

# Ben's Stem Cell Transplant

A guide for children who are having a stem cell transplant (SCT)



 leukaemia &  
blood cancer  
new zealand

our mission is to care, our vision is to cure

# About you

This booklet is yours to help you to understand why you need a stem cell transplant (SCT) and to explain some of the things that may happen to you. You probably need to have a stem cell transplant because some of your blood cells are not working properly.



my first name:  
.....

my age:  
.....

my hospital:  
.....

date of transplant:

With thanks to:



And Ward 27B Starship Children's Hospital

# Ben's Stem Cell Transplant

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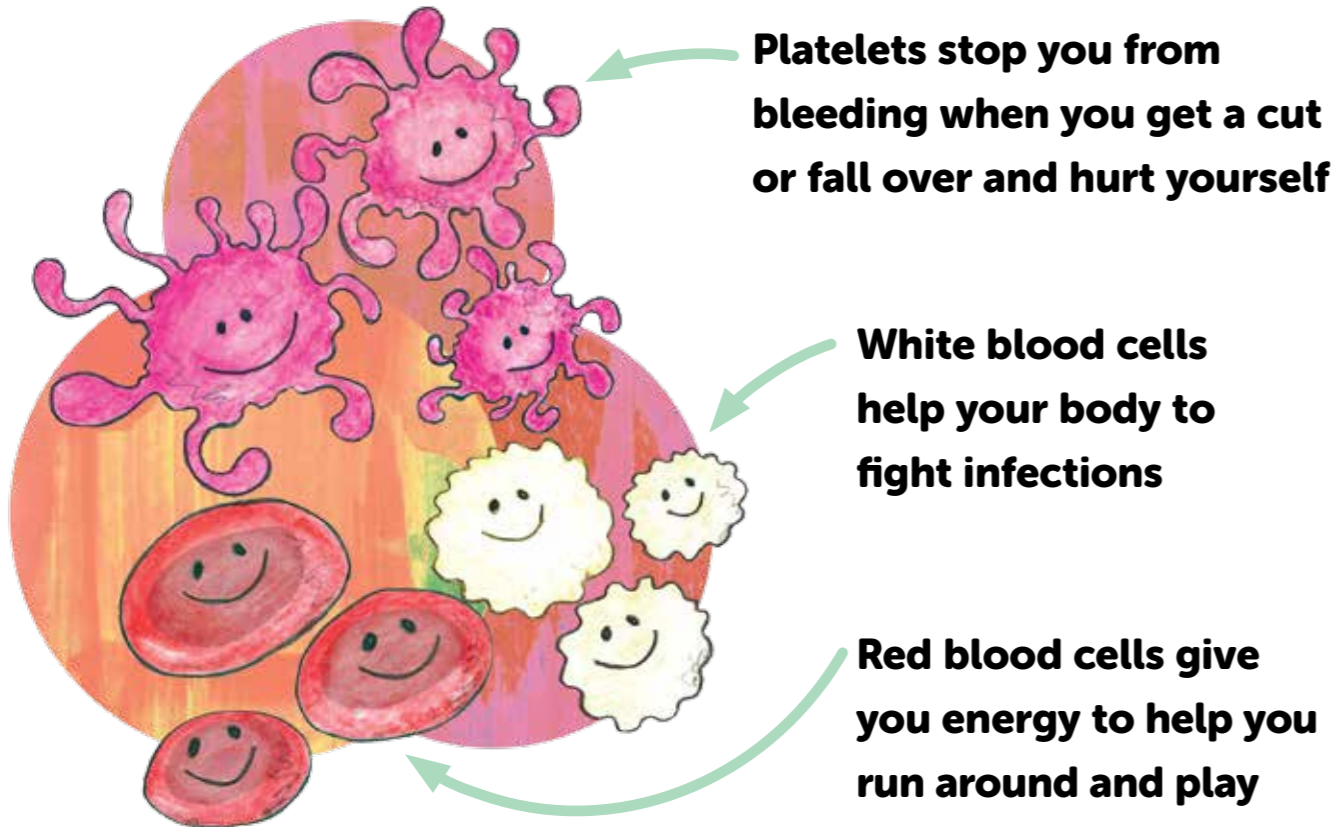
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Julie Guest.

Illustrated by  
Christine Sharp.



# What are stem cells?

Stem cells make all your blood cells in a factory called the bone marrow. Your factory isn't making some of your blood cells properly and a stem cell transplant will try to help the factory to work better.



# Meet Ben

This is Ben. He's going to tell you about what it's like to have a stem cell transplant.



# Tests



Ben will begin by telling you what happens before a transplant.

You are likely to have many different tests before your transplant, to make sure your body is ready.

Find out which of these tests or measurements you will need and if you will need to have anything else done as well.

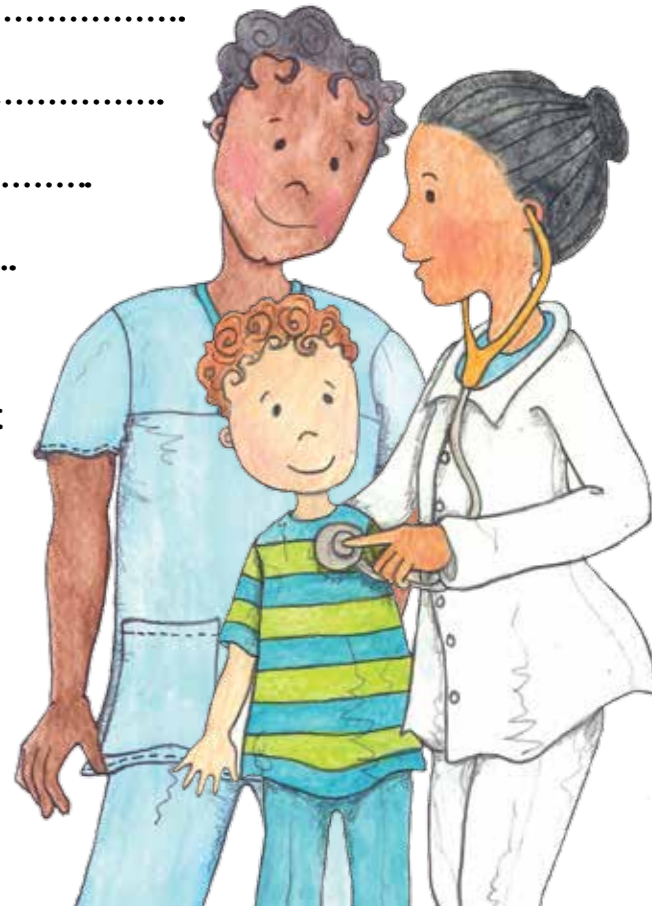
- |                     |                        |
|---------------------|------------------------|
| <b>X-ray</b>        | <b>Breathing tests</b> |
| <b>Blood tests</b>  | <b>Kidney test</b>     |
| <b>Dental check</b> | <b>Height</b>          |
| <b>Heart scan</b>   | <b>Weight</b>          |

# Hospital staff

Ben met lots of new people during his stem cell transplant. Here's a list of the different people you may meet.

