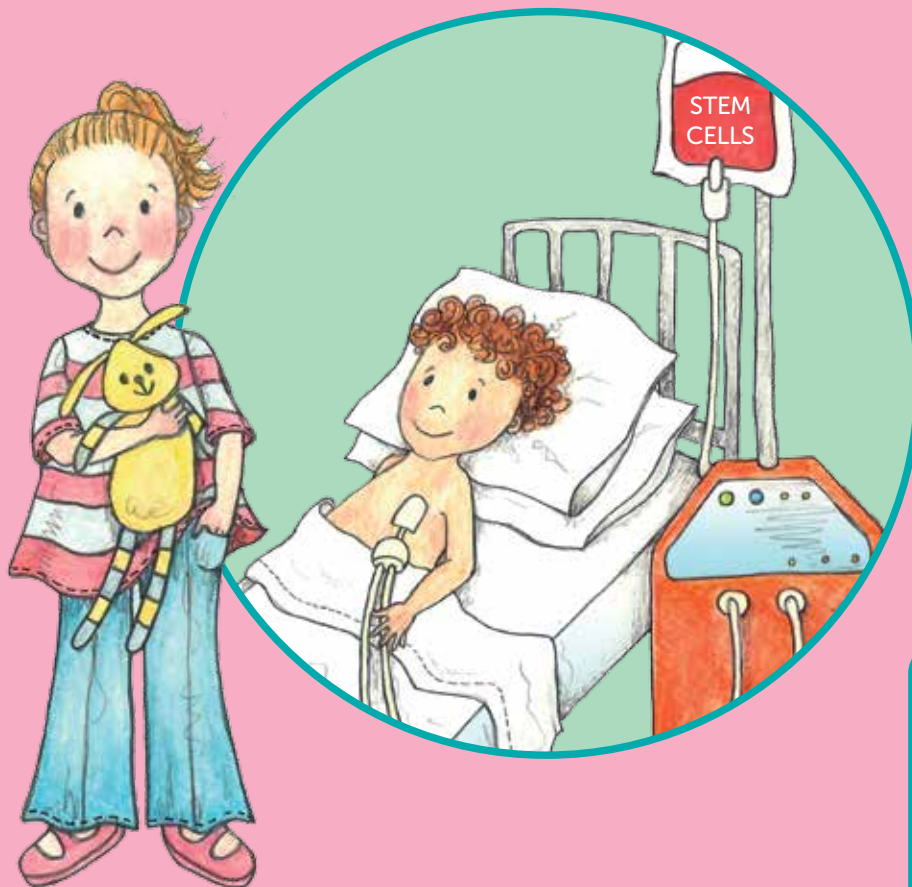


Jess' Stem Cell Donation

A guide for children who are stem cell donors



 leukaemia &
blood cancer
new zealand

our mission is to care, our vision is to cure

About you

This booklet is yours to help explain about being a stem cell donor and some of the things that may happen to you.



my first name:

.....

my age:

.....

my hospital:

.....

date of donation:

.....

I am donating my stem cells to:

.....

With thanks to:



And Ward 27B Starship Children's Hospital

Jess' Stem Cell Donation

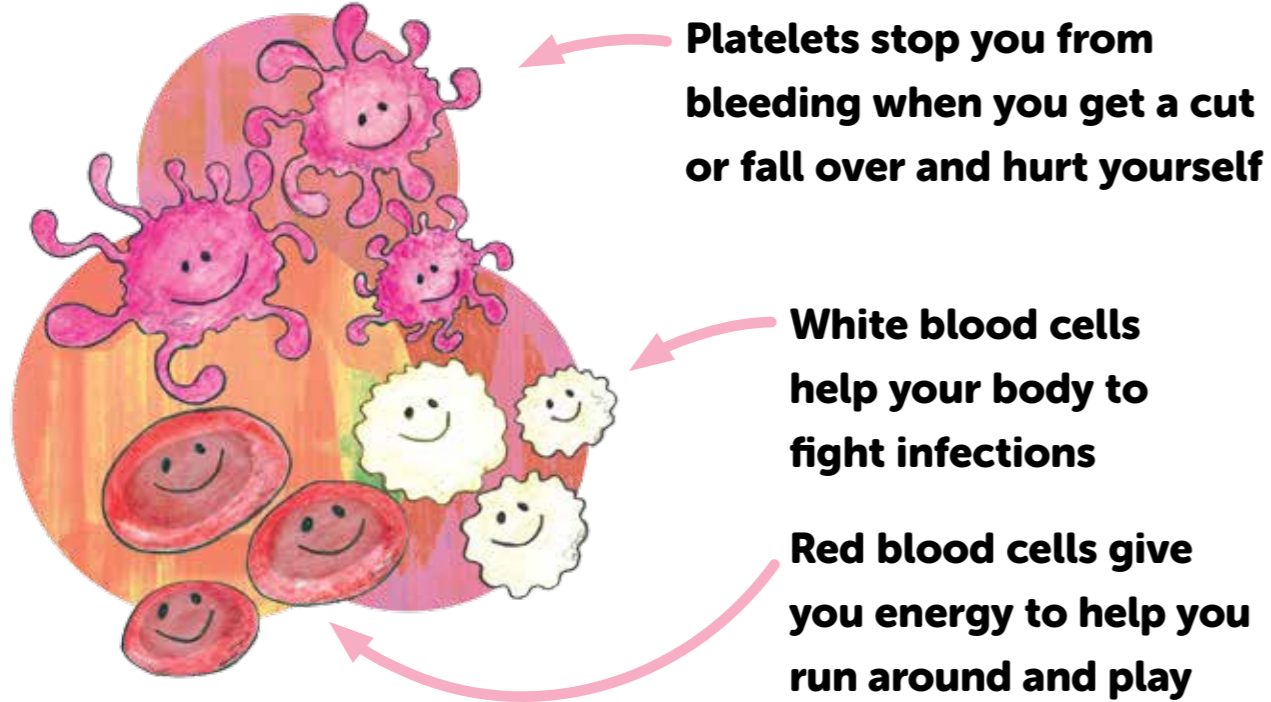
Original version written by Jenny Astall
and edited by Lesley Edwards and
Penny Owens on behalf of the
Children's Cancer and Leukaemia
Group Publications Committee (UK).

