



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Ben's stem cell transplant

A children's guide to a donor (allogeneic) stem cell transplant



www.cclg.org.uk



**If you need to have
a donor stem cell transplant,
this booklet is for you.**

It tells the story of a boy called
Ben who also had a stem cell transplant.

If there is anything you are not
sure about, ask a grown
up to help you.

About you

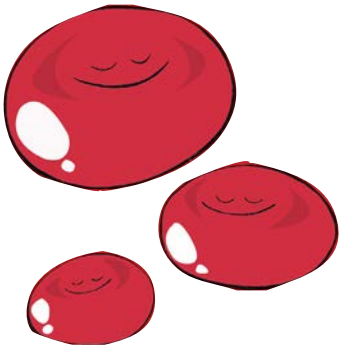
This booklet is yours to help you understand why you need a stem cell transplant and to explain some of the things that may happen to you.

My first name:

My age:

My hospital:

Date of transplant:



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

What is a donor stem cell transplant?

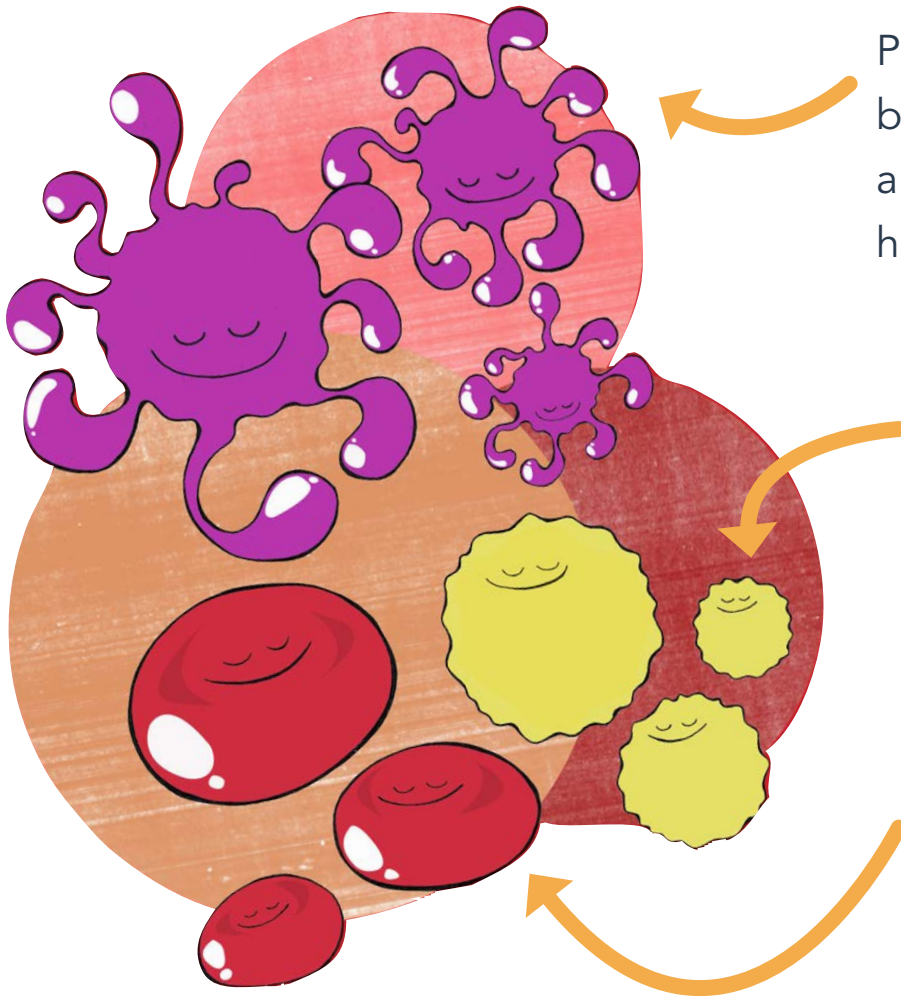
Stem cells are baby cells before they become the different parts of your blood. Stem cells are found inside the soft bit in the middle of your bones, called bone marrow. This is like a factory where all of your blood is made.

