Children's Cancer and Leukaemia Group

Jess's bone marrow donation

A children's guide to bone marrow donation

www.cclg.org.uk

About you

This booklet is yours to help explain about being a bone marrow donor (sometimes called a stem cell donor) and some of the things that may happen to you.

My name: ……………………………………………………………

My age: ……………………………………………………………

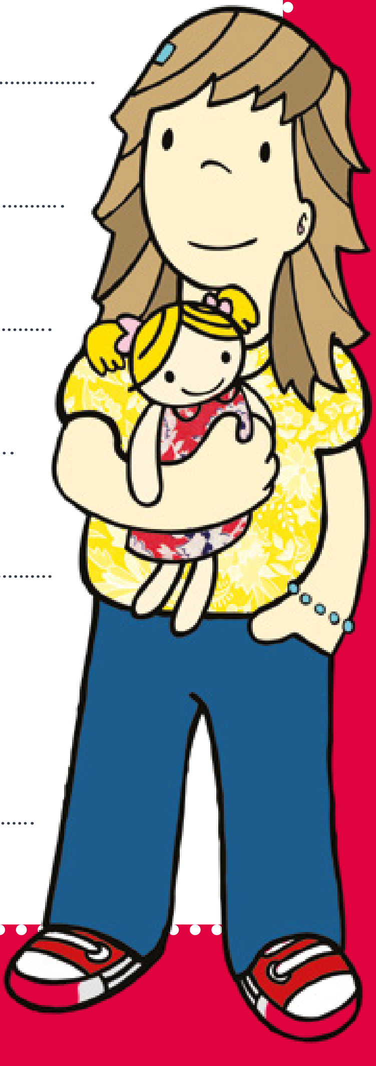
My hospital: ……………………………………………………………

……………………………………………………………

Date of donation: ……………………………………………………………

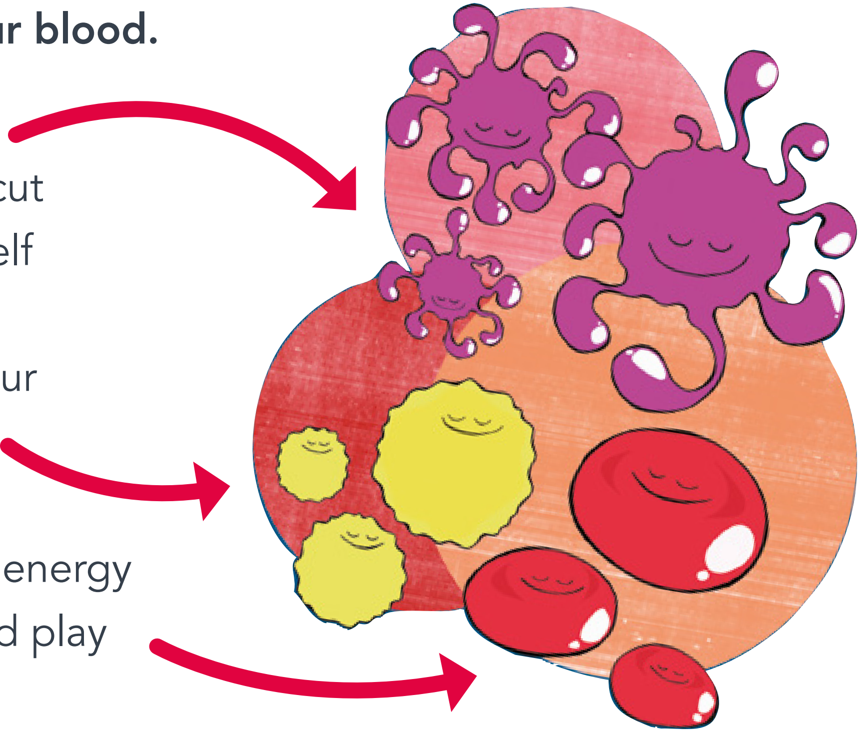
I am donating my bone marrow to:

……………………………………………………………



Bone marrow

The bone marrow is the soft bit in the middle of your bones and is the factory where all of your blood is made.
The bone marrow contains stem cells, and they will become the different parts of your blood.