Illustrated by
Christine Sharp.



What are stem cells?

Stem cells make all your blood cells in a factory called the bone marrow.



The stem cells of your brother, sister or other relative aren't working properly. This is why they need a stem cell transplant. We need to give them new stem cells that are working well, to help make them better.

Meet Jess

This is Jess. She is going to tell you about what it is like to be a stem cell donor.

Being a stem cell donor means the stem cells in your bone marrow are healthy and working well and a blood test shows your stem cells match the cells of your brother, sister or relative.



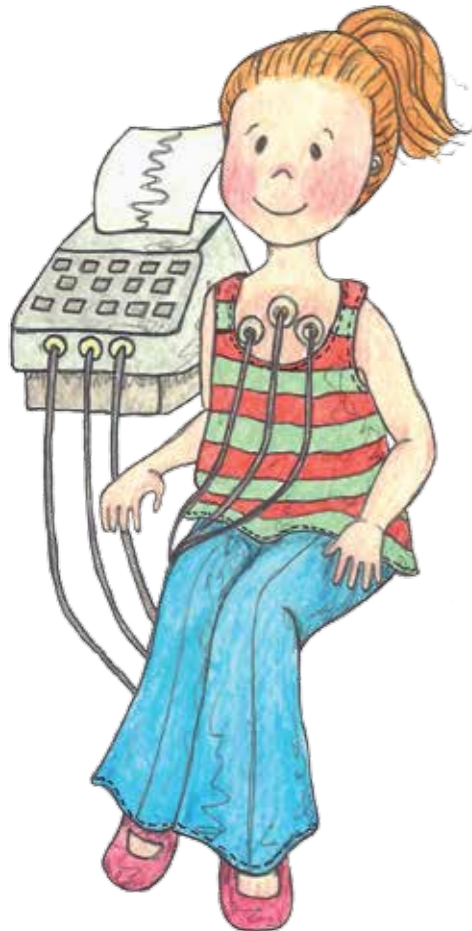
Before you give some stem cells

Jess wants to tell you what will happen before you donate your stem cells, once we know you are a match for your relative.

You will have a little more blood taken for blood tests.