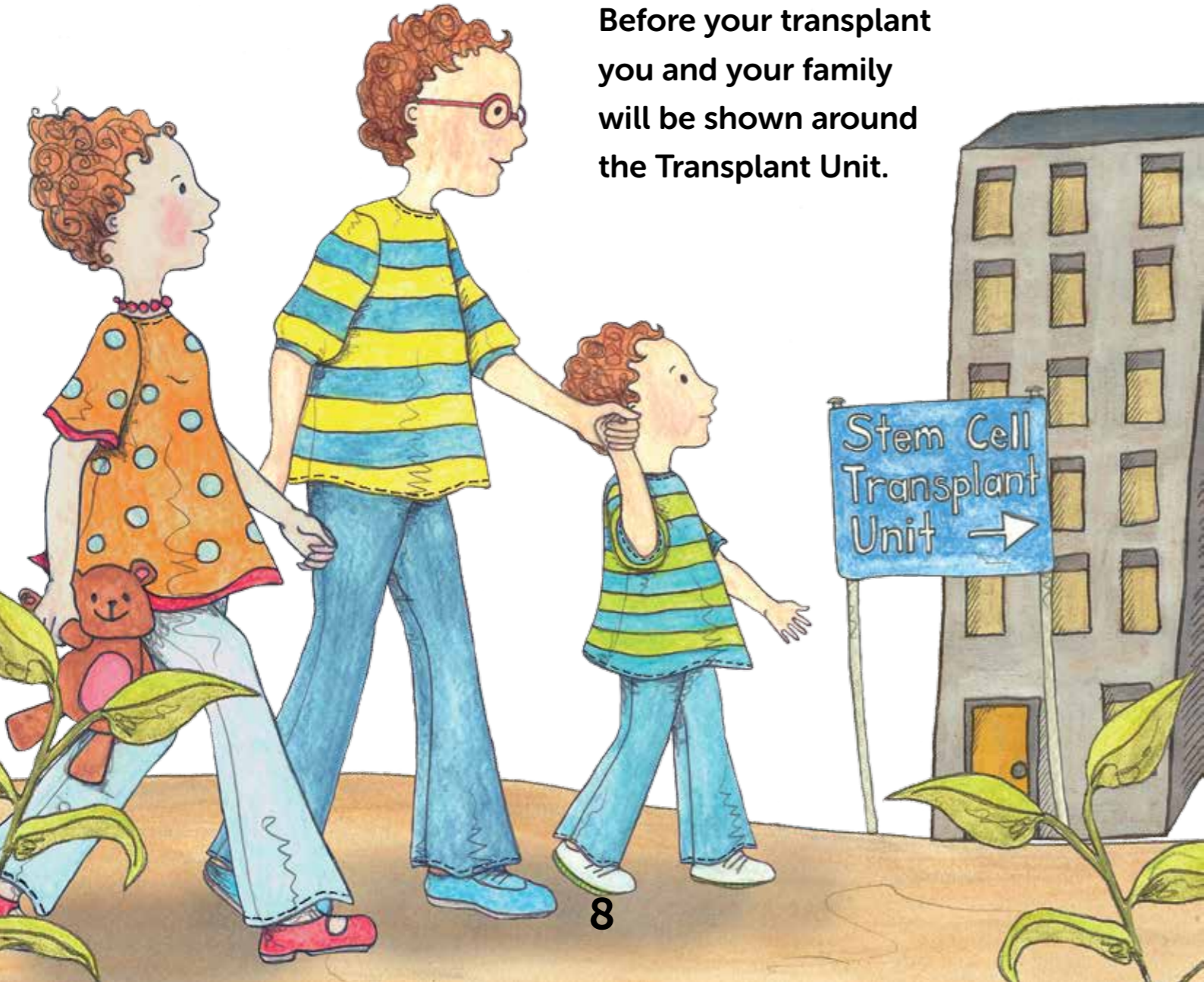
You might like to write down their names to help you remember them, or draw a picture of them.

- Transplant doctors .....
- Transplant nurses .....
- Dietitian .....
- Teachers .....
- Social worker .....
- Physiotherapist / Occupational therapist .....
- Psychologist .....
- Health care assistant / Cleaners .....



# The Stem Cell Transplant Unit

Before your transplant you and your family will be shown around the Transplant Unit.



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Coming into hospital for your stem cell transplant can feel strange. You may stay in hospital for around six weeks, sometimes longer. This may seem a long time and you probably want to know what will happen and how you will feel.

Everyone feels differently about going to hospital. Do you feel excited, nervous, happy, frightened, sad, angry, scared or worried? You may find it helps to talk about these feelings.

When you have your transplant you need to go into a room on your own which will be your special bedroom. You may hear people calling this 'isolation', but your family and friends can visit you there.



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## Ben's treatment

Before I started my treatment for transplant, I went to theatre to have a central line put in.

A central line, which is sometimes called a 'Hickman line', is used for blood tests and to give you the treatments you need.

If you don't already have a central line, you will need a central line put in before your transplant. It will stay in for a few months and will not stop you playing or going to school, but you will not be able to go swimming.

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Before you can have your transplant, you will be given some treatment to get your body ready for the transplant. For some children this treatment is for a couple of days and for others it can last up to two weeks. This treatment may include chemotherapy, or radiotherapy, or both.

Chemotherapy is a special treatment with medicine. These medicines may be given through your central line or into your mouth. Their main job is to kill any cells in your body that don't work properly and to destroy your own stem cells so they can't fight with the new stem cells after they are given to you.

Ben found it helped to think of chemotherapy as being members of an army.