Your body needs new stem cells to replace the blood cells that are not working properly. This is called a **stem cell transplant**.

The new stem cells will come from somebody else. This might be someone in your family or could be someone you don't know. This person is called a donor.

Your donor will have tests to make sure that their stem cells are like yours. This is called a 'match'. Your donor will go to hospital to have their stem cells collected. Their stem cells will be given to you.

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.

Meet Ben

We would like you to meet Ben. He is going to tell you what it's like to have a stem cell transplant.

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 like a long time. 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?

Ben found it helpful to talk to his family and stem cell transplant team about his feelings.



Having tests

To begin with, Ben had lots of tests to make sure his body was ready for his stem cell transplant.

You are likely to have many tests too. Try and find out which tests you will need and tick them off below.

- X-ray
- Ultrasound scan
- Blood tests
- Seeing a dentist
- Heart scan
- Breathing tests
- Kidney test
- Height check
- Weight check



Fitting a central line (wiggly)

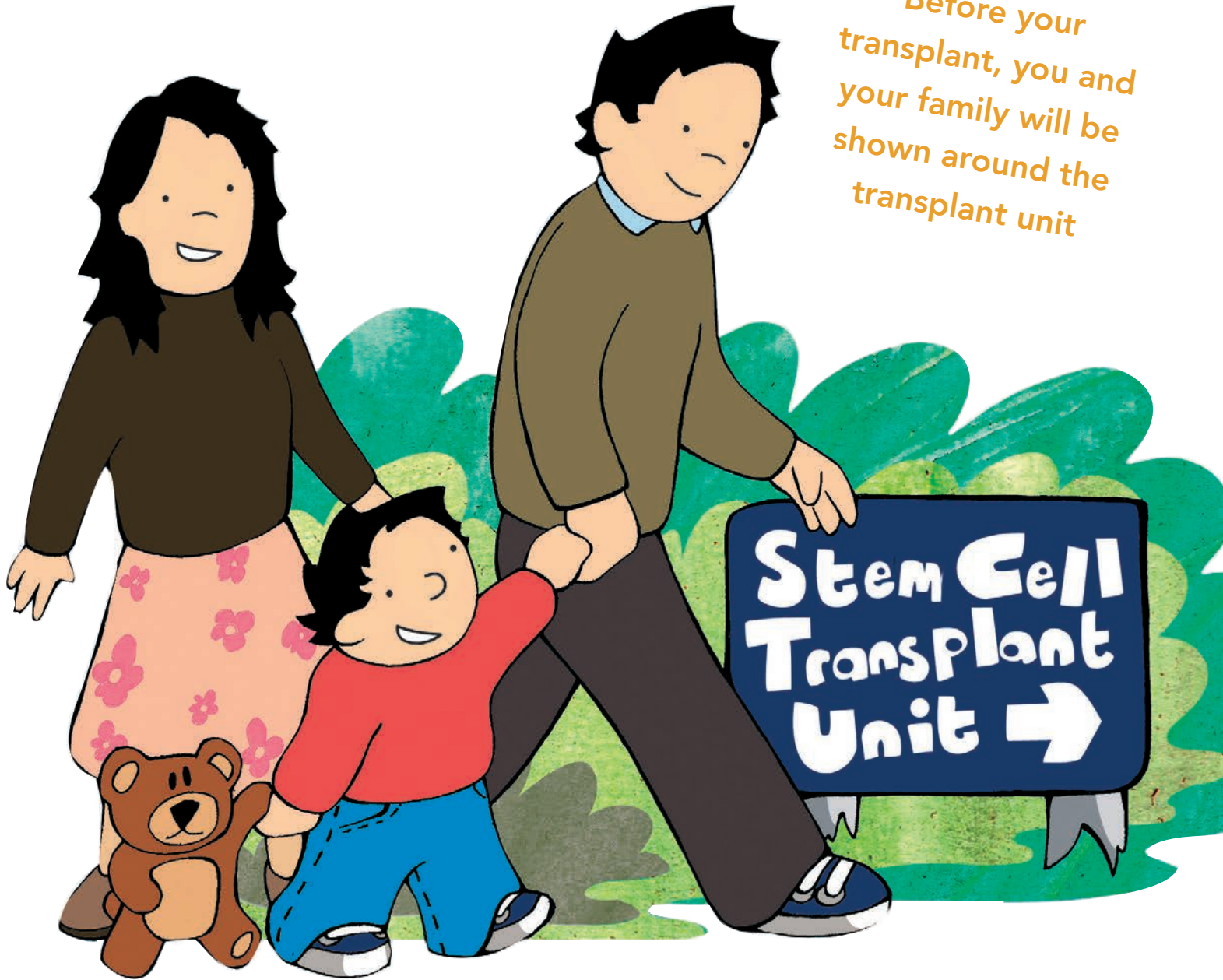


Ben says:
"Before I started my treatment for transplant, I had an operation to have a central line put in. I call it my wiggly."

A central line is used for blood tests and to give you the treatments you will need. Some children already have a central line but Ben needed his to be 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.

Before your
transplant, you and
your family will be
shown around the
transplant unit



Meeting hospital staff

Ben met lots of new people during his stem cell transplant. Here is a list of some of the people you may meet. You might like to write down their names or draw a picture of them.

