Having my stem cell transplant

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> saving the lives of people with blood cancer



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Having my stem cell transplant



saving the lives of people with blood cancer



What's in these activity booklets?

We've produced this series of activity booklets for children aged between 5 and 11 who are about to have a stem cell transplant (sometimes also called a bone marrow transplant). It will help them understand why they need a transplant, what will happen to them and how to look after themselves as they recover. The accompanying parents' guide — Helping your child through their stem cell transplant — covers the same subjects in more detail so you can answer any questions they might have.

It's been written with guidance and advice from parents who have been where you are now, as well as specialist healthcare and teaching professionals, to help you manage your current situation. Each transplant centre will do things differently, so the information in this booklet is a general guide and isn't intended to replace advice from your child's doctor and transplant team.

We are here for you and your child on every step of their transplant journey. Our website contains lots of transplant related advice and highlights our other services too. If you need to ask us any questions, or you would like some more advice, please get in touch with the Anthony Nolan Patient Services team at **patientinfo@anthonynolan.org** or on **0303 303 0303**

All about you

This is your activity book. You can write and draw things in it.

It will help you understand why you have been feeling poorly and get you ready for your stem cell transplant.



I am going to be looked after at

Meeting your transplant team

Now you've arrived at hospital, you will be looked after by lots of people. They all have different jobs to do. You might not have met everyone yet, but you will see them as you go.

Here are the hospital staff you're likely to see. Try and find out their names and ask them what they do in their job. You can write what you find out below.

Doctor

Clinical nurse specialists Nurses

Dietician

Physiotherapist

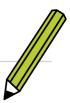


Hospital teacher

Counsellor or therapist

Porter

Cleaner





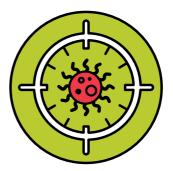
Treatment before your transplant

Before your transplant, the hospital staff will make sure your body is ready for your new stem cells. This is done using a special kind of medicine called **conditioning therapy**.

For your conditioning therapy you will be given **chemotherapy** and maybe **radiotherapy** as well.



Chemotherapy is a medicine the nurse will give you as either a tablet to swallow or through your central line. You will have it every day for up to two weeks. Its job is to remove all the blood cells making you poorly. It also creates space for your new stem cells to live in.



Radiotherapy is a type of X-ray. It does the same job as chemotherapy, but you can't see it or feel it. You will only need it a few times and your doctor might decide you don't need it at all. It looks like a big machine that will move around you as you lie very still. It's similar to some of the scans you might have already had.

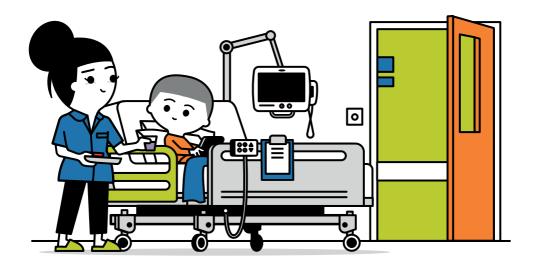


Unfortunately, conditioning therapy will make you feel poorly. But this means it's working properly too. The hospital staff will do everything they can to make you feel better and your family will help look after you too.

Conditioning therapy and the transplant friends

When our transplant friends had their conditioning therapy, it made them feel poorly too.

Ava's chemotherapy lasted a few days and it made her tummy hurt and she didn't want to eat her food. She was so tired she stayed in bed lots.



Tim and Hasan's chemotherapy lasted for longer and Tim had to have some radiotherapy too. They were both sick at times and found it hard to eat food. Like Ava, they were both very tired.

The nurses gave them some medicine for their tummies and after a few days they started to feel a bit better.



How are you feeling after your conditioning therapy?

It's important to tell the hospital staff if anything is wrong so they can help you.

Hair loss

Your conditioning therapy is likely to make your hair fall out. It might not happen for a few weeks though. Some children decide to have their hair cut short first to get used to the idea.

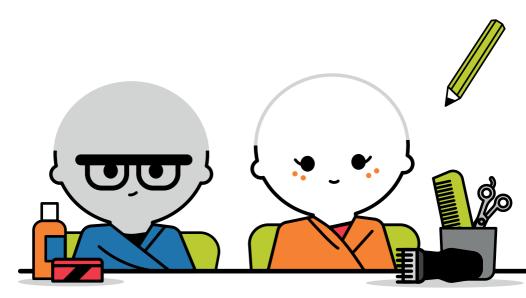
Our transplant friends are deciding what they want to do when they lose their hair.