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# Radiotherapy

Radiotherapy is not given to all children who have a stem cell transplant. Radiotherapy is a special kind of X-ray that kills any cells in your body that don't work properly and also destroys your stem cells too.

Having radiotherapy does not hurt but it is very important that you keep very still during this treatment. Radiotherapy lasts for about 20 minutes. The X-ray machine makes a funny noise. No one else can stay in the room with you while you have your radiotherapy but usually they can see and hear you on a special television screen.

Do you need to have radiotherapy before your transplant?

Ben found watching his favourite movie or listening to his favourite music helped to pass the time.



Think about which DVD or music you will take with you.

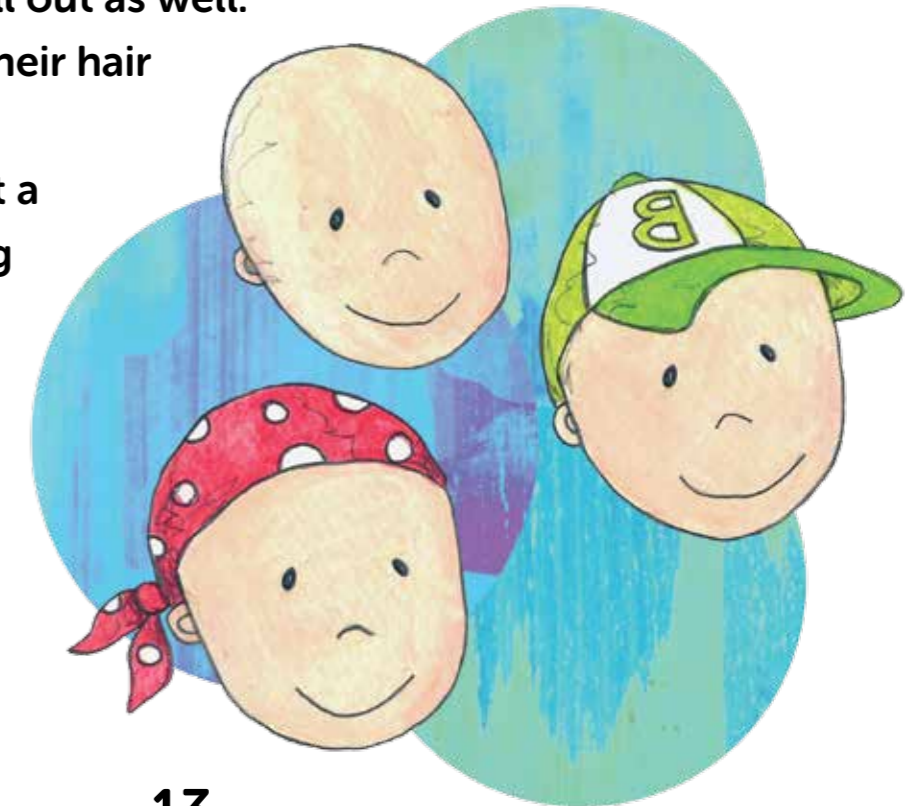
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# Transplant Day

After your chemotherapy or radiotherapy or both, you will be given the stem cells through your Hickman or central line. Your doctors and nurses call transplant day 'day 0'.

About two weeks after chemotherapy and radiotherapy your hair may begin to fall out. This will not hurt. Your eyebrows and eyelashes may fall out as well.

Some children have their hair cut short before their transplant. Others get a special cap, hat or wig to wear until their hair grows back. New hair grows back after 3–6 months.



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## Ben looked after his mouth

Chemotherapy and radiotherapy can make you feel sick. After your treatment has finished this feeling may carry on because of other medicines or problems. The nurses will give you medicine in your mouth or central line to help stop this sick feeling.



It is really important to tell the nurses if you feel sick so they can try to help you.

Ben found it really helped to suck ice cubes or drink small sips of water regularly.

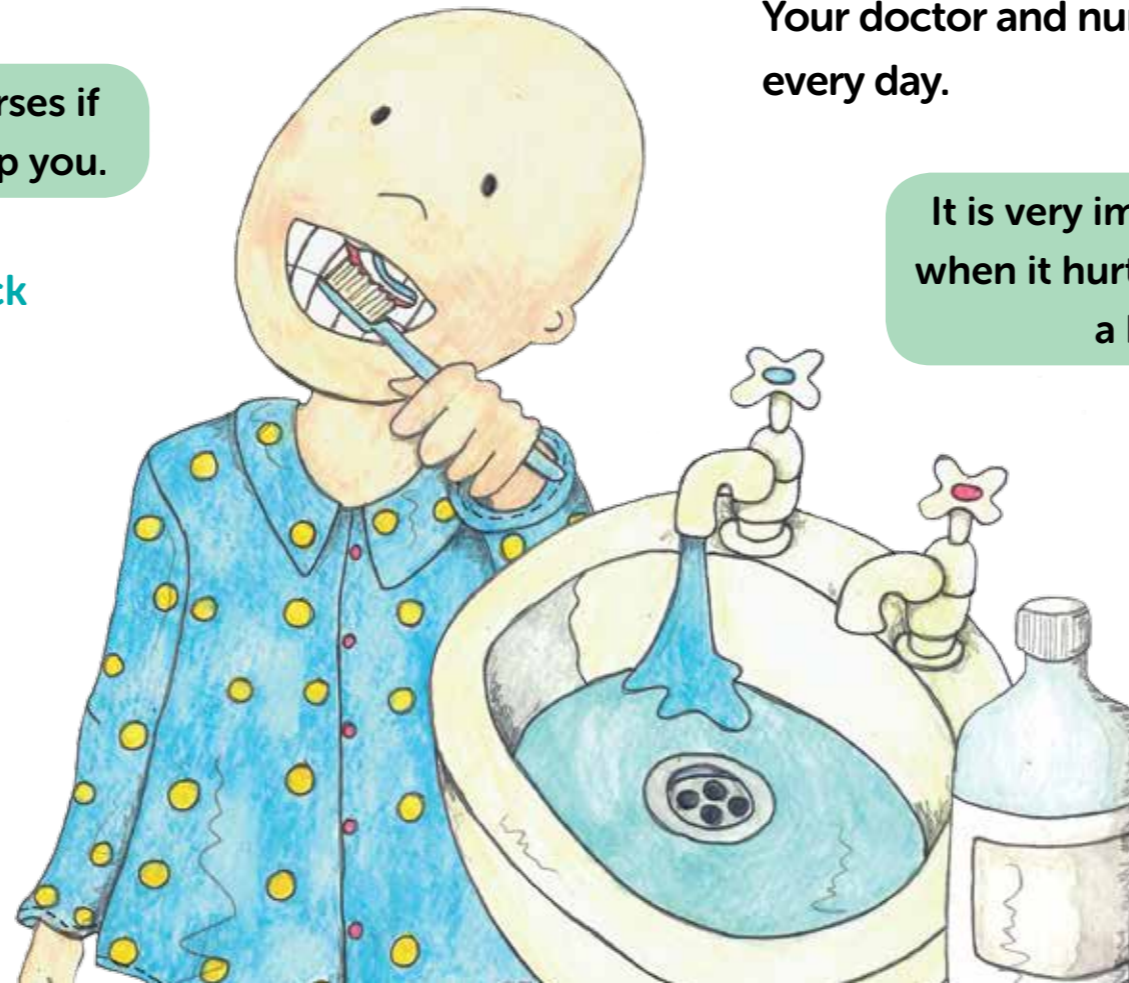
Chemotherapy and radiotherapy can make your mouth sore because they kill the good cells as well as the bad ones. The best way to help this problem is to keep your mouth clean.