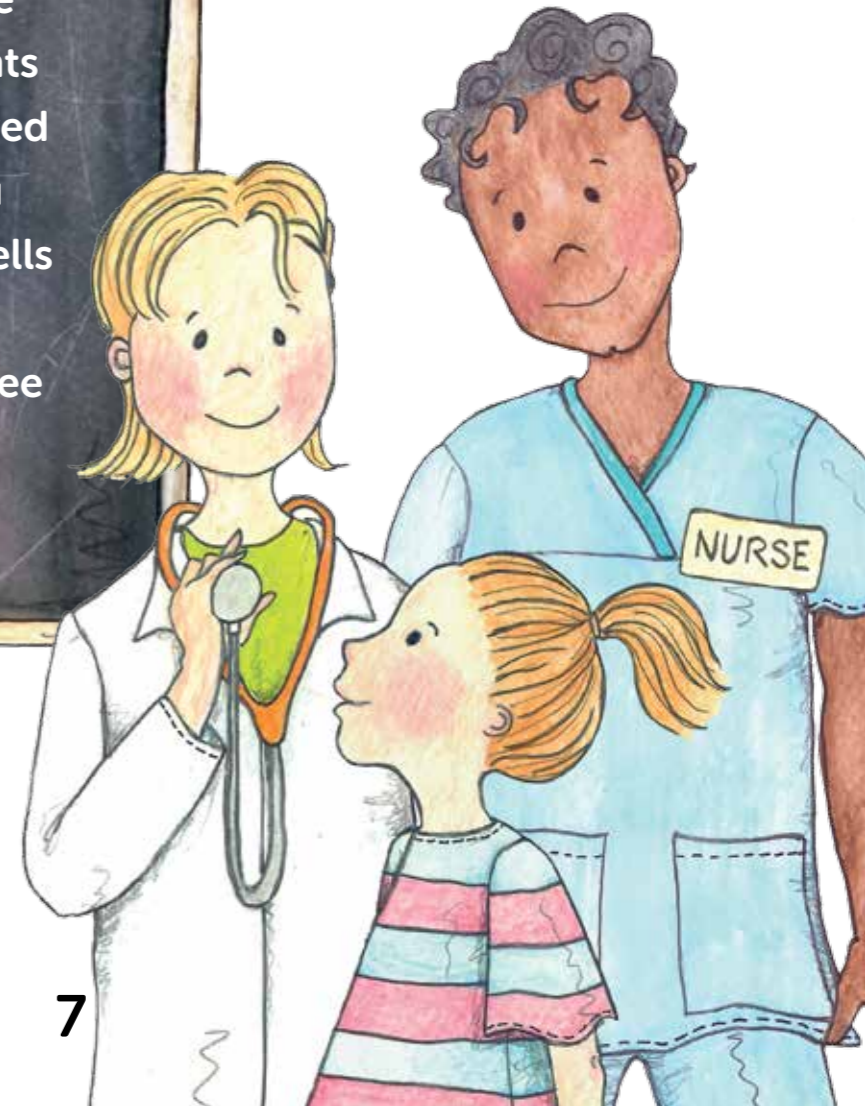
You will meet a doctor and a nurse who will explain all about being a stem cell donor and make sure you are fit and well.

You also will meet with somebody called a donor advocate. They will make sure you understand what will happen when you come into hospital to be a stem cell donor and that you are OK with being a stem cell donor.



What is a donor advocate?

The donor advocate's job is to make sure you and your parents know what is involved for you when you donate your stem cells and that you and your parents all agree to you making the donation.

