

Coming home after my stem cell transplant



**ANTHONY
NOLAN**

saving the lives of
people with
blood cancer



Patient Information Forum

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patientinfo@anthodynolan.org

The information contained in this booklet is correct at the time of going to print (April 2024). We plan to review this publication within three years. For updates or the latest information, visit **anthodynolan.org**

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ANTHONY NOLAN
PATIENT SERVICES

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@anthonyolan.org** or on **0303 303 0303**

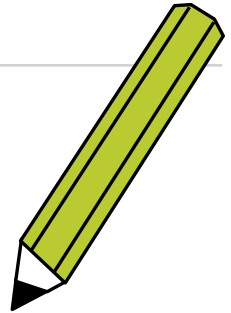
All about you

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

It will help you look after yourself now you're back home after your stem cell transplant.

My name is

I am _____ years old

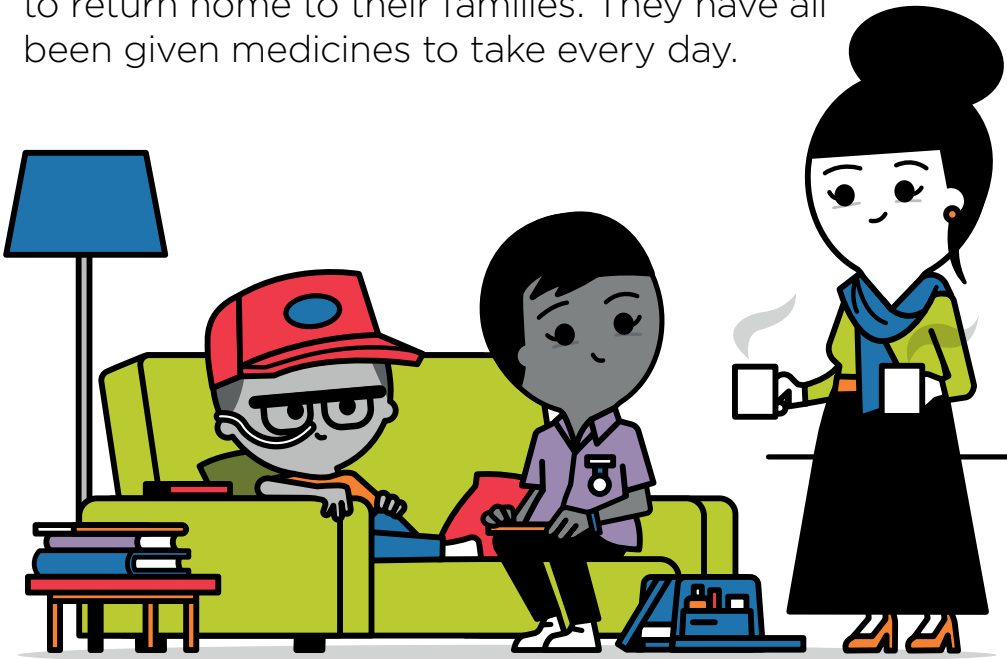


I live in

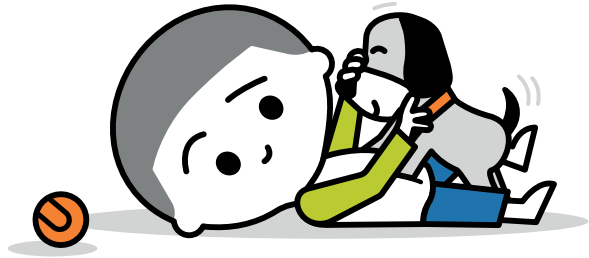
I had my stem cell transplant at

Transplant friends - going home

Our friends have all had their stem cell transplants and the doctors are happy for them to return home to their families. They have all been given medicines to take every day.



Hasan has been home for a few weeks. Although he gets tired easily, he is feeling better than he did in hospital. His community nurse visits him often to check everything is OK. She cleans his feeding tube and central line too.



Tim is happy to be back with his family and dog Benji. He must be careful and wash his hands after touching Benji so that he doesn't get poorly. He's looking forward to taking Benji for walks again soon.