We would like you to clean your teeth with a soft toothbrush and toothpaste or use a mouthwash 3–4 times a day. If your mouth becomes too sore for this you can use special sponges.

Your doctor and nurses will probably ask to look in your mouth every day.

It is very important to tell them how it feels, especially when it hurts, so they can help to make your mouth feel a bit better by giving you painkillers.

Ben found sucking ice blocks or ice cubes helped him when his mouth was sore. When his mouth was very sore Ben did not want to eat or drink. Ben's mouth did get better though.

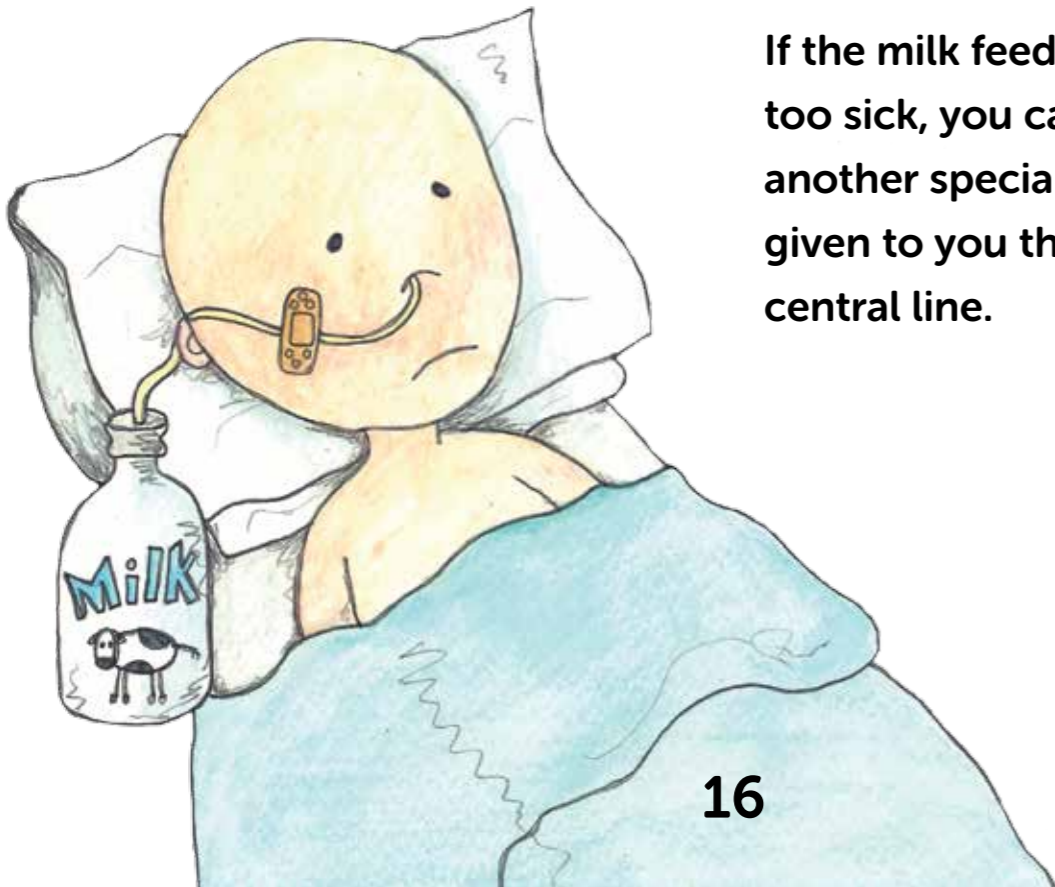




## Ben's tube

Ben had a tube down his nose and into his tummy. It was not very nice when the tube was put in but it stopped his family asking him all the time to eat and drink. The tube meant Ben could have the special milk feed that helped him stay strong during his transplant. This tube can also be used for medicines which really helped Ben.

If the milk feed makes you too sick, you can have another special feed (TPN) given to you through your central line.

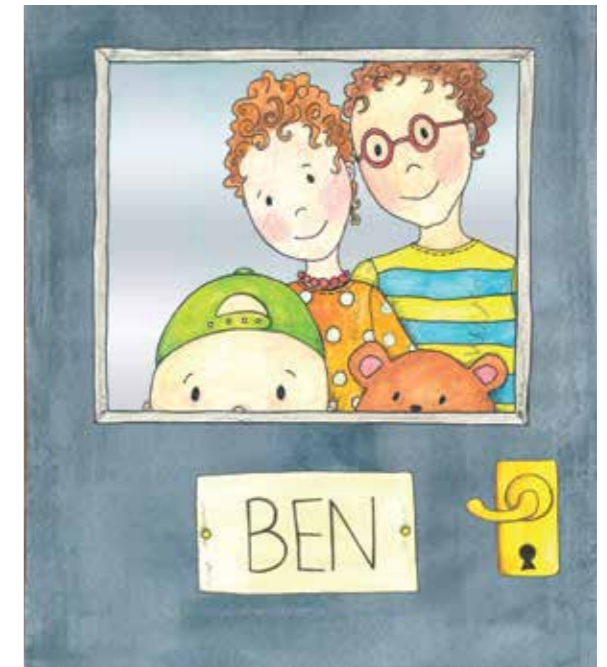


## Ben's special bedroom

The treatment you will have will destroy your old stem cells. This means you will not have many white cells left. White blood cells are important to help protect your body against infection.