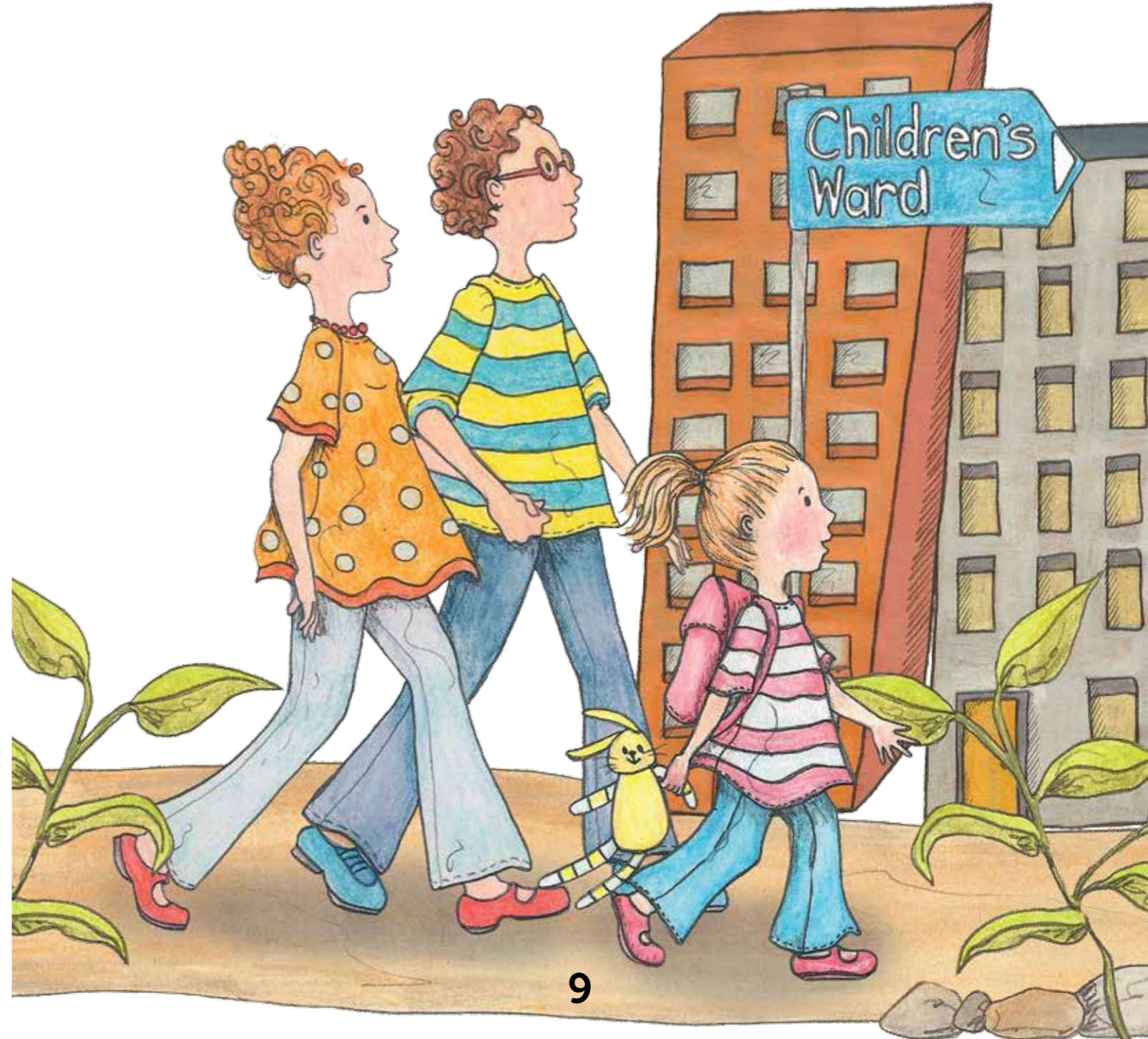
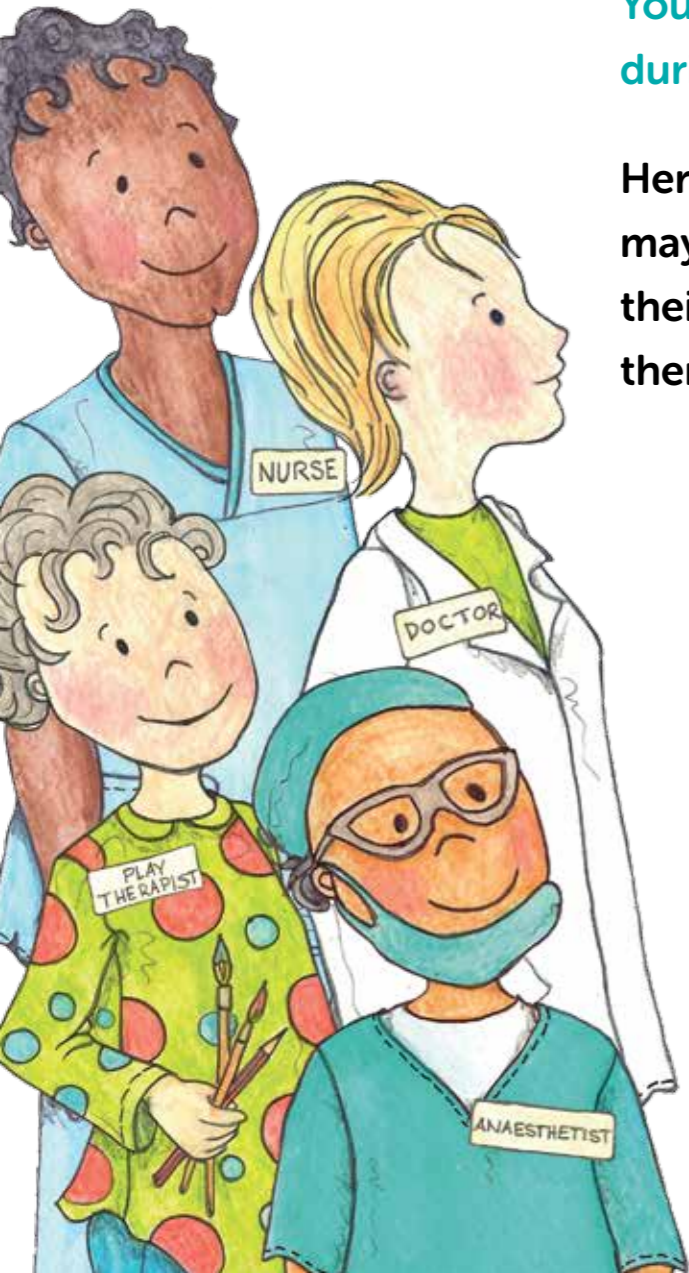


Hospital staff

You will meet lots of new people during your stem cell donation process.

Here's a list of the different people you may meet. You may like to write down their names to help you remember them or draw a picture of them.

- Transplant doctors**
- Bone marrow transplant nurses**
- Donor advocate**
- Anaesthetist**



Going to hospital

It is usual for you to stay a night or two in the children's ward when donating your stem cells.

