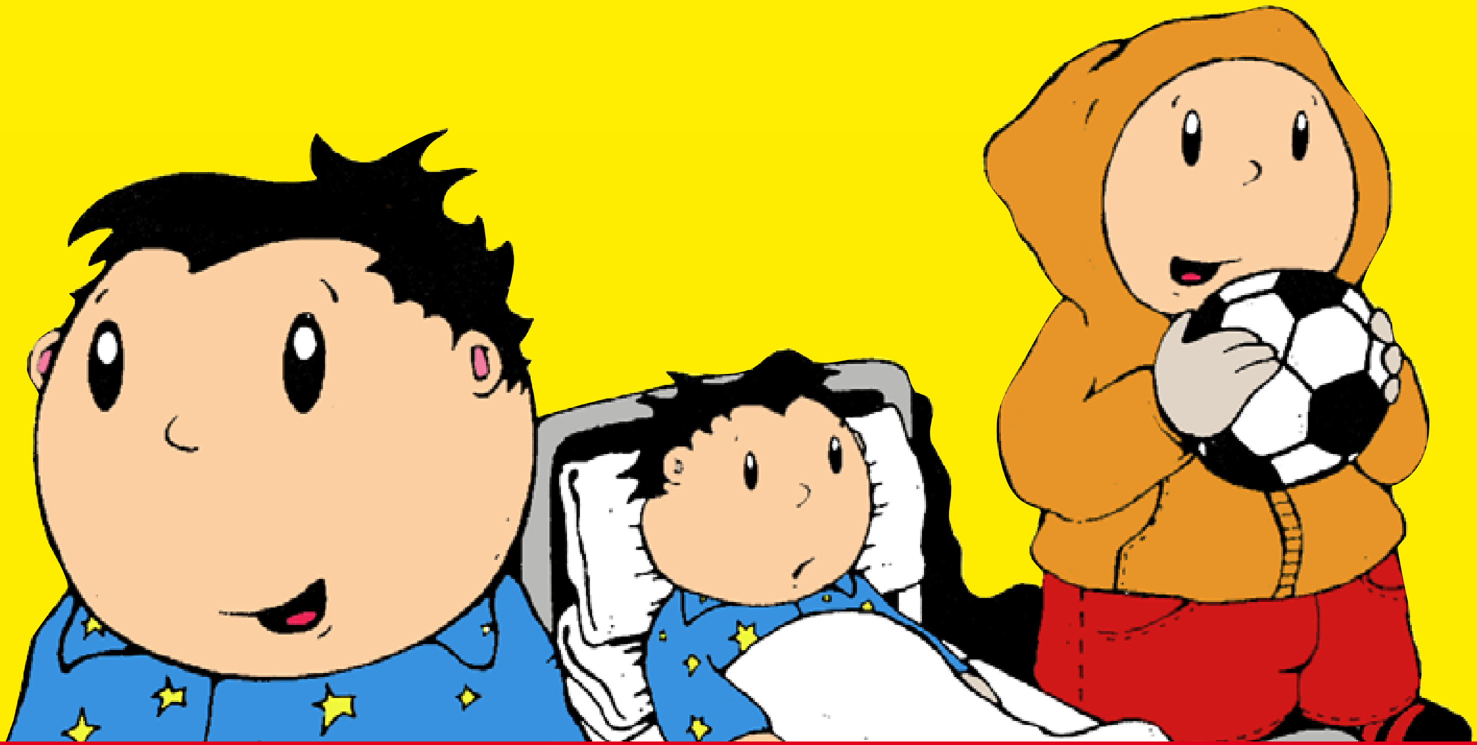
Ben's Stem Cell Transplant

A children's guide to SCT



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About you

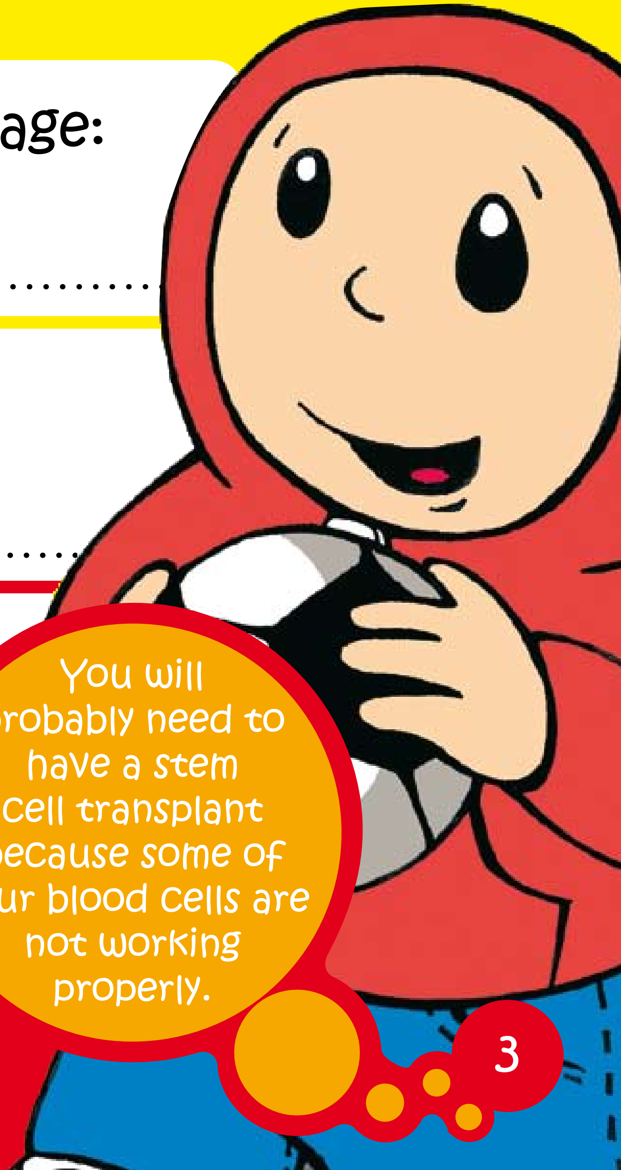
