what you and your family can do to help you get through the chemo.

Hair loss

After 2 weeks from the first chemo, you can lose your hair from your head.

Not all chemo causes hair to fall out. The nurses will tell you if this will happen to you.

It will grow back once all your chemo is finished.

If you want to wear something on your head the blood nurse can get you a hat or a scarf.





Drinking water every day

Drinking plenty of water, juice and milk keeps you strong and helps your kidneys make urine (pee) which gets rid of all the rubbish from your body.

Try and drink 1 - 2 jugs or bottles of water every day.

You can also drink tea and coffee but only 2-3 cups of these a day. As too much of these drinks can make a lot of urine which dries you out.

Wash your hands

You need to wash your hands, with soap after touching people or things, and after using the toilet.

Hands have germs on them that can make you very sick when you are having chemo.

All your family and visitors need to wash their hands before seeing you.





Clean your teeth and rinse out your mouth

When you have chemo germs can give you sores in your mouth.

These sores can hurt and stop you eating and drinking.

Cleaning your teeth and rinsing your mouth stops germs and mouth sores.

You need to gently brush your teeth morning and night, then rinse with a special mouth wash or salty water, and spit it out.

You can mix mouth rinse yourself using table salt and water ($\frac{1}{2}$ a teaspoon of salt or bi-carb in a cup of warm water).

Checking your weight

When you are having chemo, you can lose weight and get weak.

The nurses will weigh you every morning and evening, when you are in hospital.

If you are having chemo in the day unit you will be weighed before each chemo.





Eating food keeps you strong

Eating food is like putting petrol into a car to make it go. If you don't eat food your body won't keep working.

Eat some food every few hours, this can stop your stomach from churning and stops you feeling sick.

The dietician (food person) will check on how much you are eating and give you different foods to try.

Do not eat food from the cafe or take-away as it can have germs on it that can make you sick.

Feeling sick

Chemo can make you have a churned-up stomach. Or you may vomit or feel like vomiting.

There is medicine to help stop the churning and vomiting.

If you are in hospital press the buzzer to let the nurses know as soon as you are feeling like vomiting.

If you are in the hostel, you will be given tablets which stop the vomiting, you need to take these for three days after your chemo, or as soon as you start to feel sick.

After your stomach feels better you need to start eating and drinking again, so you stay strong.





Upset stomach

The chemo can give you a sore stomach, running poo or diarrhoea, or no poo.

There are medicines to help you with this.

Press your buzzer to let the nurses know.

Or if you're at a hostel call the day unit for tablets to help with this.

Keep drinking water during this time, it can also help you feel better.

Many tablets to take

You will be given other tablets to take every day, when you have chemo.

These are to stop you from getting infections and fevers from germs.

These are very important to take to keep you strong.

The pharmacist or chemist person will explain these to you.

If you are staying in the hostel the tablets can be put into a special pack (blister pack) to make it easier for you.





Exercise

Exercise is good for you and keeps your muscles strong.

When you are in hospital, to stop you getting germs from other people, you may have to stay in your room a lot of the time.

During this time, you can lose muscle strength.

To keep your muscles strong, the physiotherapist will give you a peddle machine to use to work your arms and legs.