Everybody 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.

You will only need to stay in hospital for a short time

When you go into hospital to donate your stem cells, the person who is going to receive your stem cells may already be in hospital having some medicine called chemotherapy. They also may have had some special X-rays called radiotherapy.

Soon, they will be in their isolation room to help stop them from getting germs. If you visit them, you must be well and wash your hands.



Jess comes into hospital

When you come into hospital you need to bring with you a bag of clothes and toys. And remember, there already are loads of toys and things to do in the hospital.



Don't forget:
Pyjamas / nightgown
Toothbrush and toothpaste
Clean clothes
A book to read
Toys to play with
A special doll or teddy

What else would you like to bring with you?

Write a list to remind yourself.

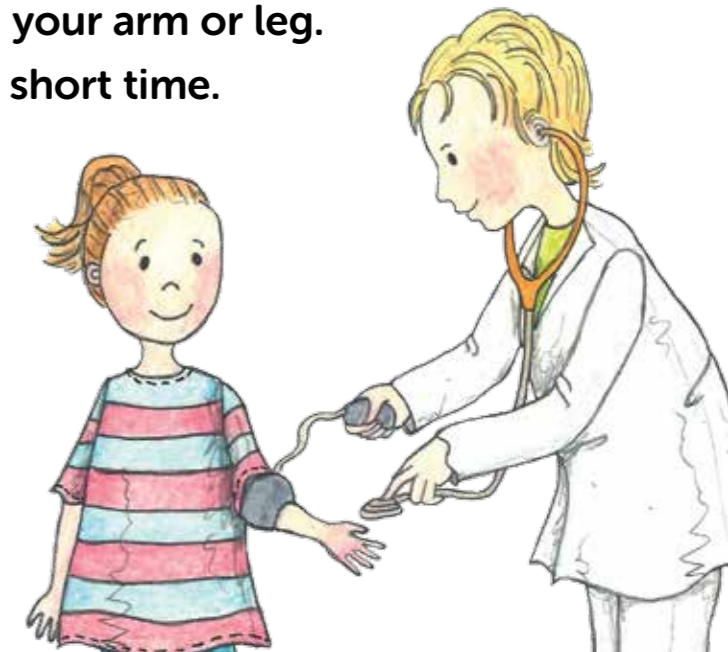
When you arrive, you will be shown around the ward and shown where you will sleep. Your bed will look different from your bed at home. It has sides that can be lifted up to stop you from falling out when you are asleep.

The nurse will check your weight and take your temperature and blood pressure. This will not hurt.

The temperature-reading machine may go in your ear or under your arm and may tickle a bit.

The blood pressure cuff can go on your arm or leg. It squeezes and will feel tight for a short time.

You will also need a blood test before you go to theatre. This will be a quick prick of your finger or you can have a special cream to numb a vein in your arm.



Preparing for Jess' operation

You need to have a small operation to take some of your stem cells.

Before the operation, the nurse and doctor will talk to you and your parents about the operation and your hospital stay.

On the day of the operation you won't be able to have anything to eat or drink for a short time, so it's a good idea to eat lots before going to bed the night before.

What will you have to eat the night before your operation?

Going to sleep for the operation

So you don't feel anything when your stem cells are being taken you will have a special medicine called anaesthetic which will make you go to sleep.

Your brother or sister may be able to tell you all about this as they would have had an anaesthetic to put in their central line, which is sometimes called a 'Hickman line'. You will go to a special room called the anaesthetic room where you will be given your anaesthetic. It will make you very sleepy.

Your mum or dad and a nurse can stay with you until you are asleep.

The doctor who will help you have this special sleep is called an anaesthetist. The anaesthetist will be wearing clothes and a hat like this and it looks a bit like they are wearing their pyjamas!



Going to sleep for the operation

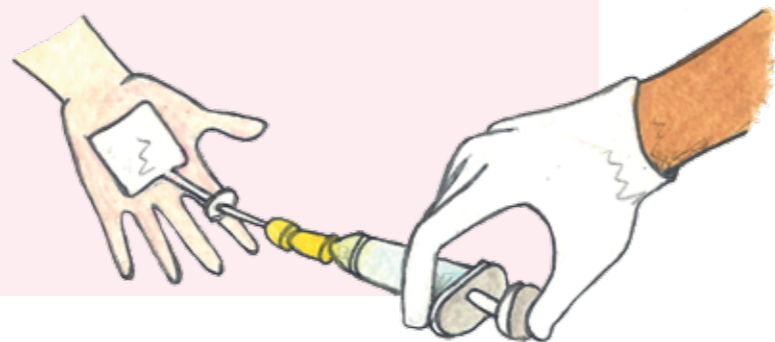
The anaesthetist can give you medicine for your special sleep in one of two ways.