Platelets stop you from bleeding when you get a cut or fall over and hurt yourself

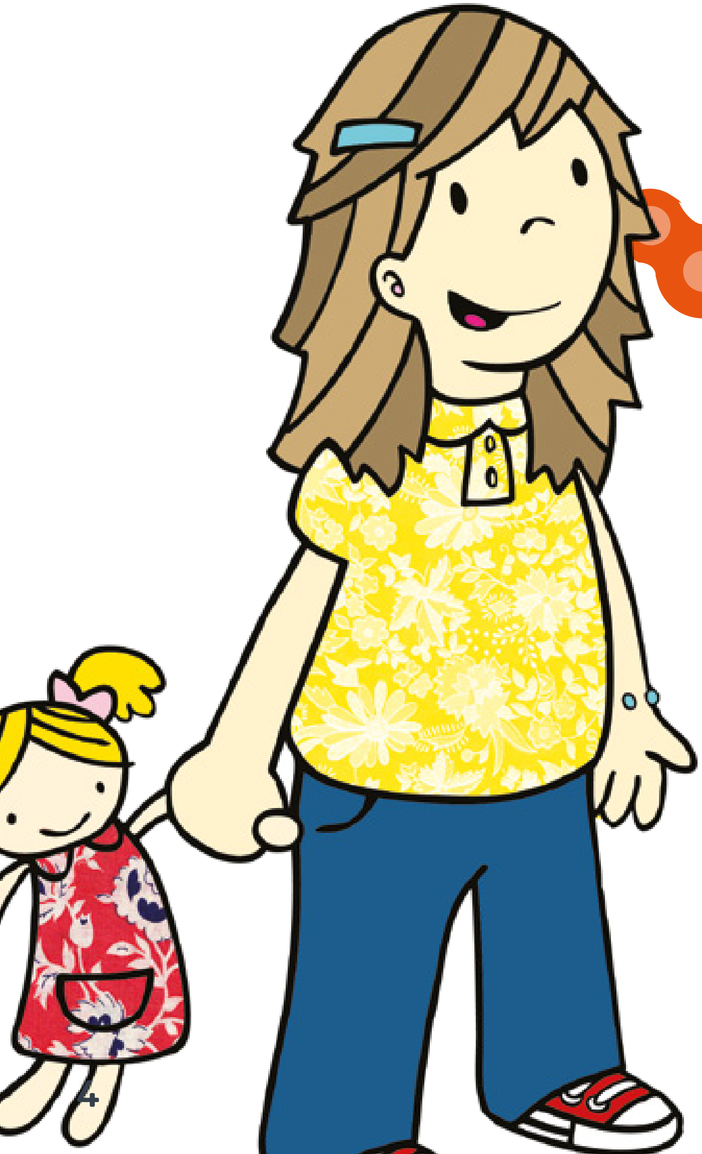
White blood cells help your body to fight infections

Red blood cells give you energy to help you run around and play

Your brother, sister or other relative's bone marrow isn't working properly. That 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

We would like you to meet Jess. Jess is going to tell you about what it is like to be a bone marrow donor.



To be a bone marrow donor means your bone marrow is healthy and working well and a blood test shows your stem cells match your relative’s stem cells.

Jess is helping her brother Ben get better by being a donor.