Transplant doctors

.....

Nurses

.....

Play specialist

.....

Dietitian

.....

Teacher

.....

Social worker

.....

Physiotherapist

.....

Psychologist

.....

Cleaner

.....



Ben's own hospital bedroom

When Ben went into hospital, he had a bedroom of his own and he did not share with any other children. This kept him safe from infection. This is called 'isolation'.

Ben's mum or dad were able to stay in his room with him to help look after him. Ben's brother and sister could talk to him through the intercom when they visited him in hospital.

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

Ben says:
"Before I went into hospital
I made a sign for my room
and decorated it."



Having a stem cell transplant

At first, Ben had some treatment to get his body ready for the transplant. For some children, this treatment is only a couple of days but for others it can last up to two weeks.

This treatment may include chemotherapy or radiotherapy, or both. The treatment kills cancer cells and your own stem cells so they cannot fight against the new stem cells when they are given to you.

The chemotherapy medicine is given through your wiggly or into your mouth. The radiotherapy uses x-rays. You may have to go to another hospital for radiotherapy.



Ben says:
"I liked to think of the
chemotherapy as an army
fighting inside my body to
make me feel better."



When Ben's treatment to get his body ready was finished, the new stem cells were given to him through his wiggly. It did not hurt.

The stem cells started to make new blood cells in Ben's body. Ben had to stay in hospital for a few weeks while his body made new, healthy blood cells. The doctors and nurses kept checking that the new stem cells were working.

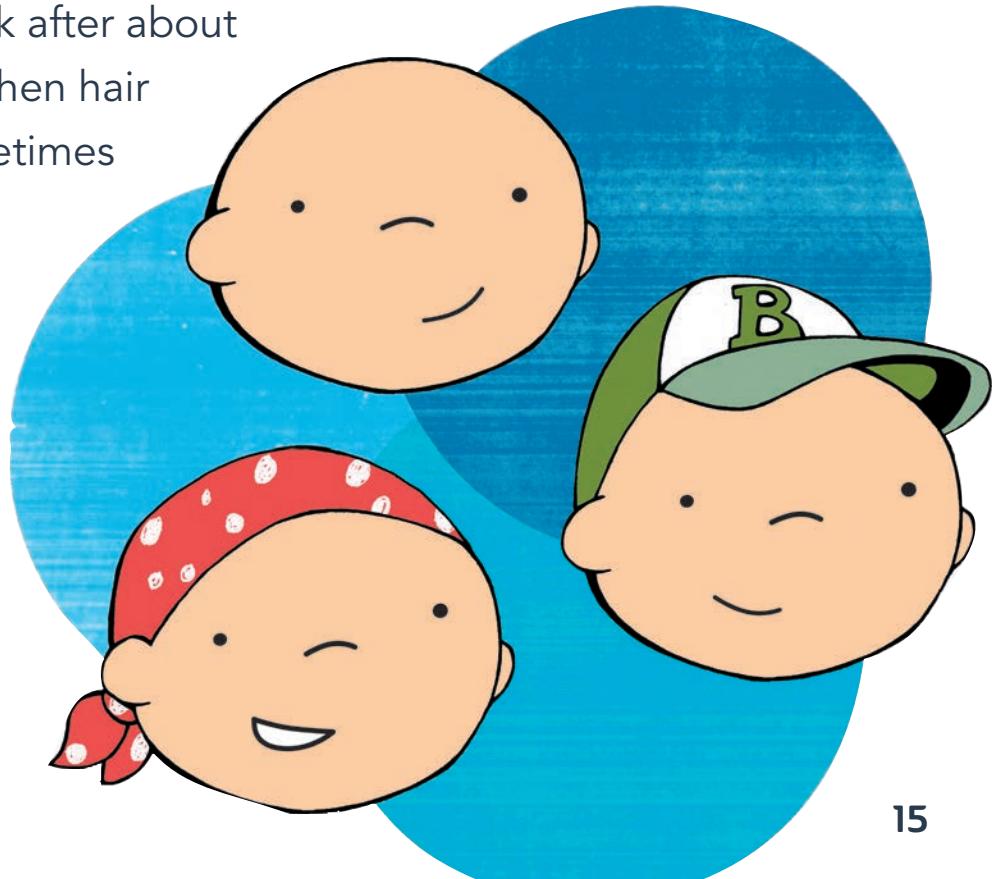
Ben says:

"My new stem cells were red and in a clear bag. The nurses gave them to me through my wiggly. It didn't take very long."

Losing hair

Chemotherapy and radiotherapy made Ben's hair fall out. His eyebrows and eyelashes also fell out. Ben decided to have his hair cut really short before his transplant. He liked to wear a cap when he had no hair. Some children buy a special cap, hat or wig to wear until their new hair grows back. Some children don't like to wear anything on their head.

Your hair will grow back after about three to six months. When hair grows back it can sometimes be a bit darker or a bit lighter. It may also be straighter or more curly than it was.



Looking after yourself

Chemotherapy and radiotherapy made Ben feel sick. The nurses gave him medicine 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. After your treatment has finished, this feeling may carry on because of other medicines or problems.

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.



Ben says:
"It really helped me
to suck ice cubes
and drink small sips
of water regularly."

Ben cleaned his teeth three or four 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. They can help to make your mouth feel a bit better by giving you painkillers. Over time, your mouth will get better.

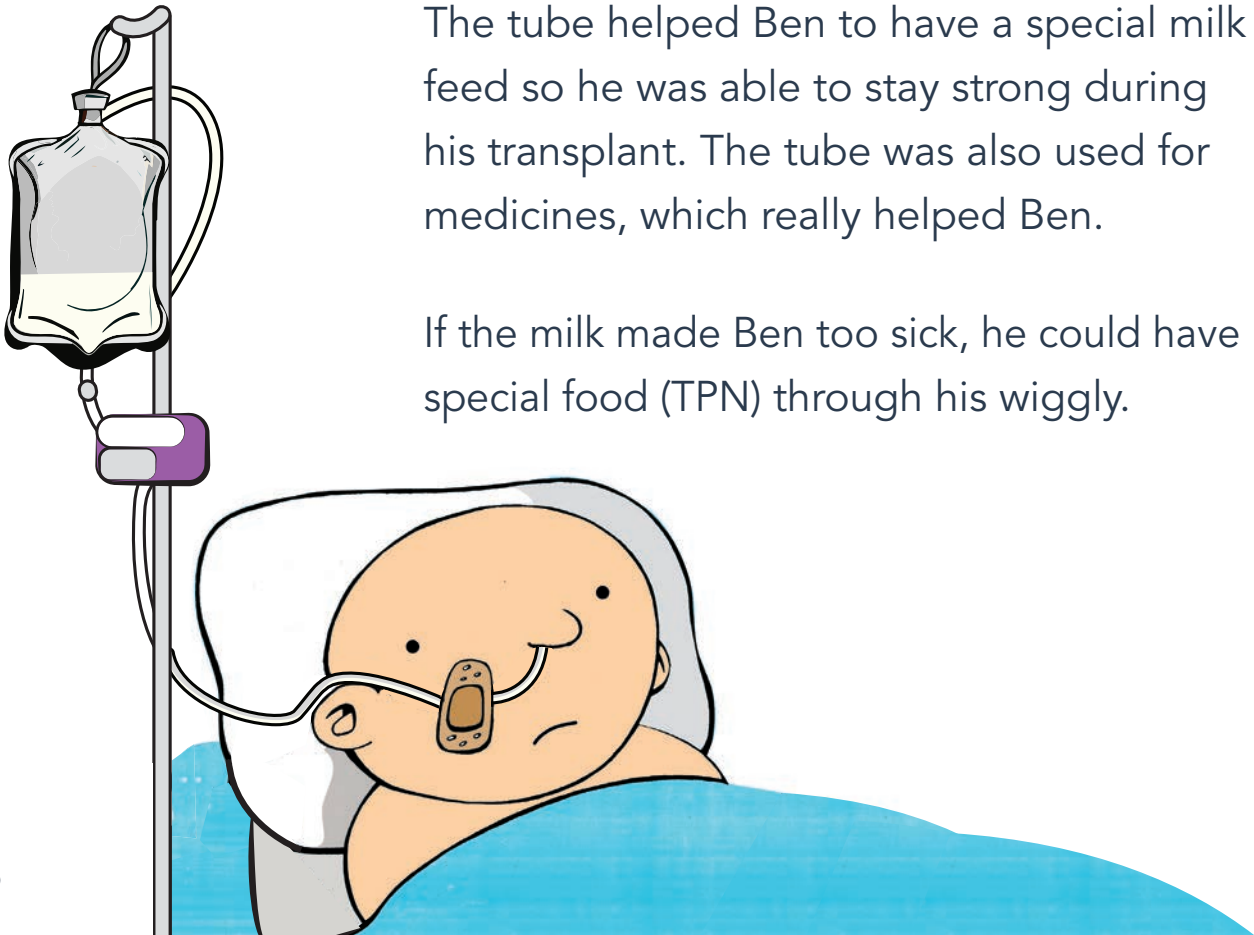


Having a feeding tube

When Ben's mouth was sore, he did not want to eat or drink. Ben had a tube down his nose into his tummy. This was not nice but it stopped his family always asking him to eat and drink.

The tube helped Ben to have a special milk feed so he was able to stay strong during his transplant. The tube was also used for medicines, which really helped Ben.

If the milk made Ben too sick, he could have special food (TPN) through his wiggly.



Keeping healthy and well

It took a while for Ben's body to get used to the new stem cells and to start feeling better. The doctors and nurses looked after Ben and gave him medicines and other treatments to help.

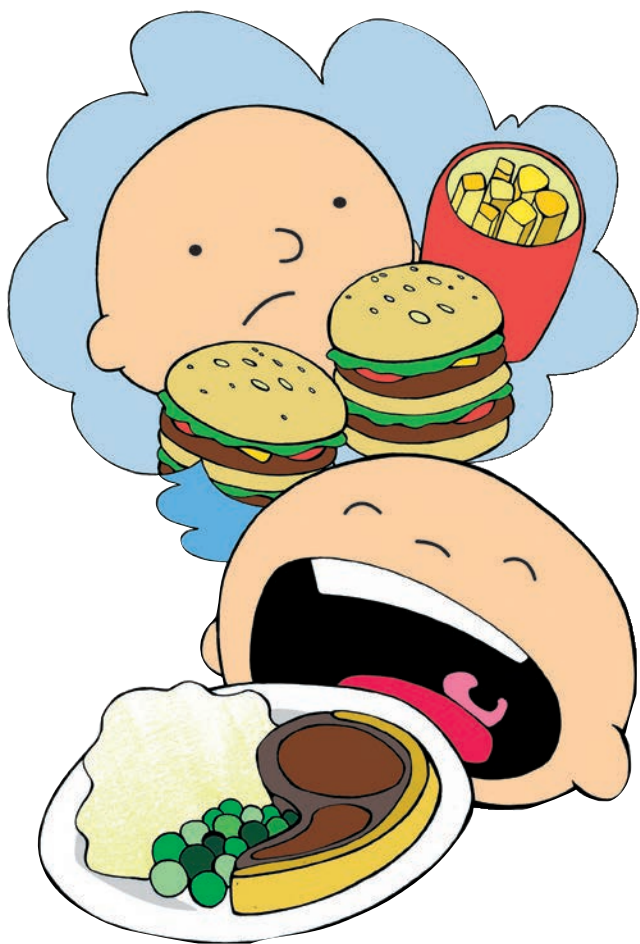
While you are recovering from the treatment and waiting for the stem cells to work, it is important to stop any infections which might make you poorly.