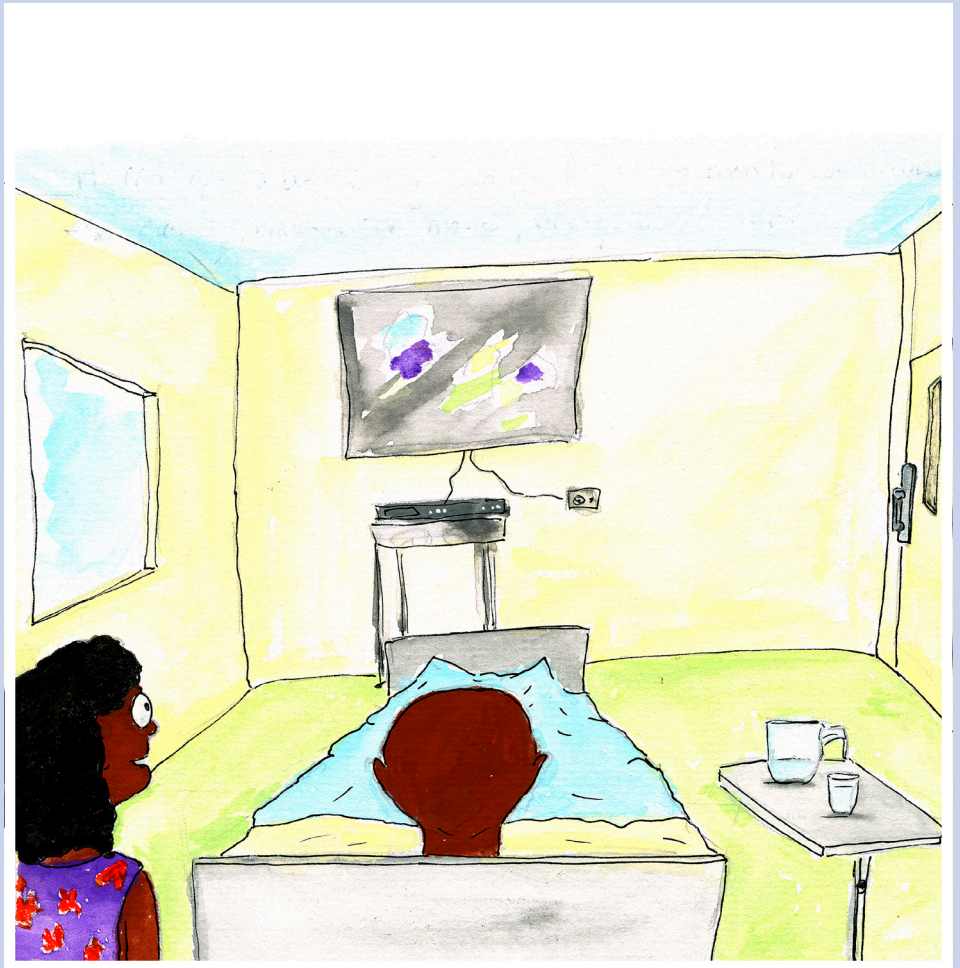
If you are staying in the hostel you need to go for short walks every day.