Hasan is thinking about having a new colourful haircut. Can you create a new hair style for him?

Ava would like to wear a wig. Can you help her pick one?

Tim would like to wear a hat to keep his head warm. Can you design one for him?

What would you like to do when you lose your hair?



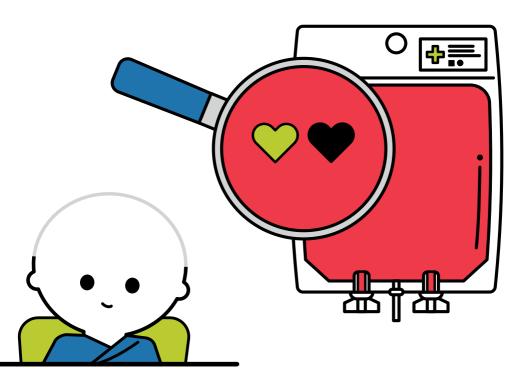
Your transplant day

Today is the big day! Today you're going to get your new stem cells that will soon help you feel better.

They will arrive in a clear plastic bag and look like a red liquid! Your nurse will carefully attach the bag to your central line and the cells will slowly enter your body.

It won't hurt at all. It's a bit like having a blood transfusion, which you might have had in the past.

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Feeling unwell afterwards

Soon after your transplant you will probably feel poorly. It can be caused by your conditioning therapy and because your body has to get used to your new stem cells.

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It's hard to know which parts of your body are going to hurt. Everybody reacts differently and some children feel unwell for longer.

When you do feel unwell, the doctors and nurses will give you medicine or other treatments to help.



After his transplant **Hasan** was very unwell. His whole body ached, and he felt tired all the time. When he felt sick the doctor gave him tablets that made it go away. He also had a sore mouth and gums, so he has a soft toothbrush to clean his teeth.



Ava was often sick after meals, so the hospital staff changed the types of food she ate. She also had to go to the toilets lots which upset her, but it cleared up when the nurse gave her some medicine.

> **Tim** started to get a red rash on his skin and his eyes were very dry. The doctor told him it was because his body was reacting to his new stem cells. He was given some eyedrops and a type of medicine called **steroids** to stop it happening.

How are you feeling after your transplant?

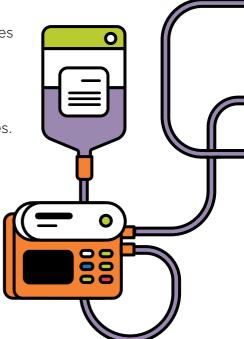
A sore mouth and feeding tubes

Lots of children find it very difficult to eat food after their stem cell transplant. If you're having problems it might be because you feel sick, find it hard to swallow or don't like the taste of some foods.

To make things easier, your doctor might decide you need a **feeding tube**. This is a bit like your central line, but it carries food into your body, rather than medicine. This isn't food like you normally eat – it's not mushy vegetables or melted ice cream! It's all the good bits from food, called **nutrients**, that you need to feel better.

There are two types of feeding tubes that enter your body at different places.

Some of them go **into your nose and down into your tummy**. This means you don't have to worry about your sore throat or how the food tastes.

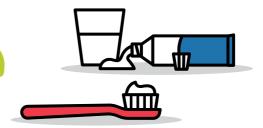


The other kind go through your skin and into your tummy.

You will need to have a small operation, like you did for your central line, to have it fitted.

It probably sounds really strange and maybe a little scary to eat your food like this.

Please try not to worry though. It's the best way to make you fit and strong again and you will only need it for a short time.



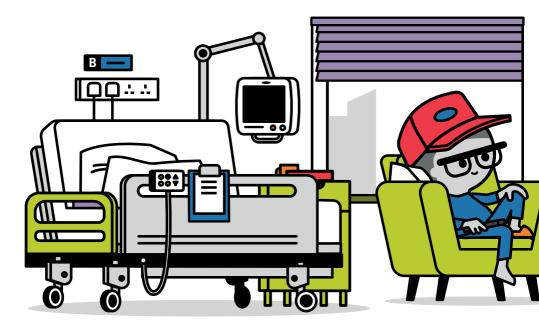
When you have your tube fitted you will still have to clean your teeth to help keep them healthy.

Your isolation room

When you receive your new stem cells it will take a few weeks for them to start making new blood cells.

This means you're more likely to get an infection from germs that could make you poorly. Normally these germs are removed by your white blood cells.

During this time, you will stay in your own isolation room to keep you safe. It will have a bed, chairs for visitors and a TV. You can have your favourite things, like toys and books, in there too to make it feel more like home.