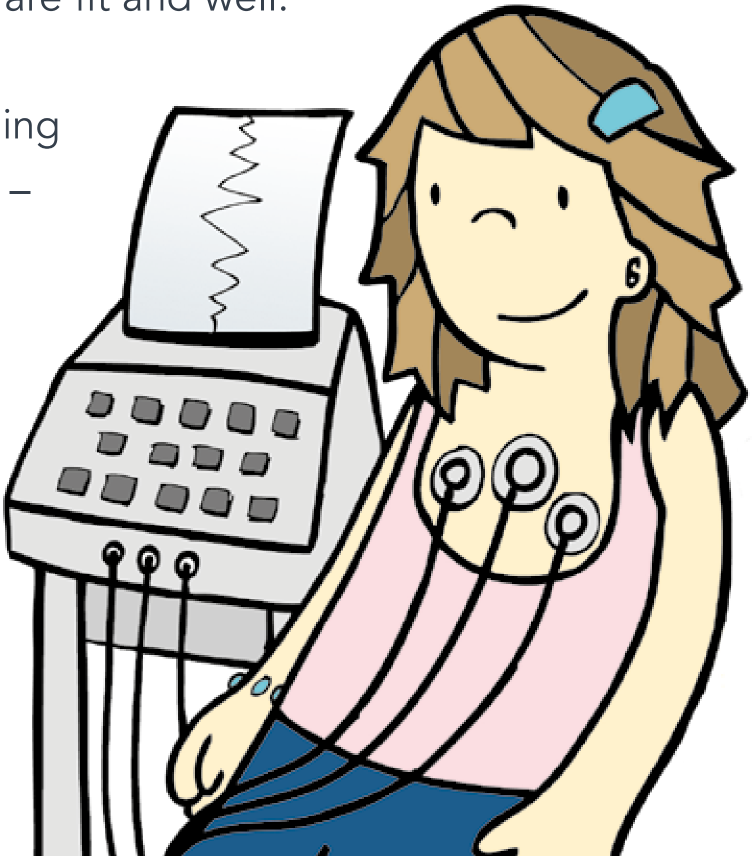
Before you give some of your bone marrow

Firstly, Jess wants to tell you what will happen before you donate your bone marrow.

You will have a little bit more blood taken for blood tests. You will meet a doctor and a nurse who will explain all about being a bone marrow donor, and make sure you are fit and well.

You may also need to have something called an ECG which does not hurt – this tells us about your heart.

Your nurse will tell you all about an ECG and how quickly it is done.



You will meet with hospital staff to make sure you understand what will happen when you come into hospital to be a bone marrow donor and you are happy with being a bone marrow donor. This is called an **HTA assessment.**

What is an HTA assessment?

HTA stands for the Human Tissue Authority. It is their job to make sure you and your parents know what is involved for you when donating bone marrow, and both you and your parents agree to you donating.


Childrens
Ward

Hospital staff

You will meet lots of new people during your bone marrow donation process. Here is a list of the types of people you may meet.

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

Transplant doctors

Transplant nurses

Play specialist

Psychologist

HTA assessor
(who may also be one of the above people)

Anaesthetist

Have you met any other people?

Coming into hospital

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

When Jess came into hospital to donate her bone marrow to Ben, he was already in hospital having his treatment. He was in his isolation room to help stop him getting germs so Jess was only allowed to wave at him through the window and talk to him on the telephone or by using their walkie talkies.

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

When you come into hospital to donate your bone marrow, you usually have to stay for a night or two.


BEN

Jess comes into hospital

When you come into hospital you will need to bring with you a bag of clothes and toys. Don't forget there will be loads of toys and things to do already 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