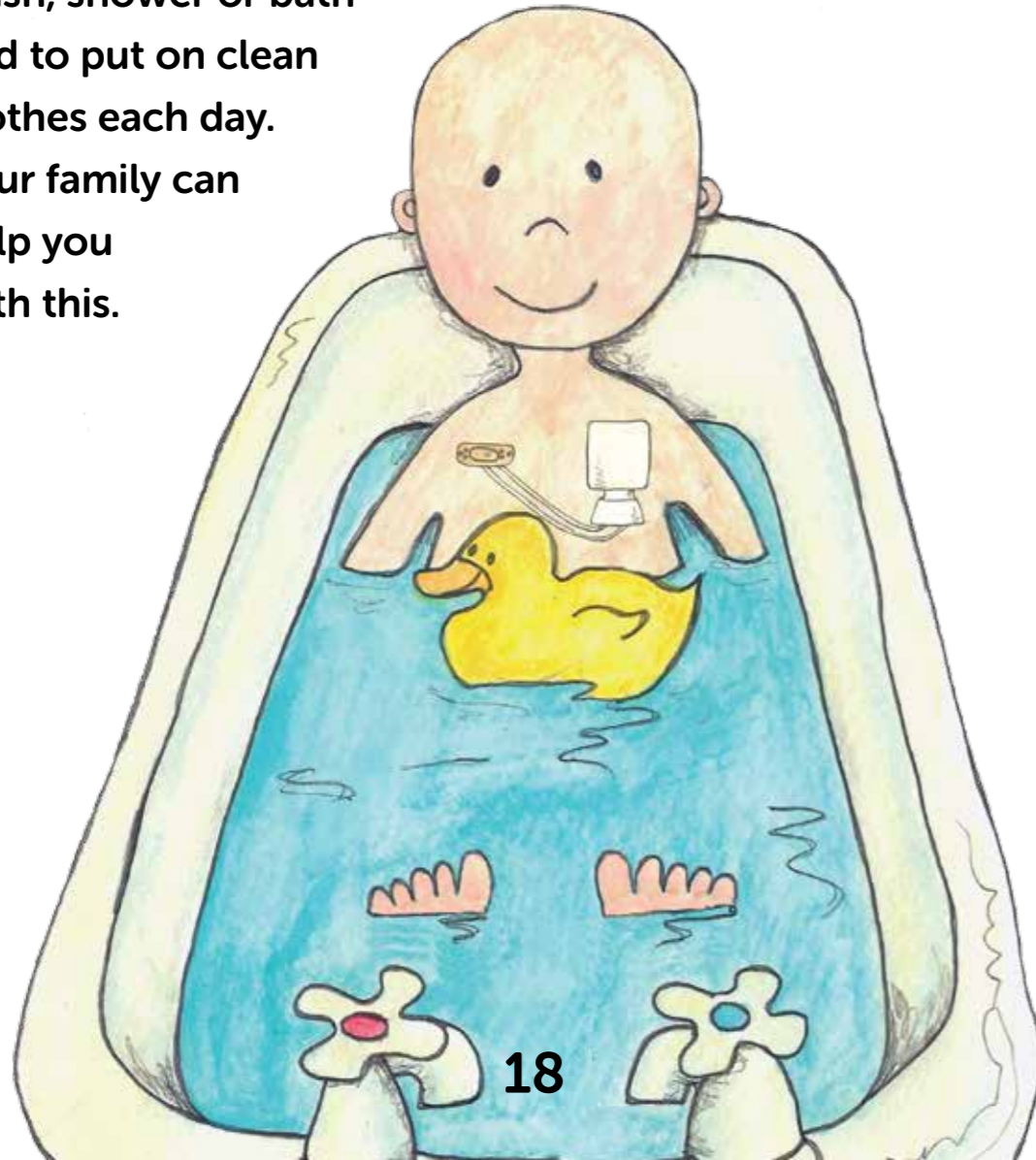
The reason you will have a special bedroom of your own in hospital rather than sharing with other children is to keep you safe from infection. Someone from your family can stay near you to look after you, and you can have visitors as long as they are well.

You may like to keep in touch with your brothers or sisters and school friends by phone, letter, text or online.



## Ben's bathtime

You will be asked to wash, shower or bath and to put on clean clothes each day. Your family can help you with this.