This booklet is yours to help you to understand why you need a stem cell transplant (SCT) and to explain some of the things that may happen to you.

my first name: ....

my age: ....

my hospital: ....

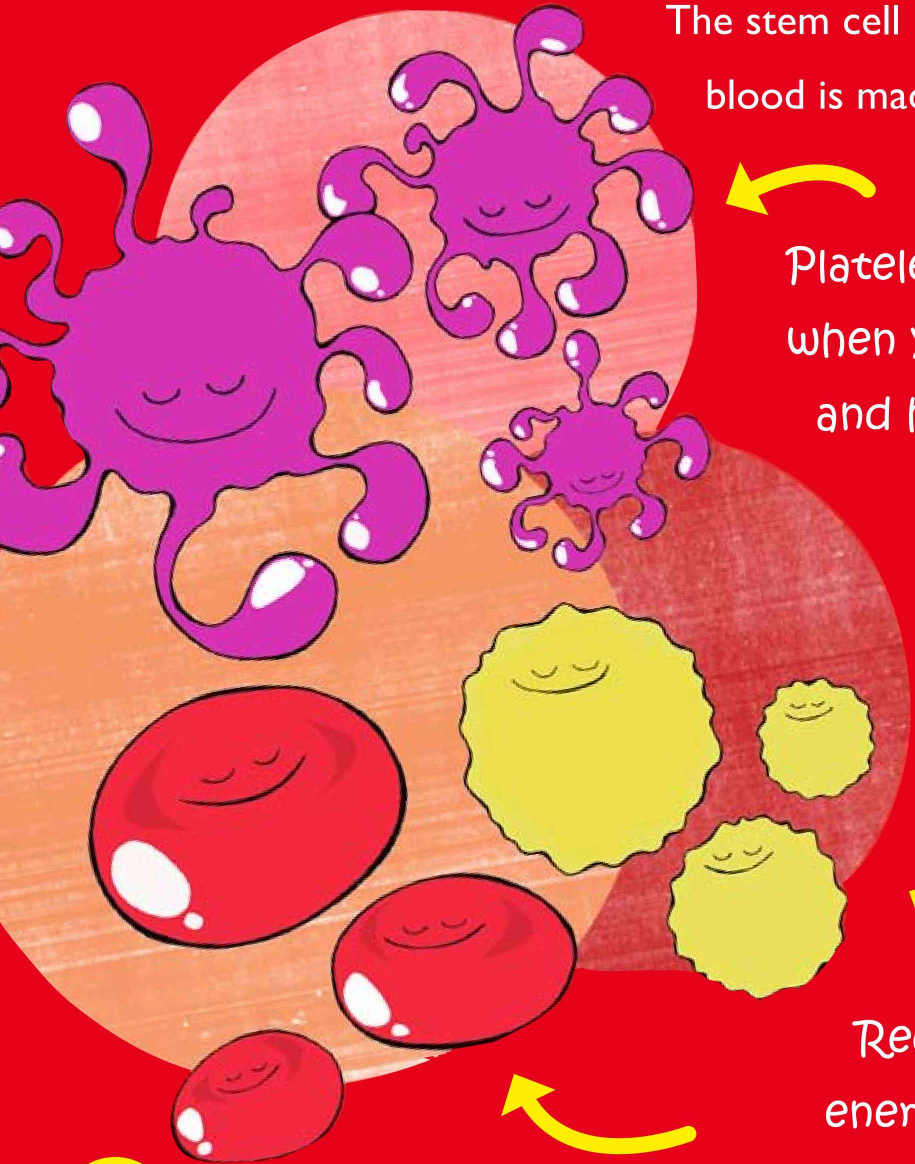
date of transplant: ....