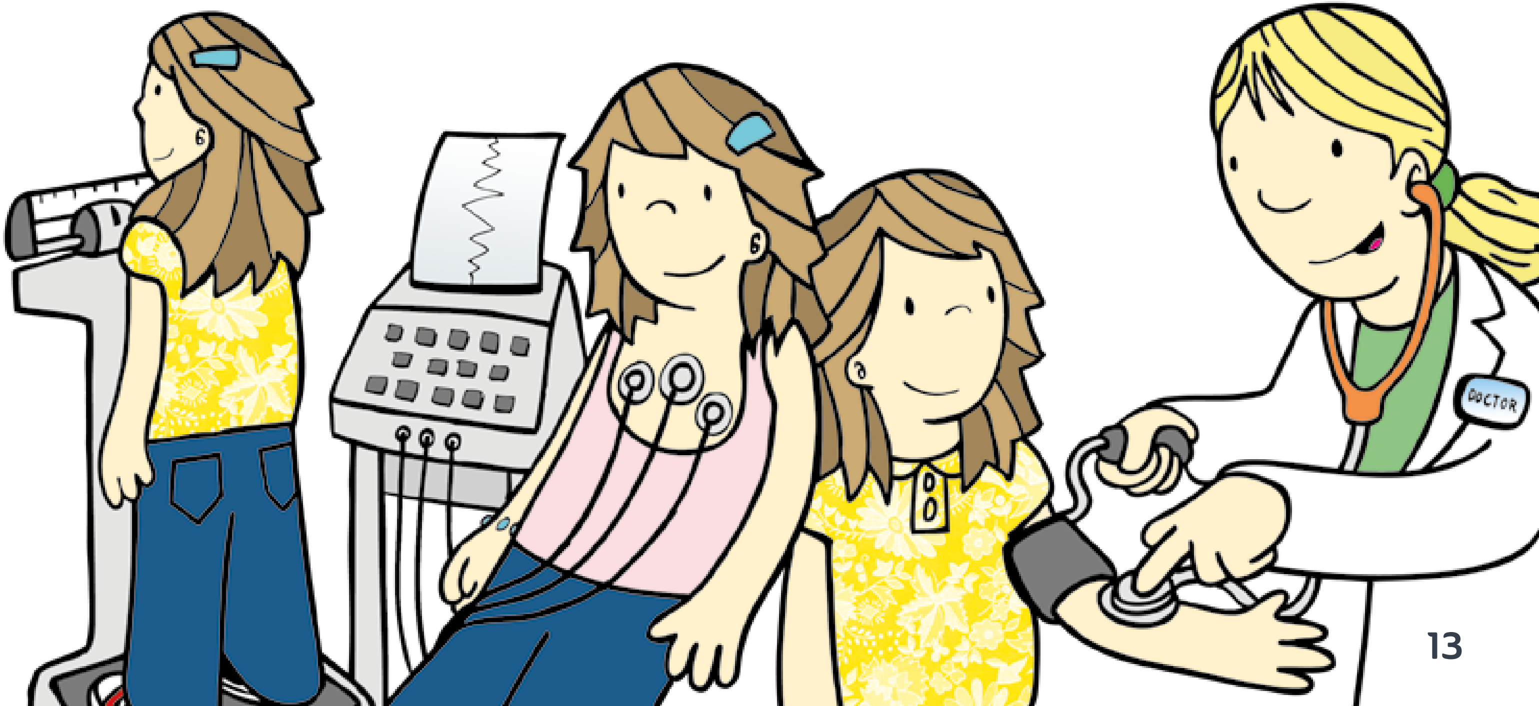
What else might you bring with you ?

Write a list to remind you.

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 falling out when you are asleep.

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



Getting ready for Jess's operation

To take some of your bone marrow you will need to a have a small operation.

On the day of your small operation you will not be able to have anything to eat or drink for a short time so remember to eat lots before going to bed!

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

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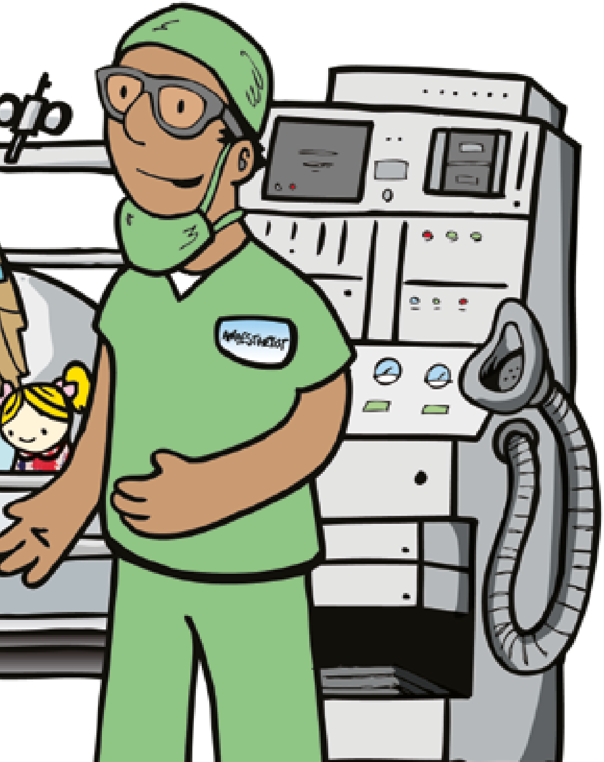
Before you have your operation the nurse and doctor will talk to you and your parents about your operation and your hospital stay.