Soon after coming home, **Ava** had to go back into hospital again because she wasn't feeling well. The doctors gave her some medicine to help her feel better. She should be home again in the next few days.

She wishes she could see her friends more often and is looking forward to going back to school.

Medicines

Just like our transplant friends, your doctor will give you medicine to take every day to make sure you continue feeling better.

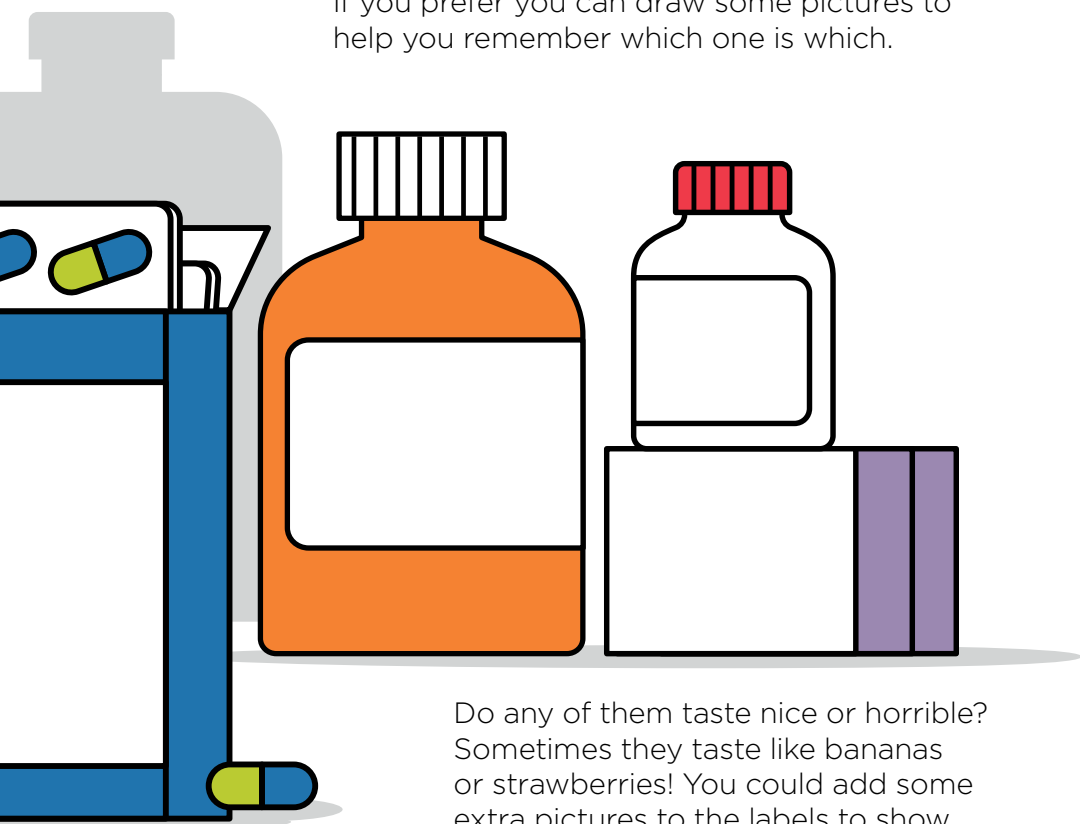
There might be many different types to take at different times of the day. This can be a bit confusing, but don't worry, your grown-up will make sure you take the right ones.

When you need more medicine, your grown-up will visit a place called a **pharmacy** (or chemist). It looks a bit like a shop but it's where you collect your medicine after seeing the doctor or nurse.





Here are some blank medicine packets and bottles. You can write the names of the medicine and what they are for on the labels. If you prefer you can draw some pictures to help you remember which one is which.



Do any of them taste nice or horrible? Sometimes they taste like bananas or strawberries! You could add some extra pictures to the labels to show how they taste.