You will probably need to have a stem cell transplant because some of your blood cells are not working properly.

Stem cell

The stem cell is the factory where all your blood is made.



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

Meet Ben

We would like you to meet Ben.

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

Tests

Firstly, Ben wants to tell you what happens before a transplant. You are likely to have many tests before your transplant to make sure that your body is ready.

- X-ray
- Ultra Sound Scan
- Blood Tests
- Dentist
- Heart Scan
- Breathing Tests
- Kidney Test
- Height
- Weight

Try and find out which of these tests you will need or if you will need to have anything else done.

Hospital staff

Ben met lots of new people during his stem cell transplant.

Here is a list of the type 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

....

Nurses

....

Play specialist

....

Dietician

....

Teachers

....

Social worker

....

Physiotherapist

....

Psychologist

....

Cleaners

....

Any other people you have met?

The Stem Cell Transplant Unit

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

Coming in for a stem cell transplant can feel very strange. You will stay in hospital for around 6 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 coming into hospital. Do you feel excited, nervous, happy, frightened, sad, angry, scared or worried? You may find that it helps to talk about these feelings.

When you have your transplant you will need to go into a room on your own which will be your special bedroom, with your family of course. You will hear people call this 'isolation.'

Ben's treatment

A central line is used for blood tests and to give the treatments that you will need. Some children already have a central line in but Ben needed his central line put in before his transplant. It will not stop you playing or going to school but you will not be able to go swimming. It will stay in for a few months.

You will be given some treatment before you can have your transplant. It helps to get your body ready for the transplant. For some children this treatment is only a couple of days but for others it can last up to 2 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 that don't work properly in your body and to destroy your own stem cells so that they cannot fight with the new stem cells when they are given to you.

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

Radiotherapy

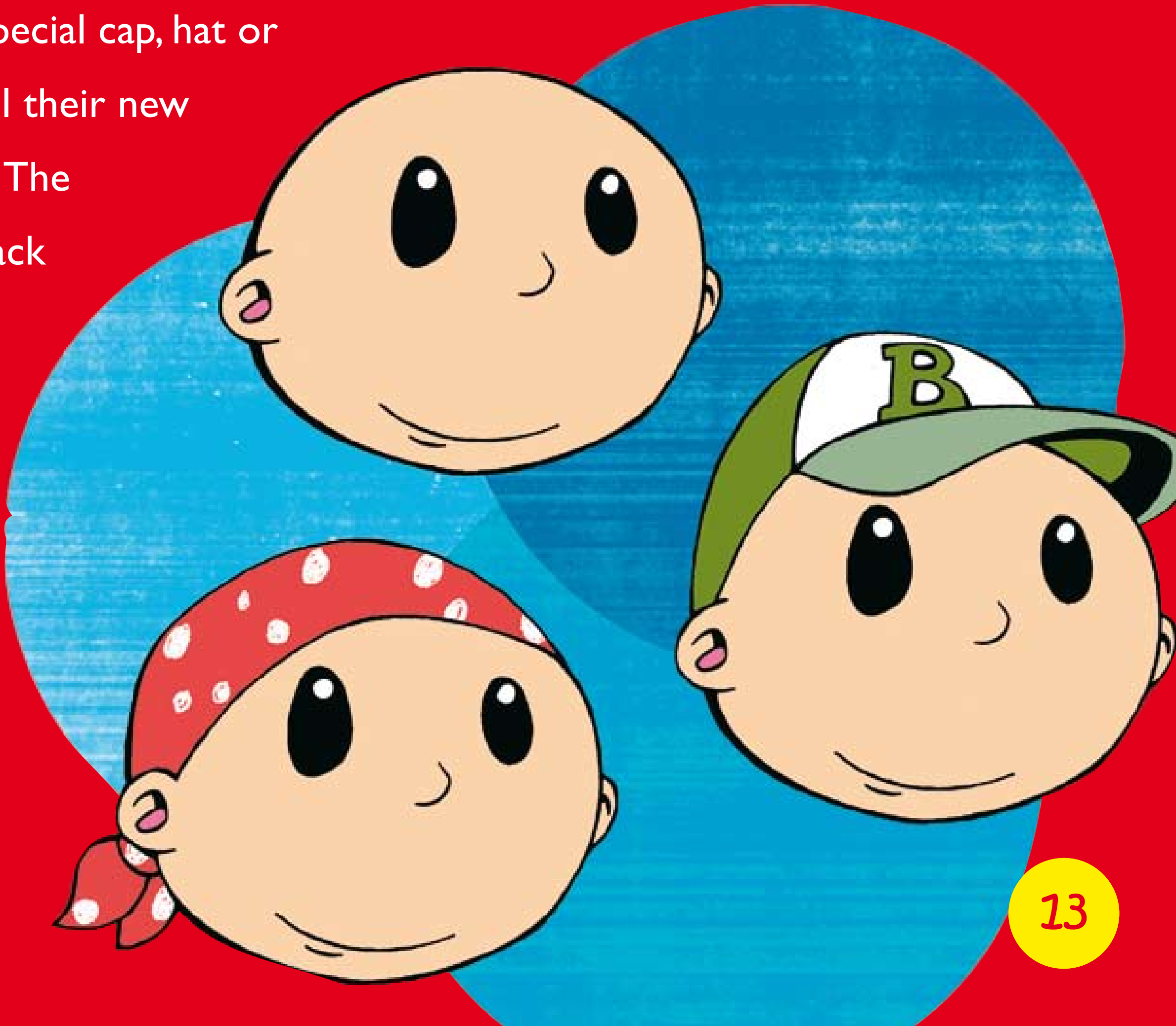
Radiotherapy is not given to all children who have a Stem Cell Transplant. Radiotherapy is a special kind of x-ray whose job it is to kill any cells in your body that don't work properly and to destroy your stem cell. You may have to go to another hospital for this part of the treatment.