One way:

You can have a tiny tube, called a cannula, put into the back of your hand. First, some cream may be put on your hand. This helps to numb the skin so you don't feel the cannula going in as much.

A bandage is put around your hand to hold the cannula in place.

Then the anaesthetist puts the medicine into the cannula that helps you have the special sleep.



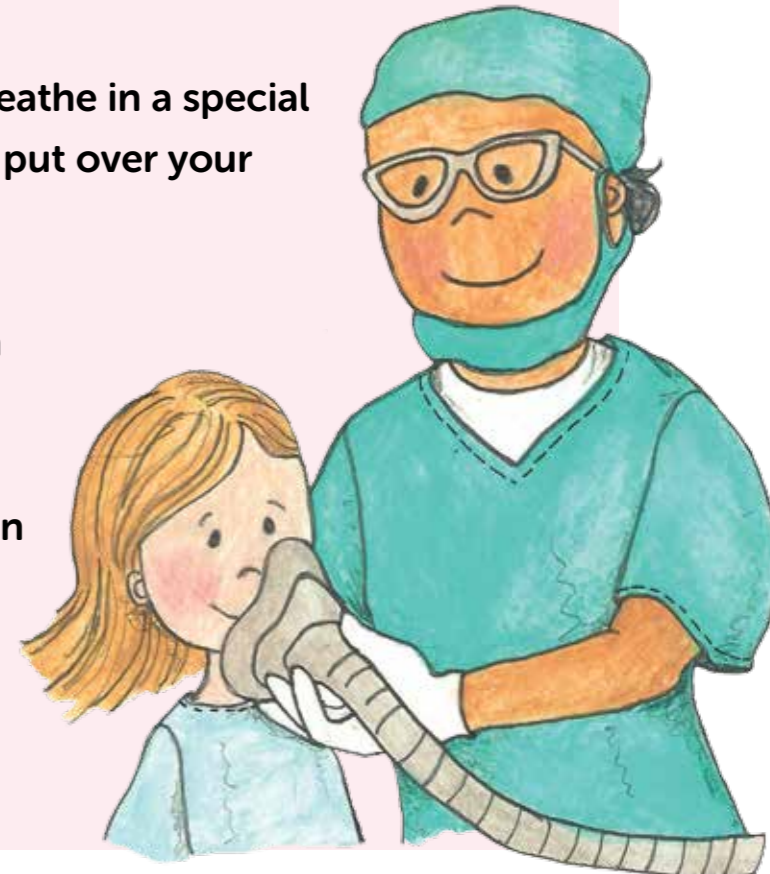
OR

The second way:

The anaesthetist will let you breathe in a special gas through a soft mask that is put over your mouth and nose.

Your mum or dad can stay with you in the anaesthetic room.

When you go for your operation you will wear either a special gown or your pyjamas.



Jess' operation

Once you are asleep, the doctor will take a small amount of stem cells from your hip bones. Your bone marrow is a liquid that contains stem cells and it looks a bit like blood. Your body has lots of bone marrow and the doctor only needs to take a little bit.



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After the operation

You will wake up in the recovery room after your operation. A nurse and your parents will come to take you back to the ward.

When you are back on the ward you may still be a little sleepy. This is OK.

Your back will feel a bit sore for a while but the nurse can give you some medicine to help this feel better.

You will have a band-aid on your back where the doctors took some of your stem cells. This can be removed the next day.

When you wake up your cannula may still be in. It may have some fluids running through it.

The cannula will be taken out before you go home. Your nurse can take the cannula out and it doesn't hurt.



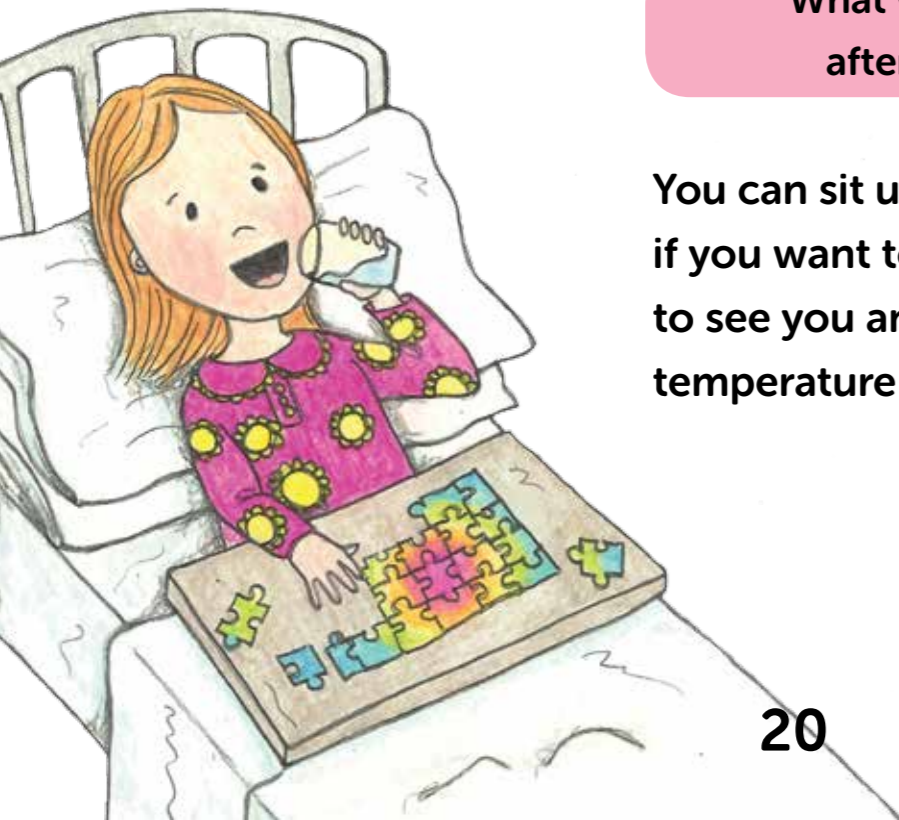
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Jess has something to eat and drink