To help keep his body really clean, Ben had to wash, shower or bath and put on clean clothes every day. Ben's family helped him with this.



To stop Ben from having a sore tummy or runny poo, he was not able to eat some of his favourite foods, such as takeaways, for a while.

You will probably be able to eat most things, but there will be a few changes like not eating the skin on fruit and not having a soft boiled egg.



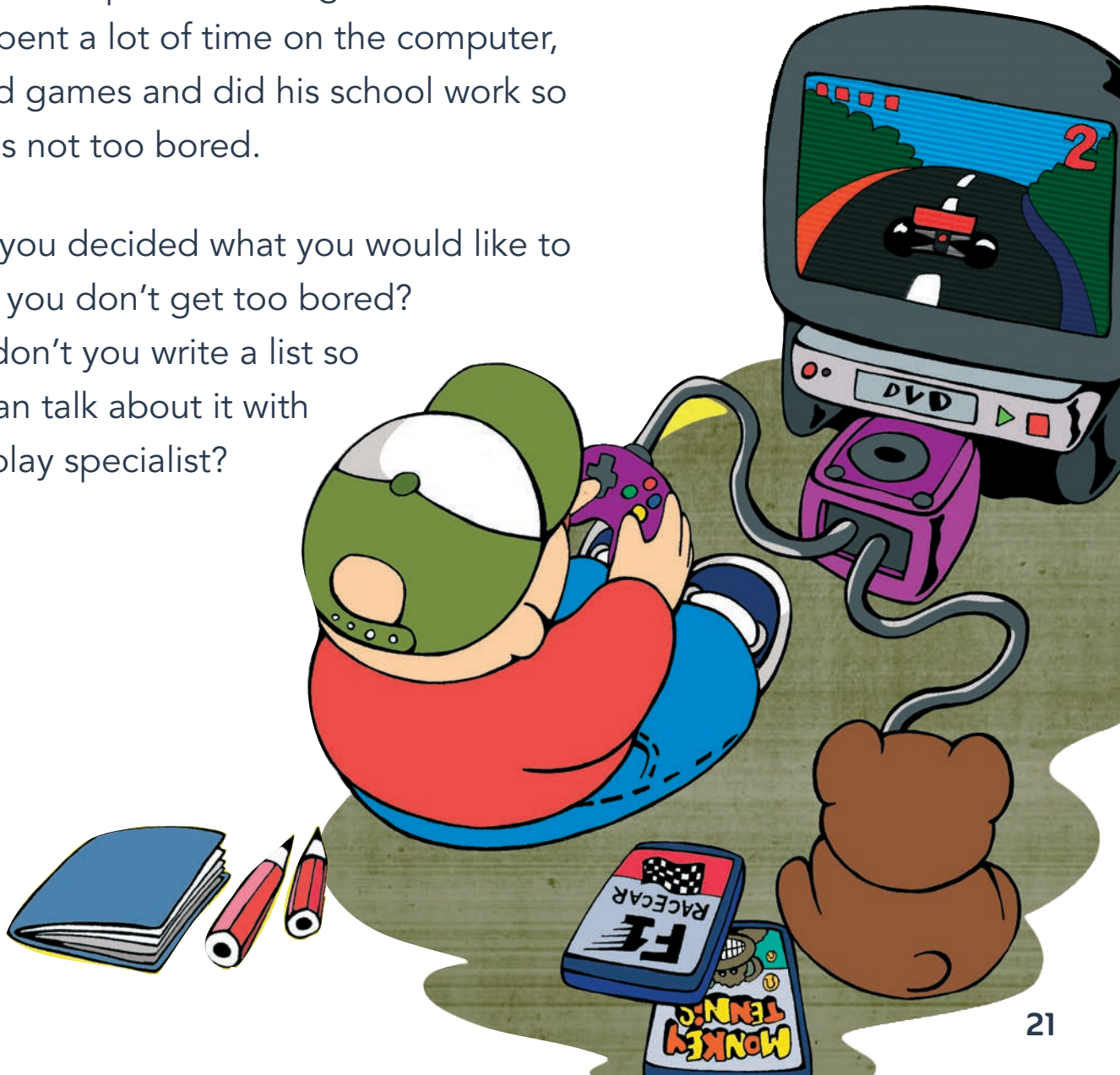
Ben says:
"I made a list of my favourite foods to help me talk to the nurses about what I was allowed to eat during my transplant."