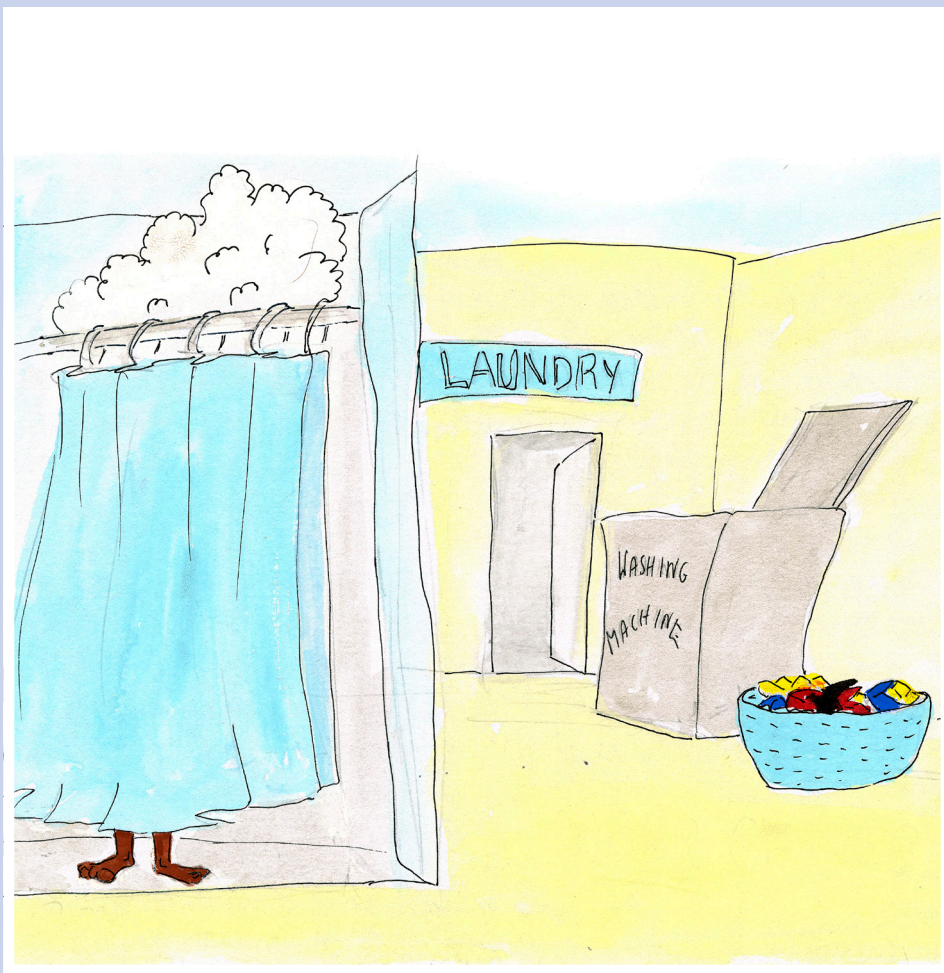
Something to do

Being in hospital can be boring.

The nurses can give you a DVD player or the 'Play Station' to use, so you have something to do.

There are also radios to listen to, or pens and pencils for drawing. The nurses can give you these.





Shower daily and wash your clothes

You need to shower every day, to keep your skin free from germs.

Wash your clothes often, the hostel will have washing machines.

If you are in hospital the nurses can help your family to use the washing machine to wash your clothes.

If you do not have many clothes, you can also wear hospital pyjamas.

Blood bags

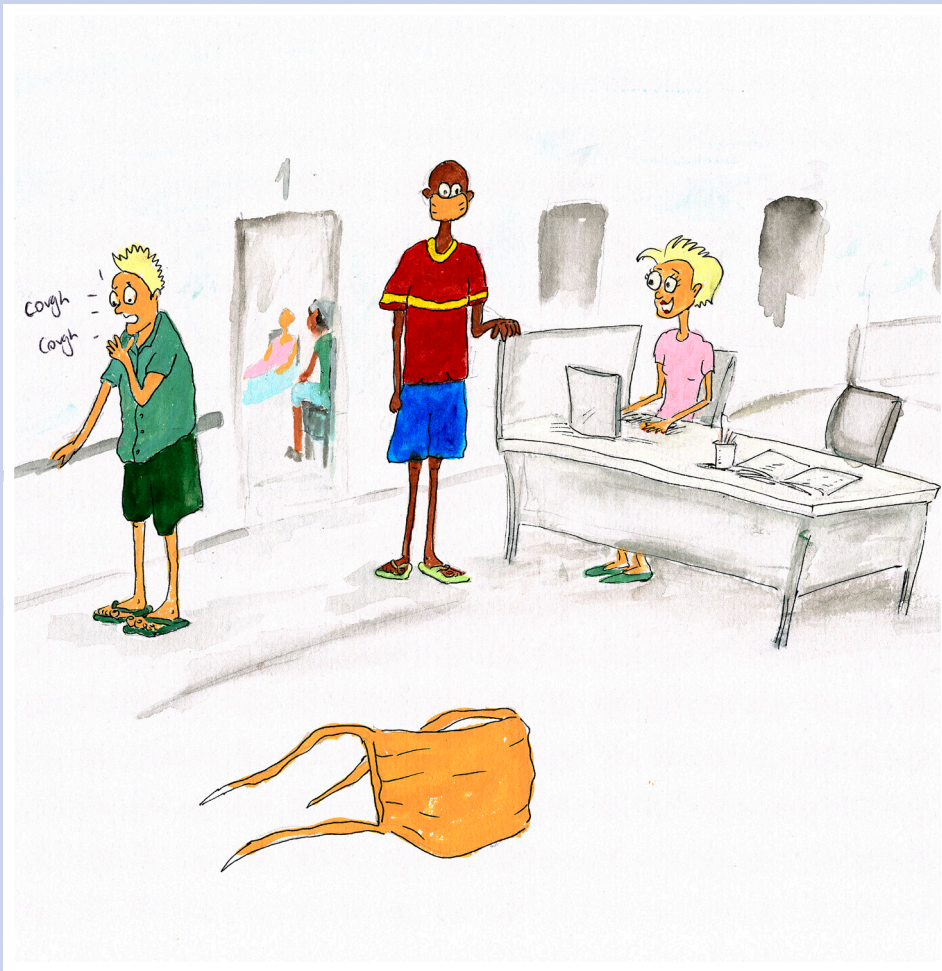
The chemo will kill some of your healthy blood cells, that keep you well.