After waking up from your special sleep you can have something to eat or drink when you feel ready. You need to be eating and drinking before the doctors will let you go home. It is important to go to the toilet to do a wee after your special sleep and the nurses need to know when you have done this.

What will you have to eat after your operation?

You can sit up and play with your toys if you want to. The nurses will come to see you and check your temperature and blood pressure.



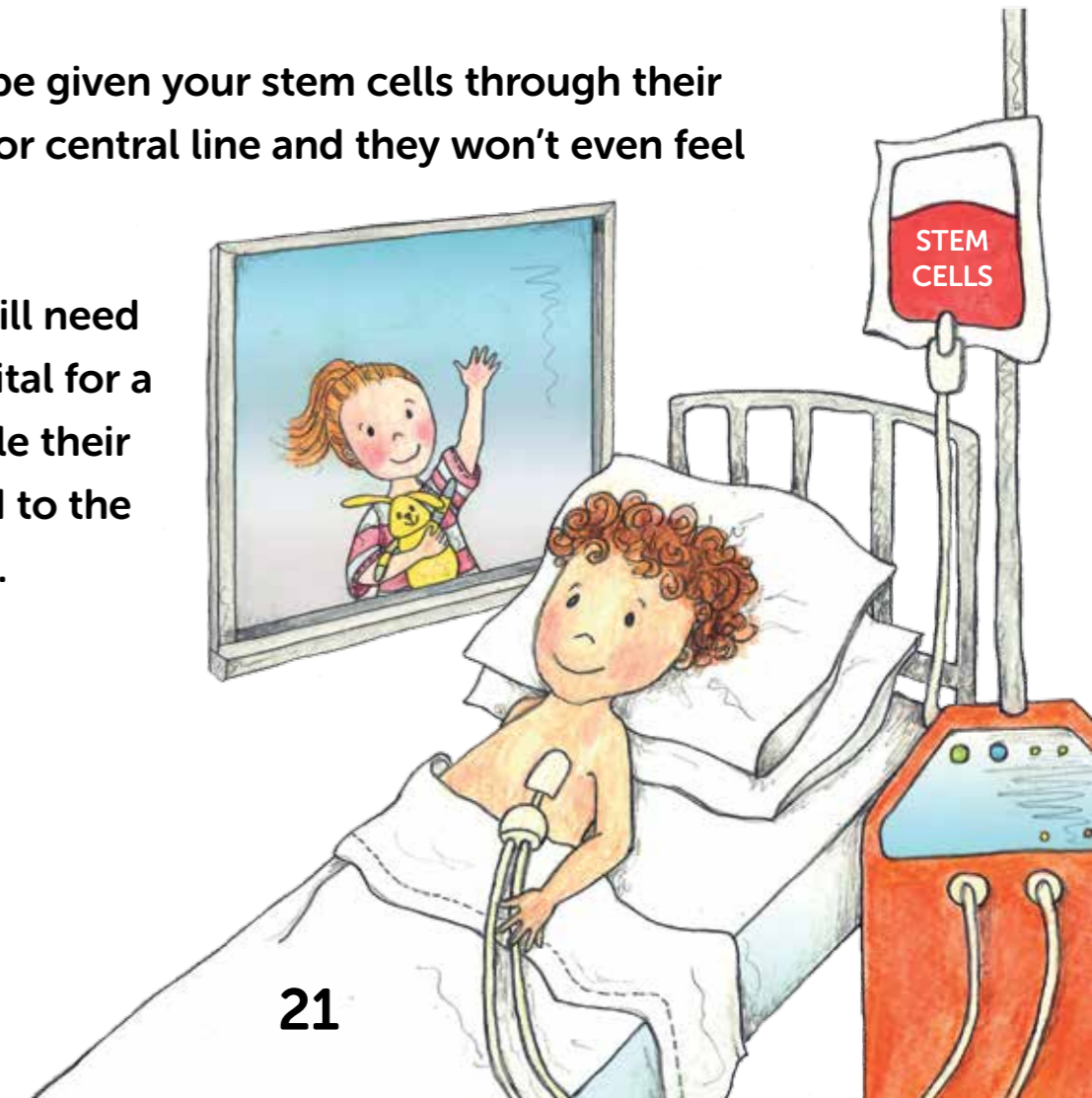
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What happens to Jess' stem cells?