Having radiotherapy does not hurt. It is very important that you keep still for your radiotherapy that will last 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 they can usually see and hear you on a special television screen.

Do you need to have radiotherapy before your transplant?

Ben found watching his favourite film or listening to his favourite music helped to pass the time. Try to think which DVD or music you will take with you.

Chemotherapy and radiotherapy can make your hair fall out about 2 weeks later. You may also notice that your eyebrows and eyelashes also fall out. Some children choose to have their hair cut short before their transplant. Other children buy a special cap, hat or wig to wear until their new hair grows back. The hair will grow back after about 3-6 months.



Ben looked after his mouth

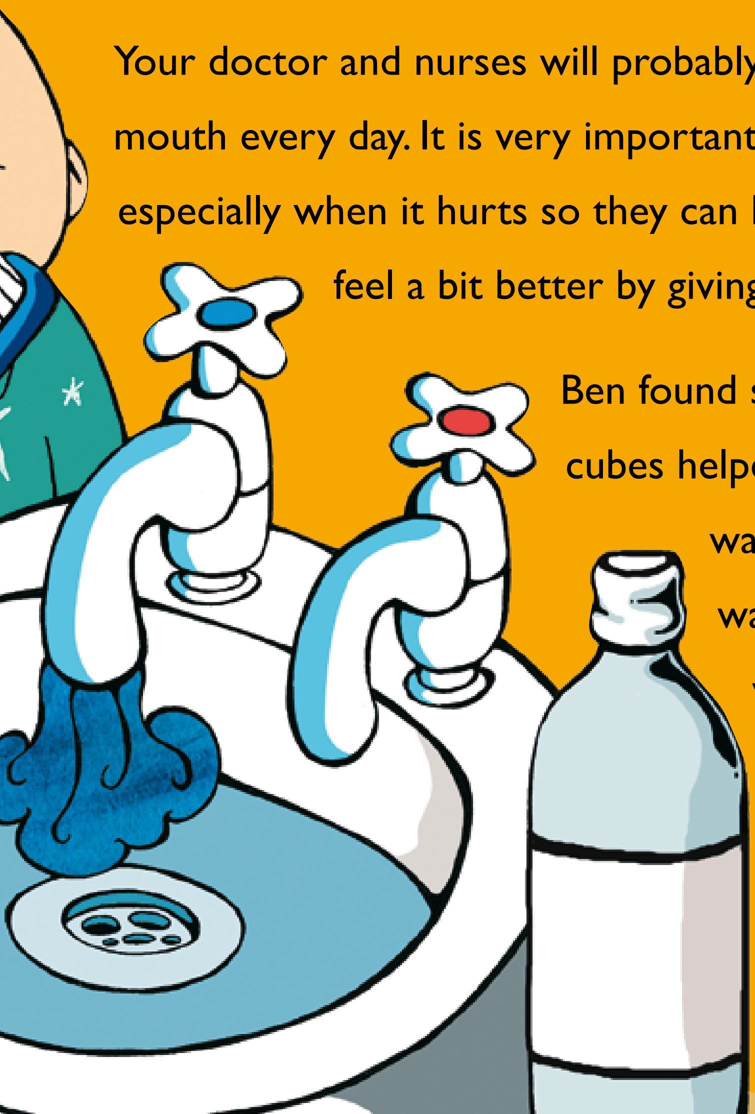
Chemotherapy and radiotherapy can make you feel sick. After your treatment has finished this feeling may carry on because of other medicines or problems. The nurses will give you medicine in your mouth or central line to try to stop this feeling. It is really important to tell the nurses if you feel 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. The best way to help this problem is to keep your mouth clean.