This can leave you feeling weak and tired.

The doctors will give you bags of blood to make you feel stronger. You may need a few of these bags after you have chemo.

You may need bags of platelets too, these are yellow looking blood cells, which help your blood heal and clot.





Wear a mask to protect yourself

If you have your chemo in hospital the doctor will want you to stay in your room away from people's germs.

Wearing a mask can stop you getting germs.

When the doctors tell you that you are strong enough to go for a walk around the ward. You must always wear a mask.

Treatment is long

It can be lonely and hard being away from family and country for so long.

Stay strong, every day you are doing a great job healing your body of the blood cancer.





If you have worries

There are hospital staff you can talk to, to help you get through the tough times, or when you have worries or are missing family and country.

Talking about your worries can make you feel a lot better.

The church ministers can see you to talk and pray with you.

The ILO, interpreter, social worker or blood nurse can also visit and talk with you.

Having visitors can cheer you up.

Talk to family on the phone

Talking to family keeps you connected to your home and country.

The nurses can hook up the TV link so you can talk and see family back home.

If you are in hospital, you can use the ward phone to call home.

Or ask the blood nurse if there is some help with your phone credit.





The nurses will check on you often

Chemo can make your body weak and unwell from germs, even though you do everything right.

If you feel hot, sweaty or crook, press the buzzer straight away and tell the nurses.

If your temperature goes up high (38 degrees or more) you have a fever.

When you have a fever, you will need antibiotic medicine through your PICC line or drip, to make you better.

Checking your temperature at the hostel

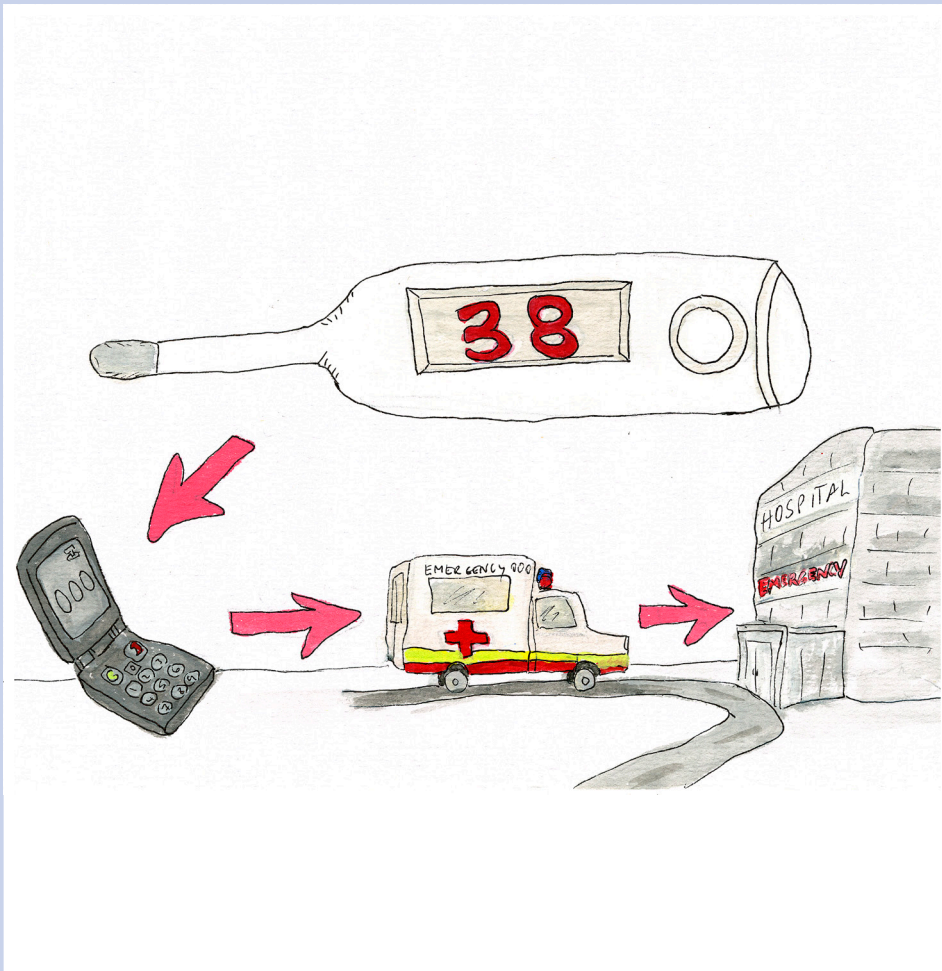
If you are staying in the hostel, the nurses will give you a thermometer to use.