Once the doctors have taken some of your stem cells they will get it ready to give to your brother or sister. The doctors will then give lots of different medicines.

Next they will be given your stem cells through their 'Hickman line' or central line and they won't even feel them going in.

Your relative will need to stay in hospital for a few weeks while their body gets used to the new stem cells.



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Jess goes home

You may have to stay in hospital for a night so the doctors and nurses can make sure you are OK.

After giving some of your stem cells your iron levels (which are part of your red blood cells) may be a little low. If they are, you may need to take some iron tablets or syrup to help.

Before you leave hospital and go home you may be able to visit your relative. You can wave to them through their window or talk to them on the telephone or walkie-talkie. You may not be able to play with them until after they come out of their isolation room, as we need to make sure they don't catch any infections.

One day after you get home, you may need to come back to see the doctor to make sure you are still well.

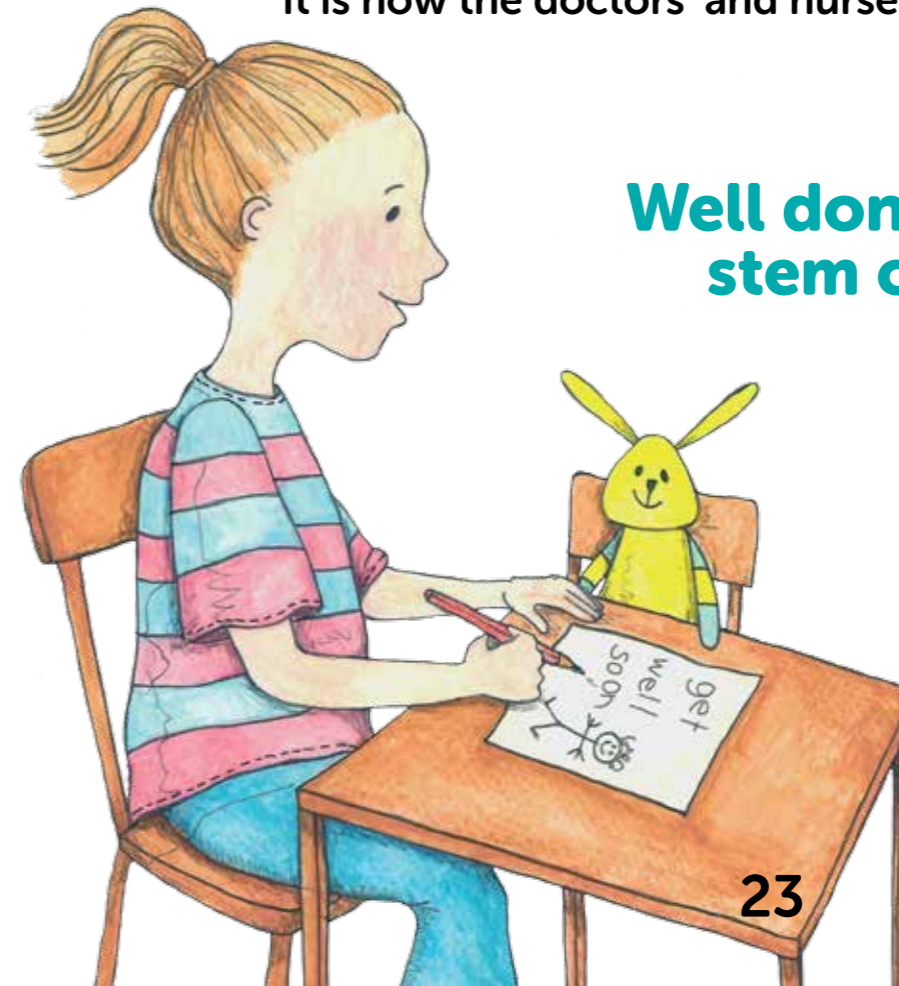


One very important job is now finished

You now have another extra special job to do while your relative stays in hospital. You can send them cards and pictures and visit them if you are well.

It is now the doctors' and nurses' job to look after them.

Well done for being a stem cell donor!



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.

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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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