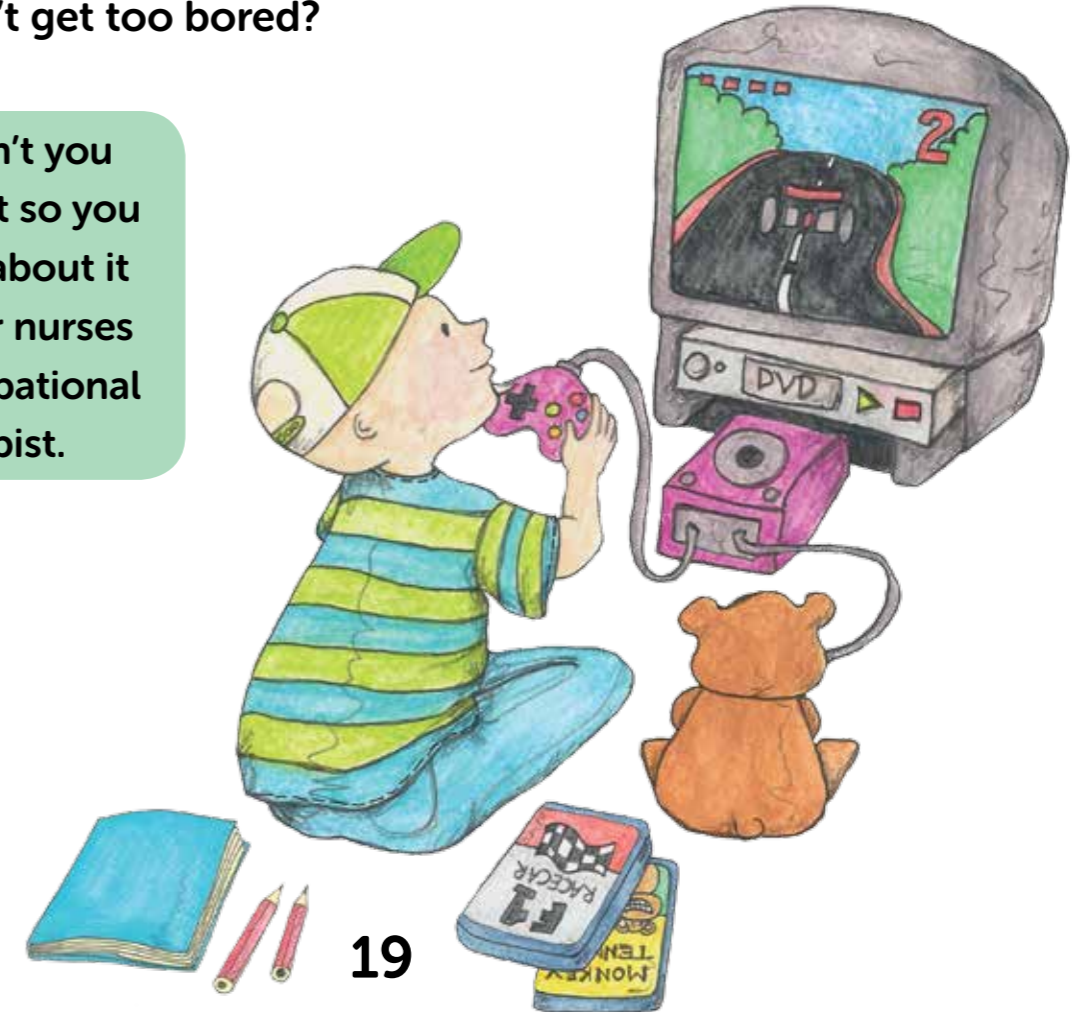
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## How Ben kept busy

Ben spent a lot of time on the computer, he played games and did his schoolwork so he wasn't too bored.

Have you decided what you would like to do so you don't get too bored?

Why don't you write a list so you can talk about it with your nurses and occupational therapist.



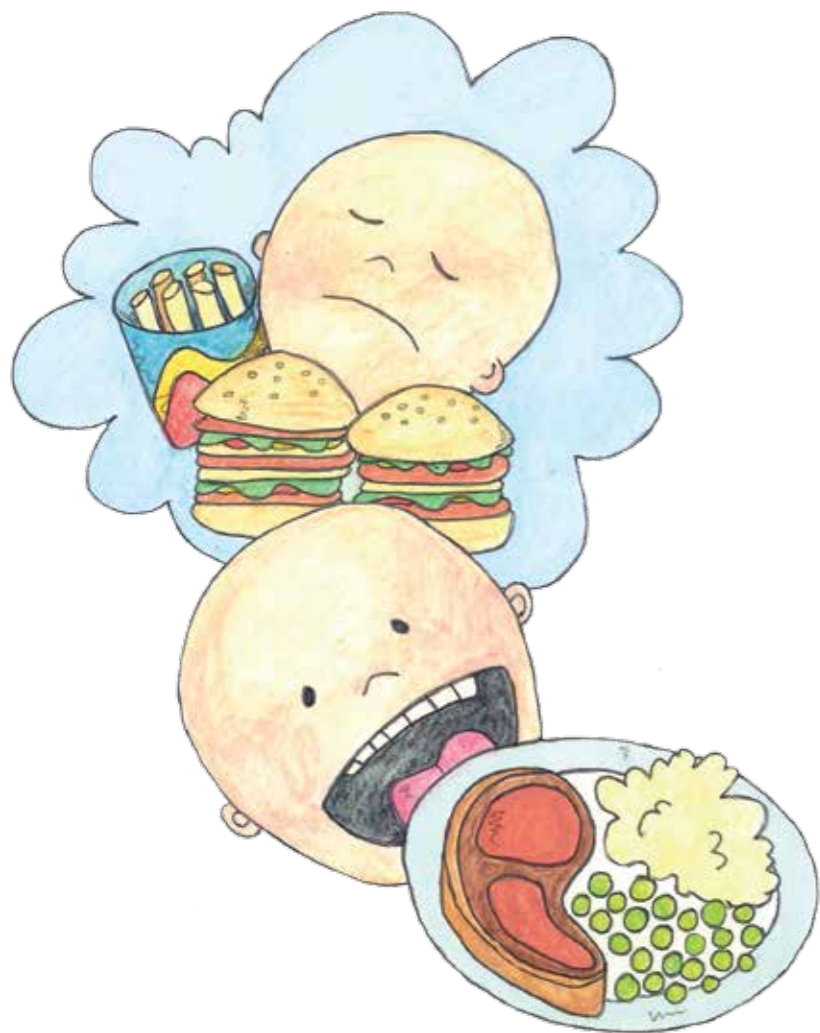
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## What Ben could eat

You may not be allowed to eat some of your favourite foods for a while because they may cause you to have a sore tummy or diarrhoea.

Make a list of the foods you like to eat so your nurse can talk to you about what you can and can't eat during your transplant.

You won't be allowed to eat the skin on fruit or have eggs with runny yolks.



## Ben was feeling better

When your new stem cells start to work you will be able to start leaving your special bedroom.

The nurses and doctors will know when you are ready to do this by checking your blood count

When Ben was told he could leave his room, he was very excited. He was a little frightened as well, because he had been in isolation for a few weeks.

Some children need to stay in isolation longer than this because of an infection.

Ben could now get ready to go home.



## Medicines



When you get home you will need to take some medicines. Usually, you can choose between tablets or liquids, so make sure you ask if you are not given this choice.

Ben found some of the medicines were easier to take with his favourite drink and that sucking on a lolly afterwards took the taste away.