You need to use your thermometer **every day**, or any time you are feeling unwell.

To use the thermometer-press the start button, put the thermometer under your tongue or under your arm, wait until it **beeps**.

If it shows the numbers: 38 or 39 it means you have a fever and need antibiotics straight away.





If you have a fever at the hostel

If the thermometer shows the numbers **38, 39 or 40.**

It means you have a **fever** and **you need to call the ambulance on 000 and come into hospital emergency department straight away.**

You can call 000 even if you have no credit, ask for the ambulance tell them you are a chemo patient.

ICU

In hospital you will have blood tests and antibiotics through your PICC line or drip.

Sometimes the antibiotics are not enough to make you better. The doctors may put you into the ICU ward (the Intensive Care Unit) in the hospital.

In ICU, you may need special machines to help you get better.

Family can see you in ICU, but they will have to wait till the nurses and doctors call them in.

You will need a lot of rest when you are in ICU.

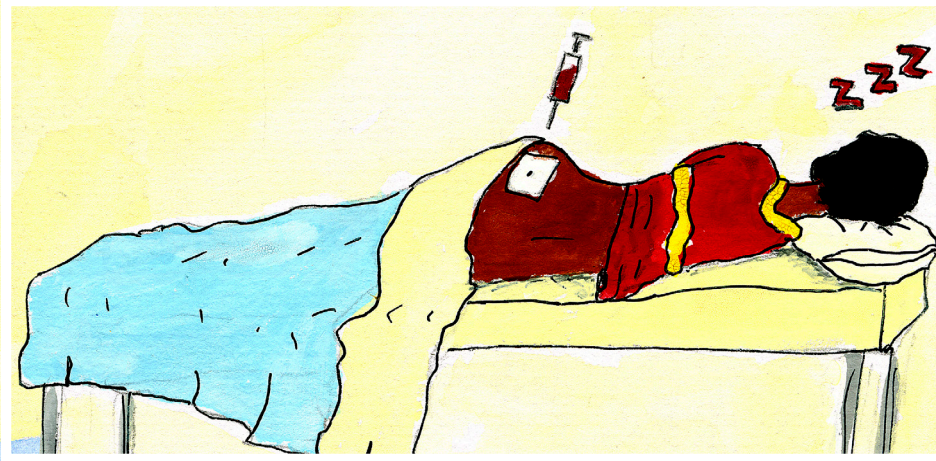




Half way through chemo

Half way through the chemo the doctors will ask you to have another lot of X-rays or scans and bone marrow tests.

This is to see how well the chemo has been healing your body from the blood cancer.



What's next?

After these tests the doctors will discuss with you and your family the results and the next plan of care.

Plan 1

The chemo has worked well, but you will need more chemo over the next months.

You may also need radiotherapy. This is a special X-ray treatment which also kills cancer cells.

When all this treatment is done, and your blood is strong you can go home and have blood tests there.

You will need to come back for regular check-ups and X-rays with the blood doctors.

Plan 2

The chemo has not worked enough. The doctors may add more chemo, or you may need another type of treatment.

Please see book Four or Five for more information on other types of treatments you may need.