Going to sleep for the operation

So you don't feel anything when your bone marrow is taken you will have medicine called an anaesthetic, which will send you to sleep. Jess was able to ask Ben what it was like to have an anaesthetic. You could ask your relative what it is like to have an anaesthetic.

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

You will go to a special room called the anaesthetic room where you will be given your anaesthetic to make you very sleepy.



The anaesthetist (the doctor who will be helping you to have your sleep) will be wearing clothes and a hat like this - they look a bit like they are wearing their pyjamas!

Going to sleep for the operation

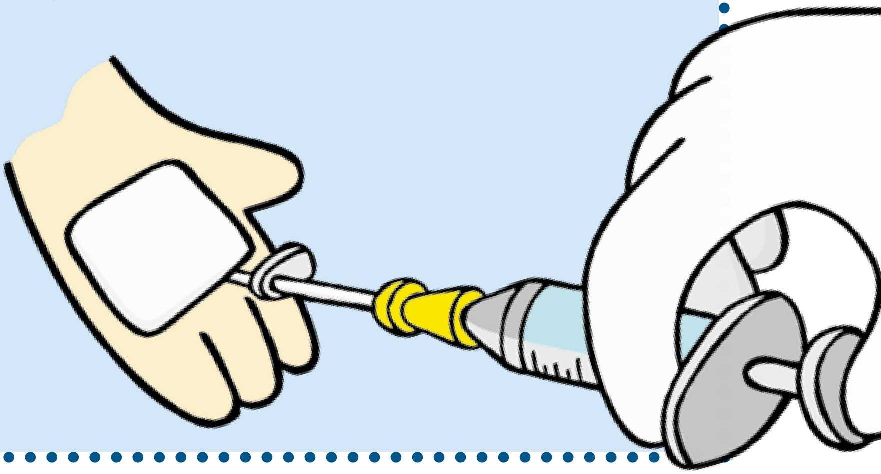
The anaesthetist can give you medicine for your special sleep in one of two ways:

The first way:

You can have a tiny tube called a cannula put into the back of your hand. You may have a bandage around your hand to hold it in place; the anaesthetist can then put the medicine which helps you have the special sleep in the cannula.

You can have some cream on your hand before you have your cannula.

The cream will help numb the skin so you don't feel the cannula going in as much.



Or the second way:

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

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

When you go for your operation you may have to wear a special gown or your pyjamas.

Jess’s operation

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

After the operation

You will wake up in the recovery room after your operation. A nurse will be there so you are not on your own. The nurse and your parents will take you back to the ward.

When back on the ward you may still feel a little sleepy. This is ok. Your back will feel a little bit sore for a while but the nurse can give you some medicine to help.