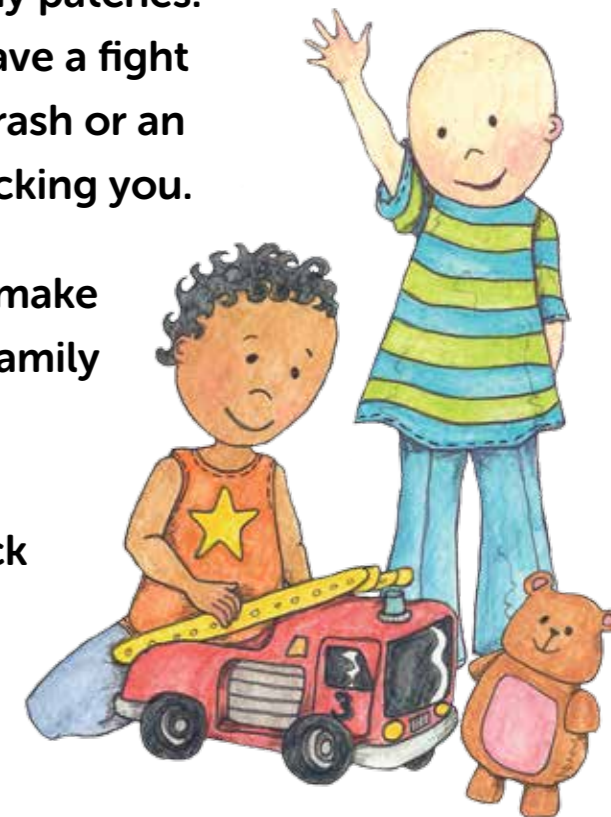
If you still have a tube in your nose to help feed you, it can be used for some of your medicines too.

## Ben's hospital visits

After Ben went home he had to go back to hospital once or twice a week to have blood taken to make sure the medicines were working. Ben liked going back to hospital because he enjoyed seeing all the doctors and nurses again.

When you come back to hospital, we will check your skin to make sure there are no spots or itchy patches. Sometimes your new stem cells can have a fight with your body which may give you a rash or an upset tummy, so we need to keep checking you.

You may need a different medicine to make this better. You always must tell your family if there is anything wrong, so they can take you to the hospital to sort it out. Sometimes you may have to come back into hospital for a few days to sort out the problem.



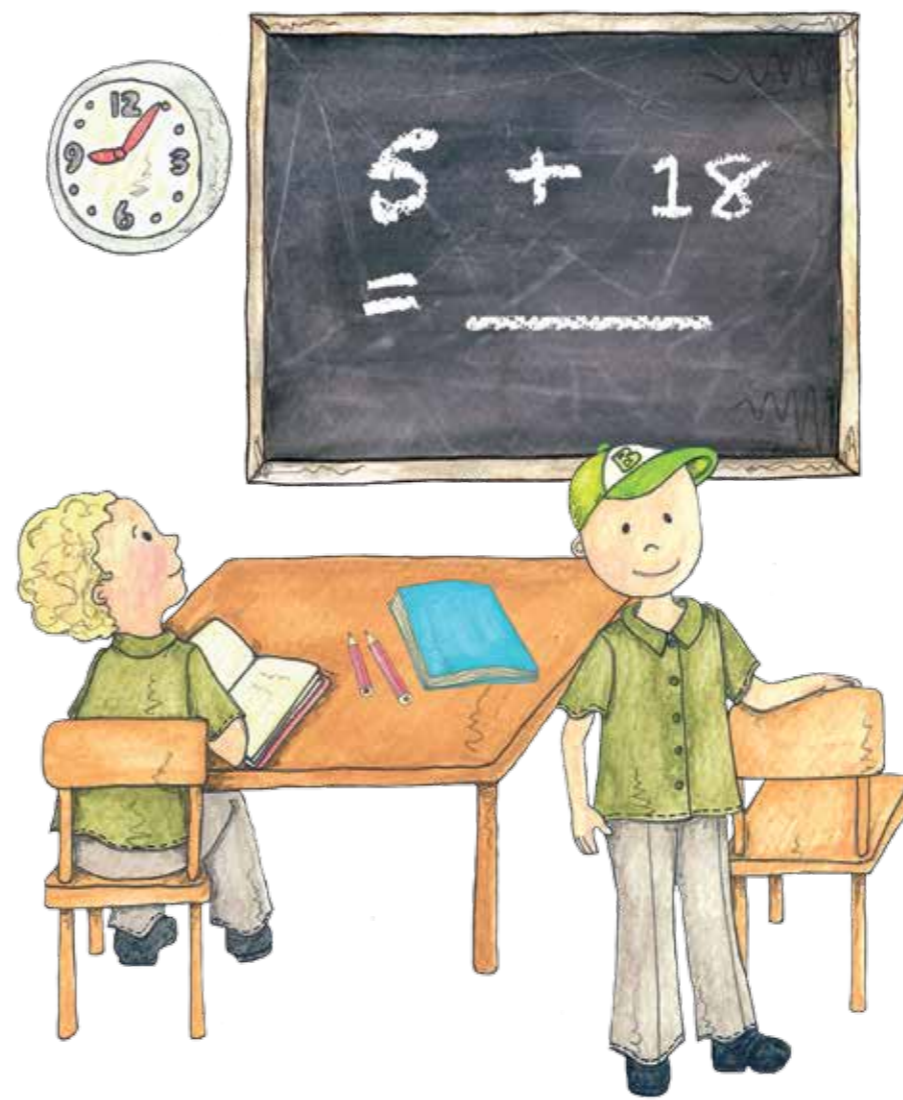
## Coming out of hospital



When you leave hospital you need to be very careful not to catch any germs. At first this means staying home and having only a couple of friends over. When your friends visit it is important they are well and don't have any infections. The nurses will tell you all about this.

You shouldn't go out to the shops or inside busy places, but you can go outside into the fresh air and take short walks to the park if you feel strong enough.

You won't be able to go back to school for a few months but your parents can arrange for your teachers to send schoolwork home instead.



You probably will feel quite tired a lot of the time too, especially if you have had radiotherapy. This is quite normal and you will get a little stronger and will be able to do a little more every day.

Don't worry if you need to sleep or have a rest during the day. When your new stem cells are strong enough you will be able to go back to school. At first, you may only go for a few hours or half a day as you may still feel very tired. Don't worry about this.

## Ben's hair started growing back

Ben's hair started to grow back a few months after his transplant.

Sometimes, hair can be a bit darker, a bit lighter, or more curly when it grows back.