We would like you to clean your teeth 3-4 times a day with a soft toothbrush and toothpaste. 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 pain killers.



Ben found sucking ice pops 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 into his tummy. This was not very nice when it was put in but it stopped his family always asking him to eat and drink. The tube helped Ben to have the special milk feed so that he was able to stay strong during his transplant. The tube could also be used for medicines which really helped Ben.

If the milk makes you too sick you can have a special feed (TPN) through your central line.

Ben's bedroom

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

To keep you safe from infection in hospital you will have a bedroom of your own rather than sharing with other children. Someone from your family will be able to stay near you to look after you.

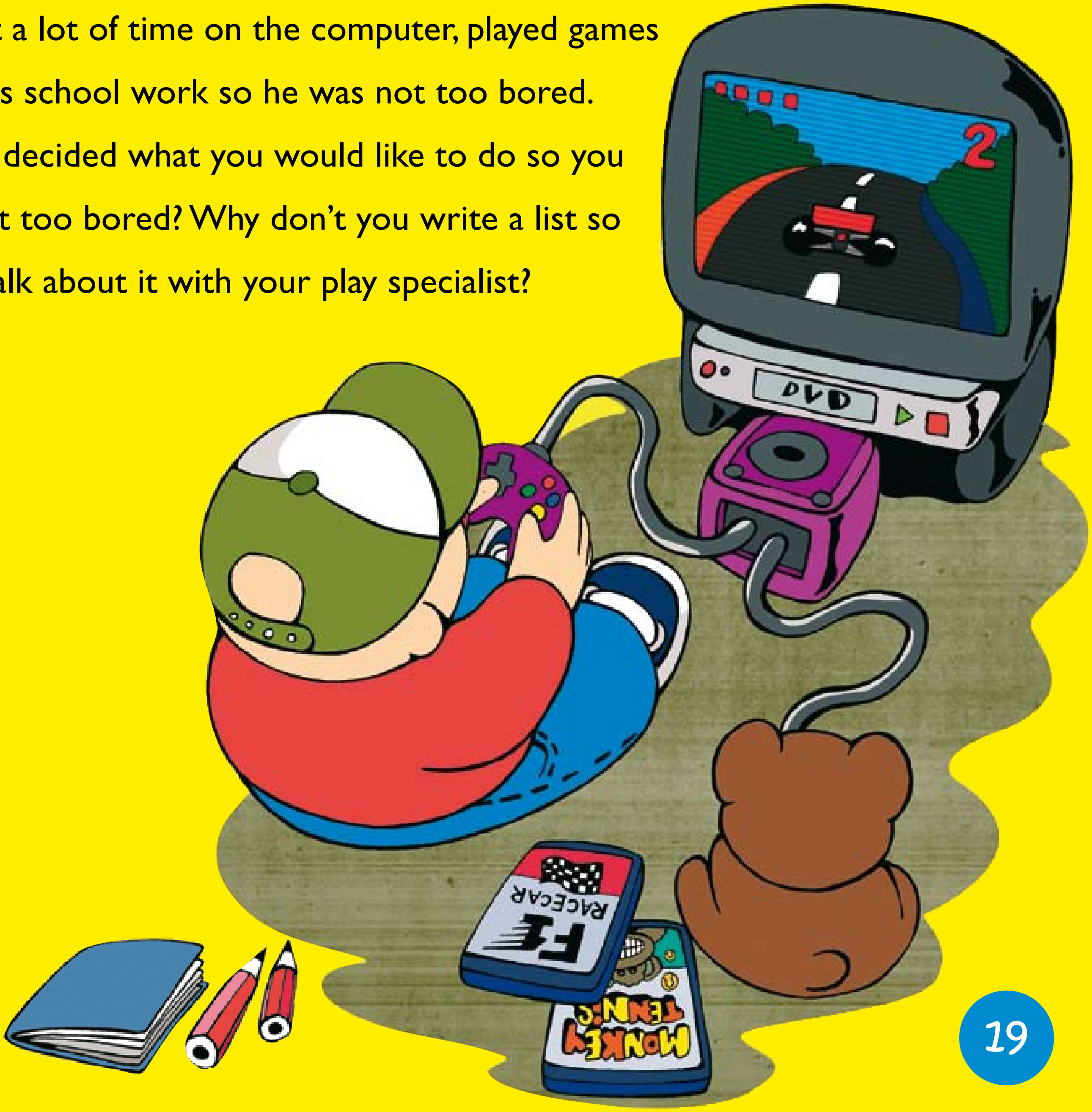
You may like to keep in touch with your brothers or sisters and school friends by phone, letter, text or online. Ben's brother and sister could talk to him through the intercom when they visited him in hospital.