Keeping busy

Being in hospital for a long time is hard. 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 don't get too bored?

Why don't you write a list so you can talk about it with your play specialist?



Taking medicines

Ben needed to take medicines to help his body recover. He had to keep on taking some of these medicines after he went home.



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

You will often be able to choose between tablets or liquids. Please ask if you are not given the choice.

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

Feeling better

When Ben's new stem cells started to work he was allowed more visitors and was able to start leaving his room. The nurses and doctors will know when you are ready to go out of your room by checking your blood count.

Ben was very excited when he was told he could leave his room, but a bit frightened as well because he had been in isolation for a few weeks. Ben could now get ready to go home.

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



Going home

When Ben came out of hospital, he had to be careful not to catch any germs. This meant he had to stay at home to begin with. He could only have two or three friends to visit if they didn't have any infections.

He could not go out to the shops or inside busy places at first. When Ben felt strong enough, he started to go outside in the fresh air and for short walks to the park. He was not able to go back to school for a few months.

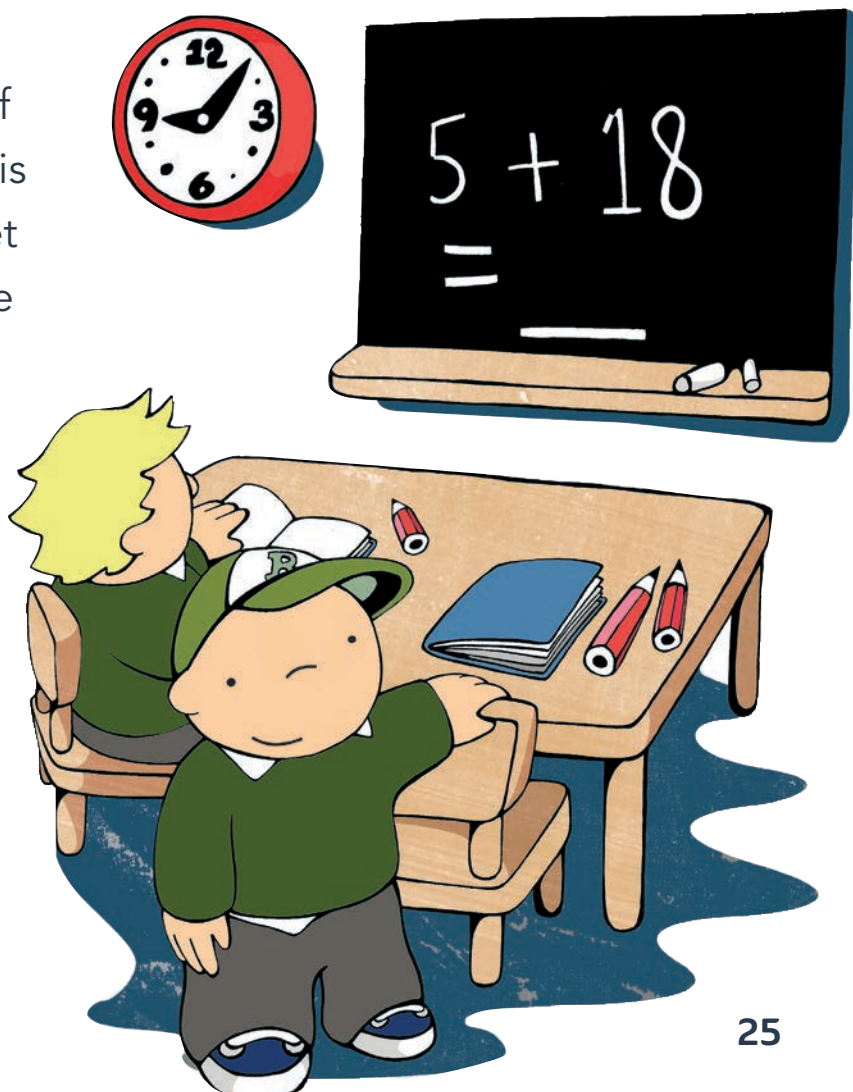


Ben says:
"Before I went back to school, I had a teacher who came to my home to help me with school work."

When Ben's new stem cells were strong enough, he went back to school. To start with, he only went for half days as he was still very tired.