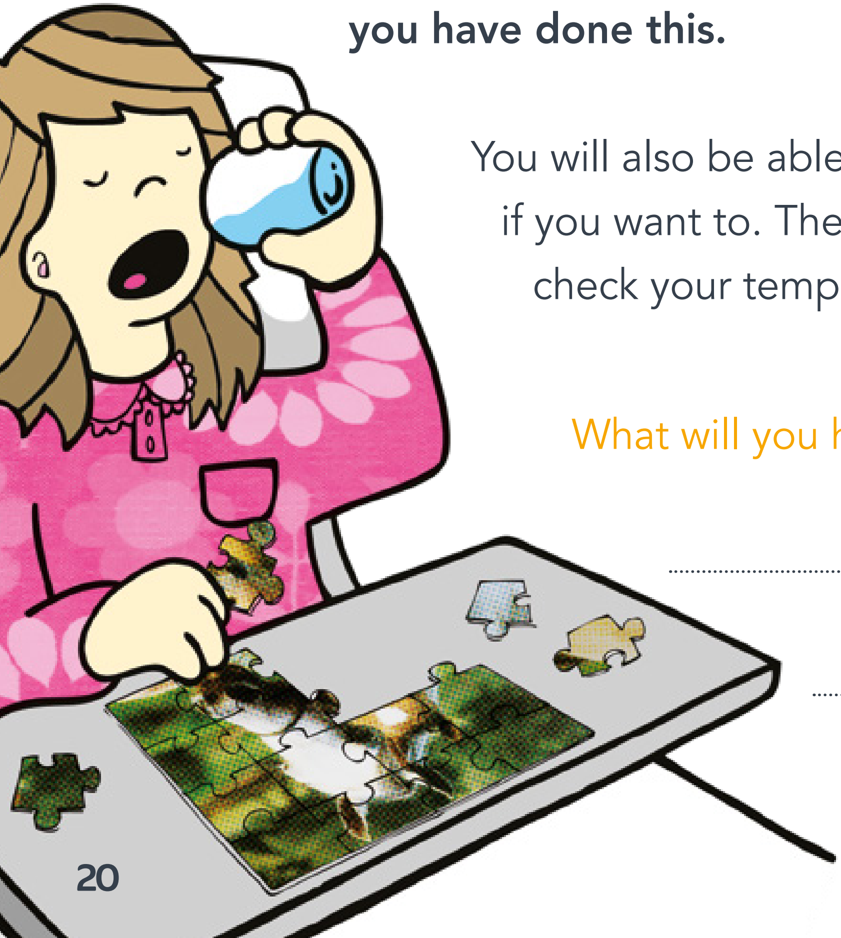
You will have plasters on your back where the doctors took some of your bone marrow.

These can be removed the next day. You may also still have your cannula in when you wake up. 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.

Jess has something to eat and drink

After you wake up from your operation you can have something to eat or drink when you feel ready. You will need to be eating and drinking before the doctors can let you go home.

It is also important to try to go to the toilet to have a wee after your special sleep - the nurses will need to know when you have done this.



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

What will you have to eat after your operation?