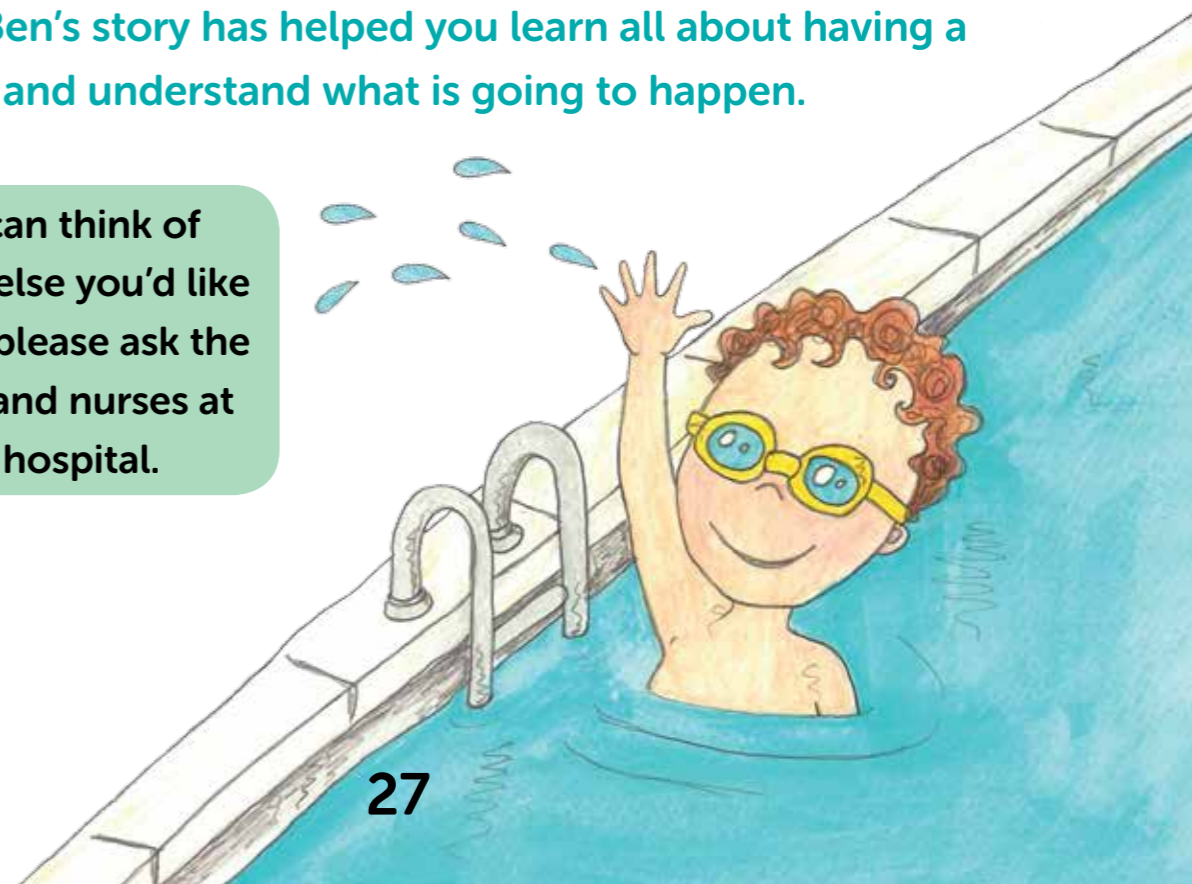
## Ben's hospital visits

When Ben stopped needing lots of blood tests or medicine, he didn't need his central line anymore. This happened about 3–6 months after his transplant and his central line was taken out. Then Ben could go swimming and have a deeper bath!

Ben also didn't need to go to the clinic as often.

We hope Ben's story has helped you learn all about having a transplant and understand what is going to happen.

If you can think of anything else you'd like to know, please ask the doctors and nurses at your hospital.



## What these words mean

You may hear lots of strange new words when you're in hospital. Below are some of the main ones and what they mean. If you're unsure about any others, just ask your doctor or nurse.

### **ANAESTHETIC**

When the doctors give you some medicine that makes you go to sleep during an operation, so you don't feel any pain.

### **BLOOD TEST**

When a tiny sample of your blood is looked at to see how many red cells, white cells and platelets you have.

### **CANCER**

When the cells in your body become abnormal (bad) and continue to grow on their own, out of control.

### **CHEMOTHERAPY**

A mixture of different medicines which treat cancer.

### **CT SCAN**

An x-ray where the doctor can look inside your body at all your organs. You need to lie very still.

## What these words mean

### **HAEMATOLOGIST**

A doctor that looks after people with blood or lymph node diseases or problems with their blood or lymph nodes.

### **HICKMAN LINE**

One or two lines are inserted under anaesthetic, the end comes out through a small hole in the skin on your chest.

### **LYMPHOMA**

Cancer of the lymphatic system.

### **LYMPH NODES**

Where the cells which fight infections and disease live. Lymph nodes become bigger when they are fighting infection and disease as they are making more cells.

### **MRI SCAN**

A scan that allows the doctors to get a clear picture of what's going on in your body. It can be quite noisy and even though it doesn't hurt, you might be given an anaesthetic or some medicine to help you relax.

## What these words mean

### **NEUTROPENIC**

When you hardly have any neutrophils (the white cells that fight infections).  
Being neutropenic means you are more at risk of getting infections.

### **ONCOLOGIST**

A doctor who treats people with cancer.

### **PET SCAN**

Another scan which lets the doctors see what's going on in your body!  
Areas where there is lymphoma will show up on the scan as bright spots.

### **PICC LINE**

One or two lines are inserted under anaesthetic the end comes out of a small  
hole in your skin on your arm.

### **PORTACATH**

A device is inserted under the skin under anaesthetic near the armpit, then  
runs under the skin to the main vein in the neck. If treatment is given or  
blood taken, 'magic cream' is put on the skin covering the portacath one hour  
beforehand – to make it go numb so it will not hurt so much when the needle  
goes in.

### **SIDE EFFECT**

Something that may happen through having treatment, for example,  
feeling sick or your hair falling out.



Leukaemia & Blood Cancer New Zealand is a national organisation in New Zealand dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma and related blood conditions.

Every family's experience is different; living with a blood cancer or condition is not easy, but you don't have to do it alone.

**0800 15 10 15**  
**[www.leukaemia.org.nz](http://www.leukaemia.org.nz)**

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Illustrated by Christine Sharp.







**If you have any questions  
or if you are unsure about anything,  
please ask a member of your treatment team  
or contact Leukaemia & Blood Cancer New Zealand.**

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