End of Book Three

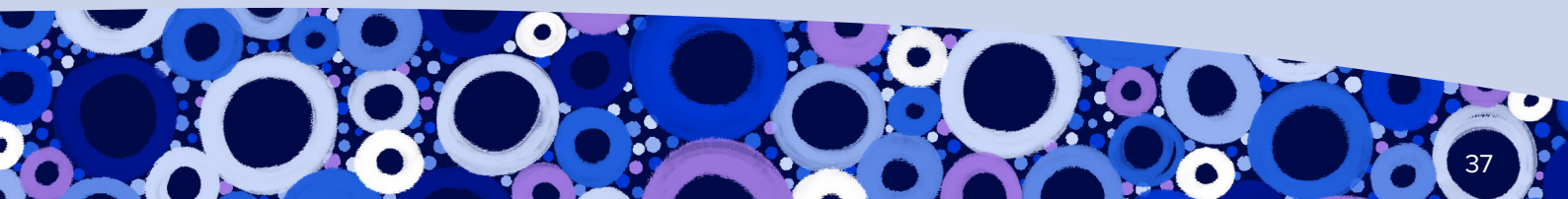
We hope this book has helped you and your family learn about:

- How chemo heals blood cancers.
- Where you will have the chemo.
- How long chemo will take.
- How chemo can change your body for a while.
- How you and family can help when you have chemo.
- What to do when you have a fever.

Please look at books Four or Five, to learn more about other treatment options for you.

Common questions

What chemo medicine looks like?	4
Where will you have your chemo?	6 - 7
What will chemo feel like, does it hurt?	8
How can you and your family help you get better?	11 - 28
What to do if you have worries?	27
Can I speak to a church minister or a social worker?	27
How can you get help to call your family?	28
How to take your temperature?	30
What you need to do if you have a fever or feel unwell?	18, 19, 30 & 31



Abbreviations and references

Bi Carb – Bicarbonate of Soda, a type of medicine which treats and stops mouth sores.

Blister/Special Packs – a special packet that contains tablets and has the days of the week and the times to take the tablets.

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.

CT Scan – (Computer Topographic Scan) is a special X-ray that shows pictures of the soft and hard areas inside your body.

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

Feeling Crook – feeling nauseated, vomiting, or having an upset stomach pain.

Germs – infection causing pathogens: bacteria; viruses; fungus.

Haematologist – specialist blood doctor.

ICU/ Intensive Care Unit – a special hospital ward for very unwell patients.

Nausea – upset stomach, which can make you want to vomit.

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

PET scan – (Positron Emission Topography) is a special X-ray that shows which parts inside your body are making a lot of new cells.

Pharmacists – a member of the team who specialises in medicines and drugs.

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

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.

Radiotherapy – special X-ray used to kill cancer cells.

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

Thermometer – a small machine that shows numbers, which can mean you have a fever.

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): _____

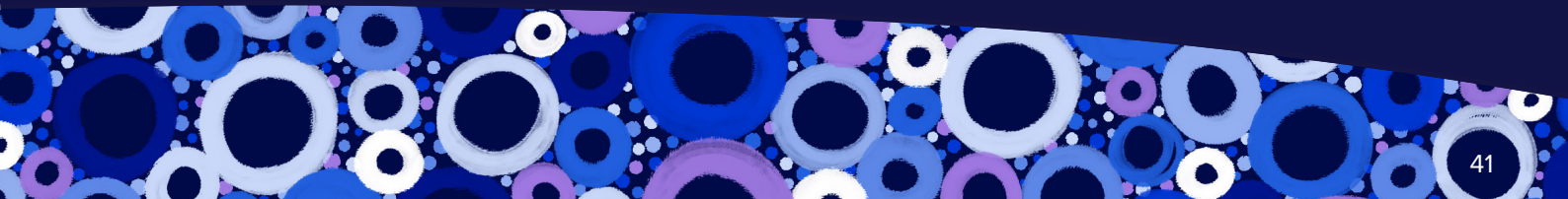
Cancer Council: _____

Health Worker: _____

ILO: _____

Cancer Day Unit: _____

Hospital number: _____





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