Ben's bathtime

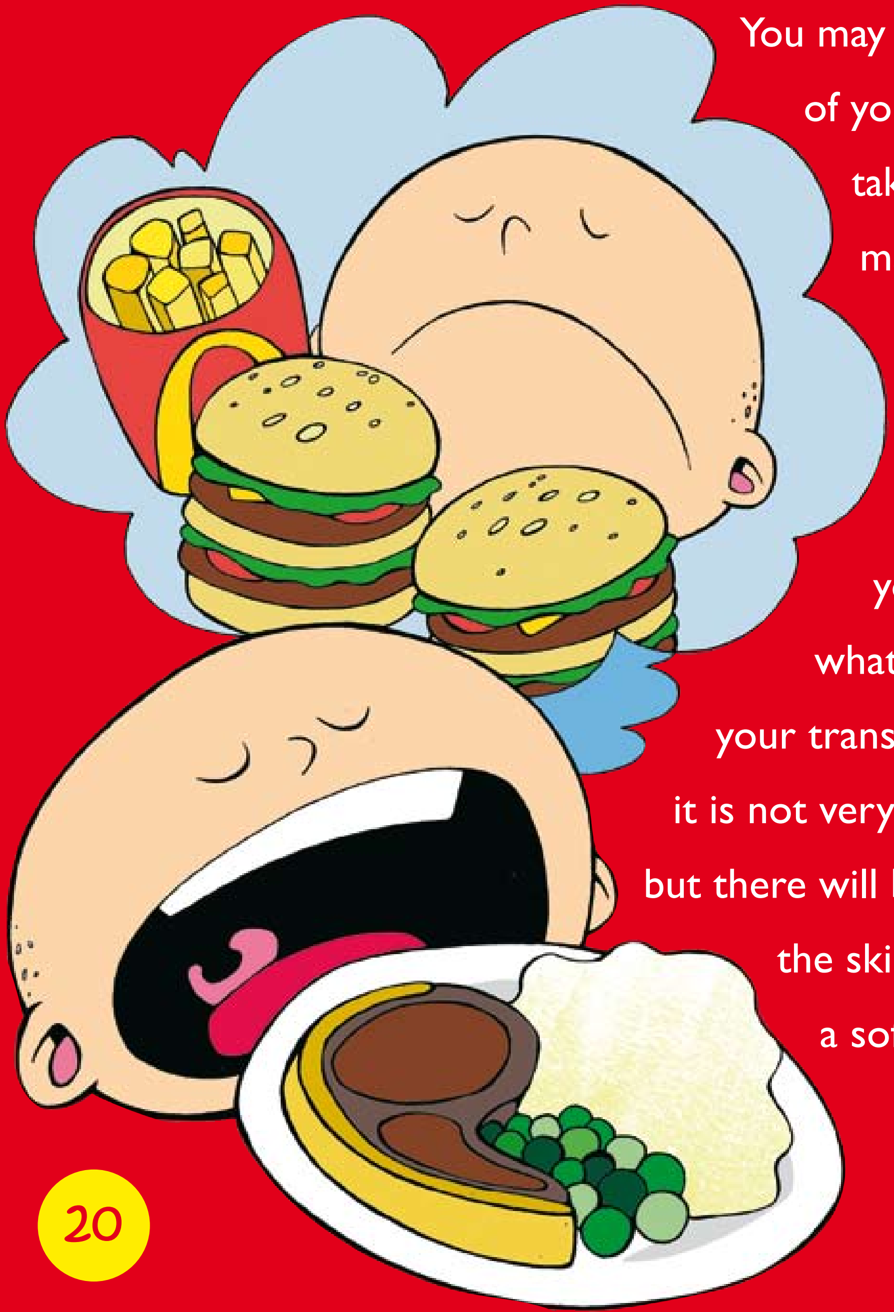
We will ask you to wash, shower or bath and to put on clean clothes each day. Your family can help you with this.

How Ben kept busy

Ben spent a lot of time on the computer, played games and did his school work so he was not too bored. Have you decided what you would like to do so you do not get too bored? Why don't you write a list so you can talk about it with your play specialist?