The doctors and nurses will check on you often and give you your medicine. They might wear funny looking clothes and masks on their faces so you can't see their mouth and nose. This is to help stop germs spreading. The room will be cleaned daily to protect you from germs too.

Your grown-ups can come into the room with you but your brothers and sisters, or other friends might not be allowed to. This is to help stop you getting an infection. Maybe they can talk to you on a phone or video call instead.

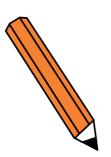
Isolation rules

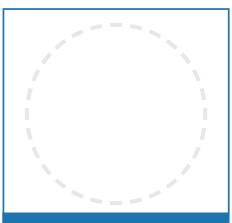
When you're in your isolation room there are some rules you and your visitors will have to follow.

Can you design some signs to help everyone remember the following rules and phrases? Think about other signs you see on roads or in the hospital to help you.



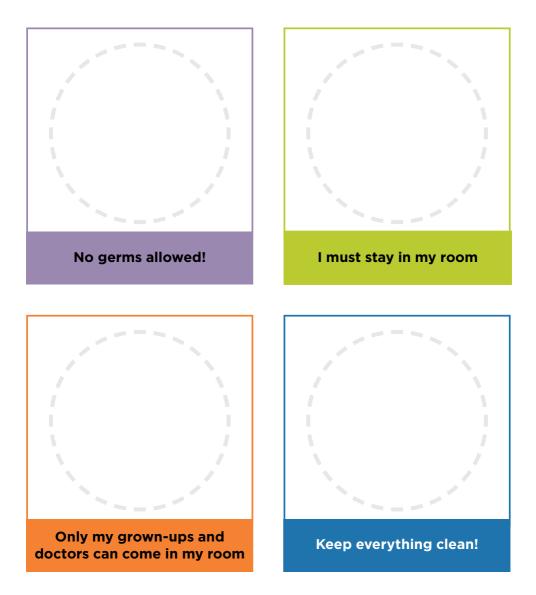
Wash your hands when you arrive and leave





Visitors must wear protective clothing





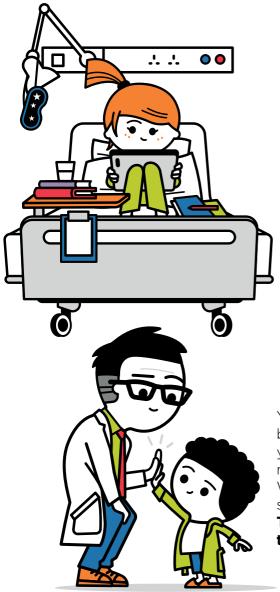
Things to do in Isolation

Staying in isolation might not sound like it's going to be much fun, but there's lots of things to do.

Someone called a **physiotherapist** will come and visit you. They will give you some stretches and gentle exercises to practise. It will make your muscles and bones stronger.

The hospital has its own **teacher**. They will listen to you read and help you with other school activities in your room. A play worker will give you some activities to do too.





There will be time to watch your favourite films and television programmes. If you have a tablet or games console you will be able to use that too.

If you start to feel sad or upset at any time, there will be someone from the hospital you can talk to.

Your doctor will test your blood every day to see if your new stem cells are making new blood cells. When they do, you will start to feel much better. **This means it will soon be time for you to go home!**

You will need to keep looking after yourself as your recovery continues. Our next booklet called *Coming Home After My Stem Cell Transplant* will help.

Can you find the following words in the grid opposite? They could be spelt horizontally, vertically or diagonally, forwards or even backwards! You can ask your grown-up to help, if you like.

| Radiotherapy – A type of X-ray which removes the blood cells making you poorly |
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| Chemotherapy – Medicine which removes the blood cells making you poorly |
| Transplant - When your new stem cells are delivered to your body |
| Stem cells - Special cells that make other types of blood cells |
| Isolation - The room you stay in after your transplant |
| Feeding tube – You might need one if you find it difficult to eat food |
| Nutrients - The food that goes into your feeding tube |
| Recovery – The time after your transplant when you start feeling better |
| Physiotherapist - Gives you exercises to make your body stronger |
| Nurse - The people who look after you every day in the hospital |
| Doctor – The person in charge of looking after you |



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It will help them understand why they need a transplant, what will happen to them and how to look after themselves as they recover.



Going to hospital for my stem cell transplant



Having my stem cell transplant



Coming home after my stem cell transplant



Helping your child through their stem cell transplant



Patient Information Forum

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