You will probably feel 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.

The nurses will talk to you about what you can do and what to expect.



Hospital check-ups

After Ben went home, he had to go back to the hospital once or twice a week to have blood taken and make sure the medicines were working. At hospital, the doctors and nurses checked Ben's skin for spots or itchy patches. Ben liked going to hospital because he enjoyed seeing all the doctors and nurses again.

Sometimes your new stem cells can fight with your body and give you a rash or a poorly tummy. You must always tell your family if there is anything wrong so they can help sort it out.

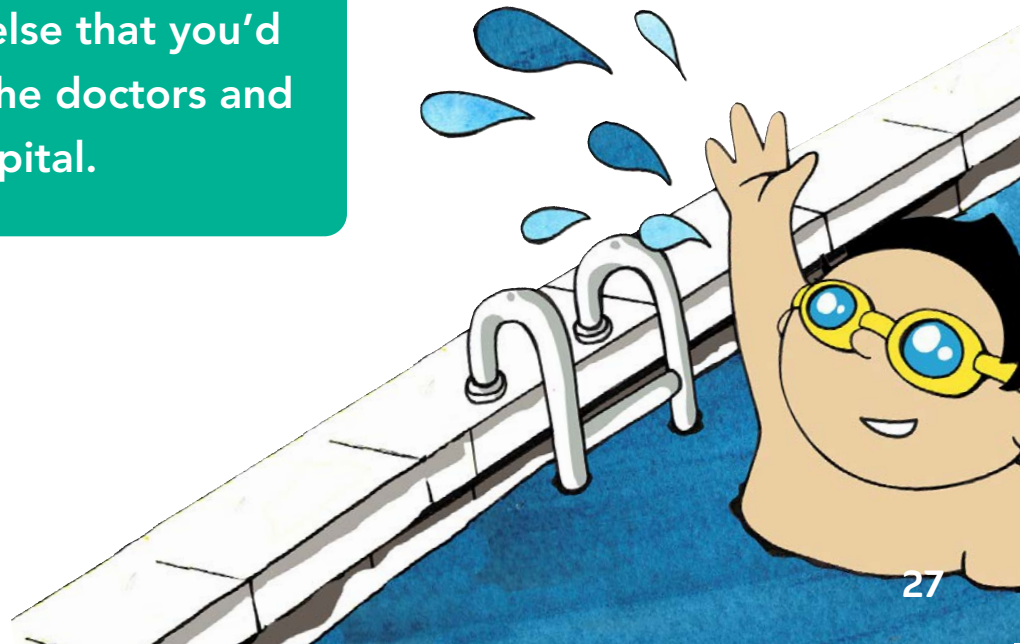
You may need medicine to make you better. You might have to go back into hospital for a few days to sort out the problem. Sometimes nurses come and see you at home so you don't have to go to hospital as much.



A few months afterwards

When Ben stopped needing blood tests or medicine, he did not need his central line anymore. This was about three to six 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 go to hospital as much then either.

We hope Ben's story has helped you learn about stem cell transplants 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.





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.

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

Our work is funded by donations. If you would like to help, text '**CCLG**' to **70085** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

Reviewed by Craig Baillie, Stem Cell Transplant Clinical Nurse Specialist, Royal Hospital for Children, Glasgow, in conjunction with the CCLG Information Advisory Group comprising parents, carers, survivors and multiprofessional experts in the field of childhood cancer.

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