What Ben could eat



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

Try to make a list of the foods that you like to eat so that your nurse can talk to you about what you can and cannot eat during your transplant. You will probably find that it is not very different to what you eat now but there will be a few changes like not eating the skin on fruit and not being allowed a soft boiled egg.

Ben was feeling better

When your new stem cells start to work you will be allowed more visitors and be able to start leaving your room. The nurses and doctors will know when you are ready to go out of the cubicle by checking your blood count.

Ben was very excited when he was told he could leave his cubicle but a bit 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

You will need to take some medicines when you are at home. You will often be able to choose between tablets or liquids – please ask if you are not given the choice.

Ben found some of the medicines easier to take with his favourite drink or to suck a sweet afterwards to take the taste away.

If you have a tube in your tummy to help to feed you it could be used for some of your medicines.

Ben's hospital visits

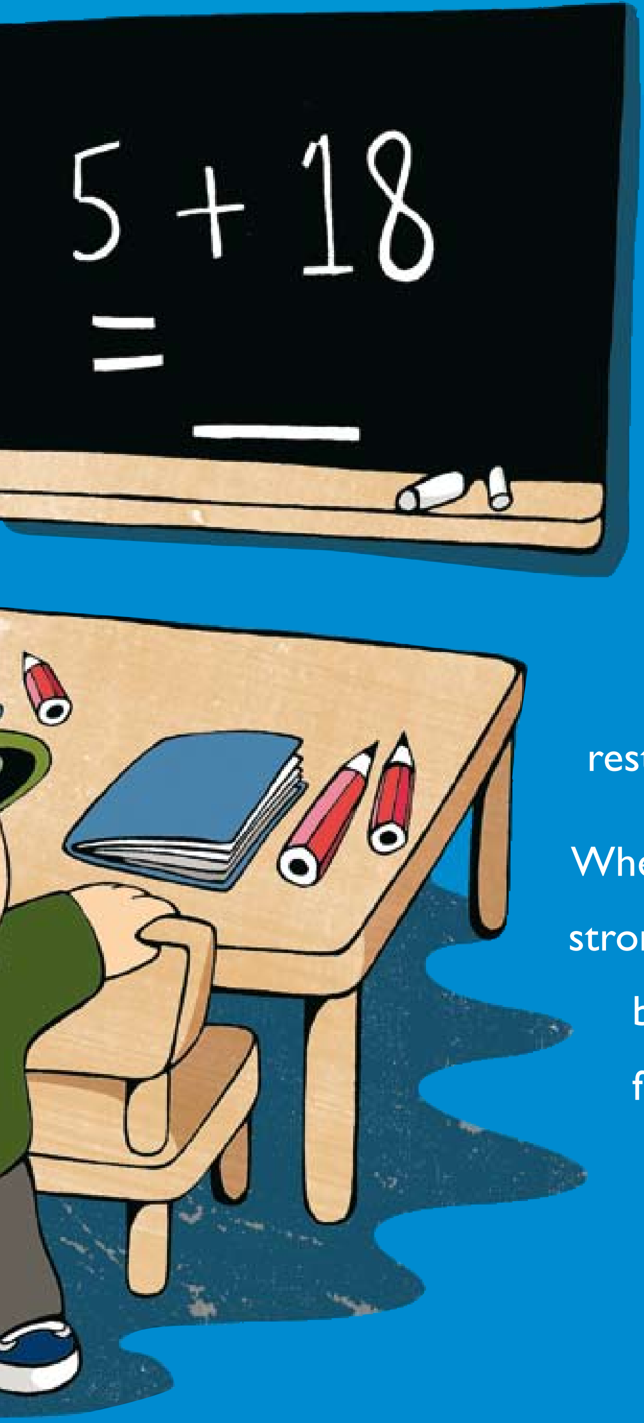
When Ben went home he had to come back to the hospital once or twice a week to have blood taken to make sure the medicines were working. Ben liked to go back to hospital because he enjoyed seeing all the doctors and nurses again.

When you return to the hospital, we will check your skin to make sure there are no spots or itchy patches. Sometimes your new stem cell can have a fight with your body and give you a rash or a bad tummy so we need to keep checking you. You may need a different medicine to make it better. This can make you very hungry and you get a bit bigger. You must always 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 come out of hospital, you will have to be careful not to catch any germs. This means staying at home to begin with and maybe having 2-3 friends to visit you as long as they have no infections but the nurses will tell you about this. You should not 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 will not be able to go back to school for a few months but you will have a teacher who comes to your house instead.