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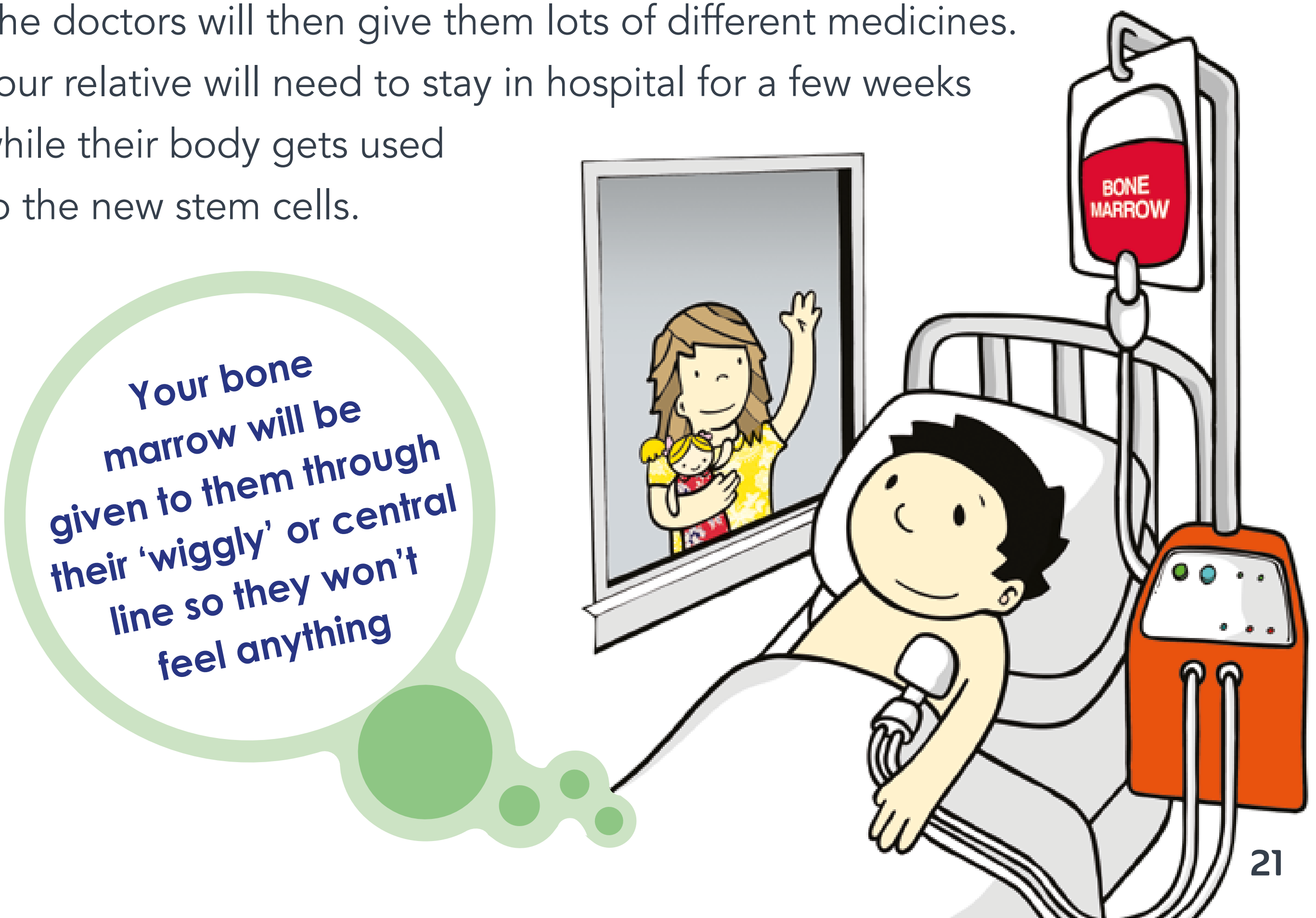
What happens to your bone marrow?

Once the doctors have taken some of your bone marrow they will take the stem cells from it and get them ready to give to your relative.

The doctors will then give them lots of different medicines. Your relative will need to stay in hospital for a few weeks while their body gets used to the new stem cells.



Jess goes home

You may have to stay in hospital overnight so the doctors and nurses can make sure you are OK. Sometimes after some of your bone marrow is taken, 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.

You will have to come back to see the doctor one day to make sure you are still well.

Before you go home you may be allowed to visit your relative, wave at them through their window or talk to them on the telephone or walkie talkie. Remember you may not be able to go in and play with them until after they have come out of their isolation room to make sure they don't catch any infections.

One very important job is now finished

You now have another extra special job while your relative stays in hospital. You can send them cards and pictures and maybe speak to them on the phone. It is now the doctors and nurses job to look after them.

Well done for being a bone marrow donor!

Children's Cancer and Leukaemia Group

the EXPERTS in CHILDHOOD CANCER

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

If you have any comments on this booklet, please contact us at publications@cclg.org.uk. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70300 to donate £3. This costs £3 plus a standard rate message.

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This edition was reviewed by Julie Guest, Stem Cell Transplant Nurse Practitioner, Great North Children's Hospital, on behalf of the CCLG Information Advisory Group, comprising multiprofessional experts in the field of children's cancer. Illustrated by Simon Pritchard.

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