You will probably feel quite tired a lot of the time too, especially if you have had radiotherapy. This is quite normal and you will get stronger every day and be able to do a bit more. Don't worry if you need a sleep or a rest in the day.

When your new stem cells are strong enough you will be able to go back to school. You may only go for half a day or for a few hours at first as you may still be very tired. Don't worry about this.

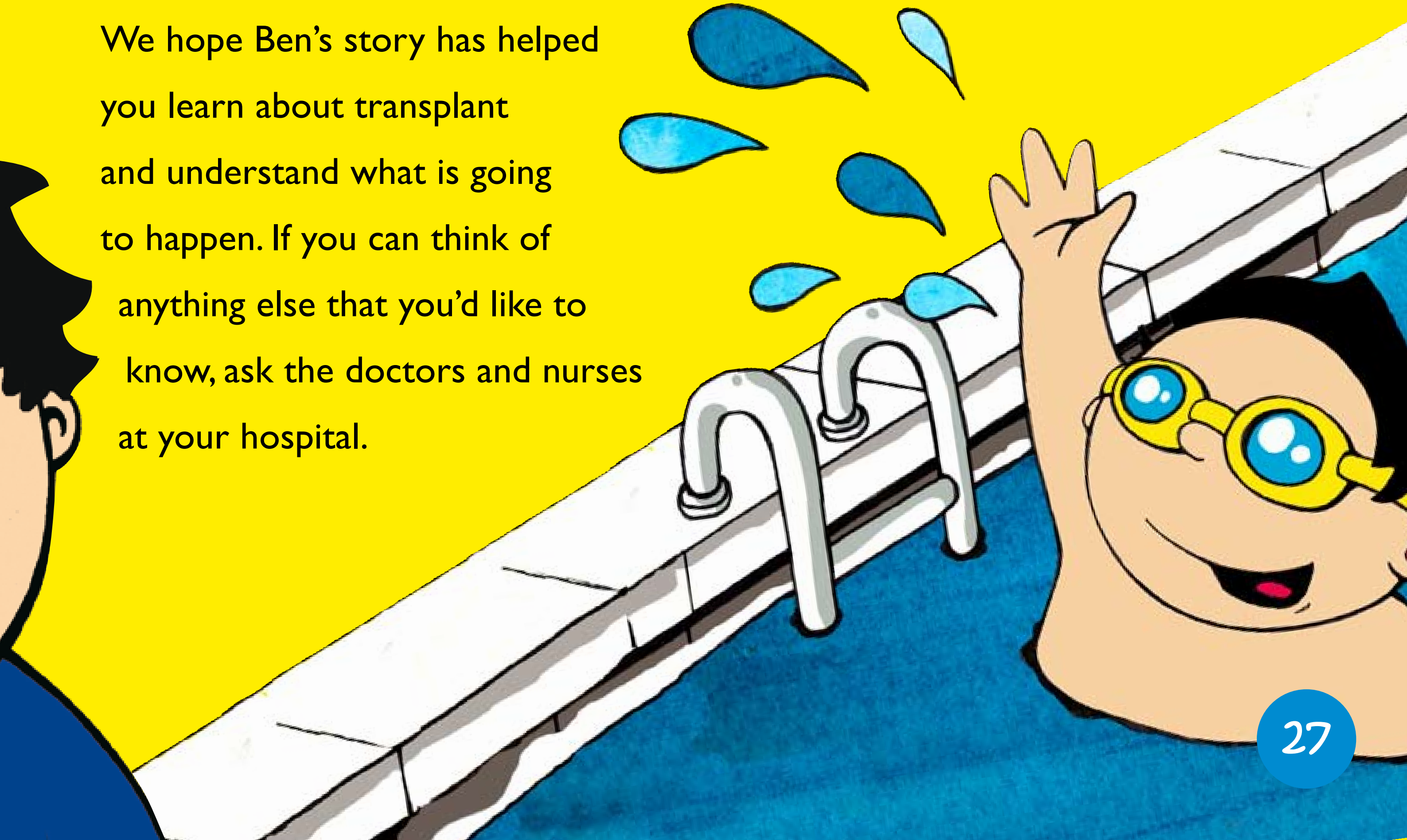
Ben's hair started growing back

Ben's hair started to grow back after a few months. Sometimes hair can be a bit darker or a bit lighter when it grows back.

Ben’s line

When Ben stopped needing blood tests or medicine he did not need his central line anymore. This was about 3-6 months after his transplant and then it was taken out. Ben could then go swimming and have a proper deep bath! Ben didn’t need to come to clinic as much then too.

We hope Ben’s story has helped you learn about transplant and understand what is going to happen. If you can think of anything else that you’d like to know, ask the doctors and nurses at your hospital.



The CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

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