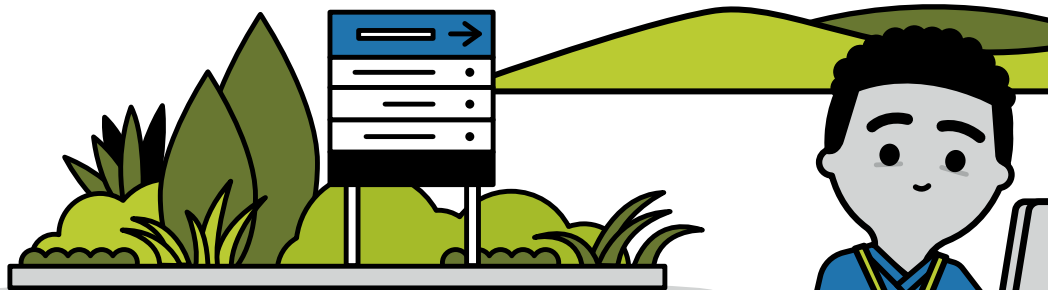
Going back to hospital



Even though you're well enough to come home, you will need to visit the hospital a few times a week.

This is just to check everything is OK and to see if you need your medicines changed.

As you get better you won't need to go quite so often.



You will have a **blood test** each time you go to the hospital to see how many cells are in your blood. They are just like the ones you had before your transplant.

Depending on how you're feeling, you might also need to see a **specialist doctor**. They will look at the parts of your body that might still be hurting. This could be a rash on your skin or an upset tummy.





There could be times when you need to stay in hospital for a few nights. This might be because you've got an infection. The doctors will give you some medicine to make it go away.

If you start to feel unwell in any way, like feeling hot or cold or feeling sick, it's very important to **tell your grown-up straight away**. They will phone the hospital and you will be checked quickly. It doesn't matter if it turns out to be nothing. You won't get in trouble for saying how you felt.



Stopping infections

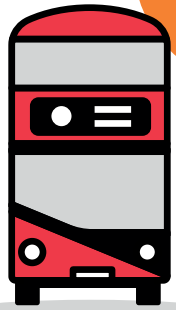
If you start to feel ill or have a high temperature, it could be because you have something called an **infection**. They are caused by germs that are so small you cannot see them.

Normally our bodies are very good at removing germs, but you're more likely to get an infection after your stem cell transplant. That's because right now, your new stem cells are working very hard, but it takes a bit of time for them to make lots of new blood cells. This includes **white blood cells** that get rid of germs.

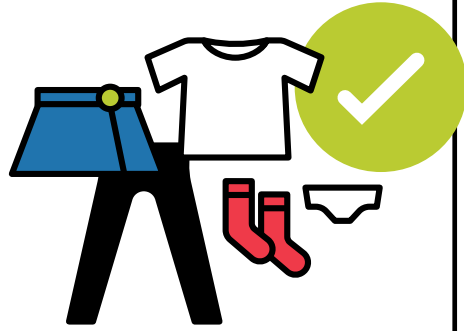
There's lots you can do to give your stem cells a helping hand. If you do the following things every day it will help stop germs spreading:



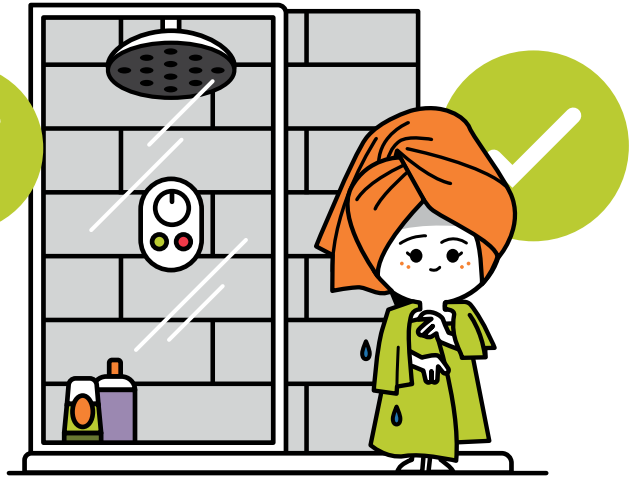
Don't go to busy places or travel on buses or trains.



Avoid people with coughs or colds.



Wash your hands after using the toilet and before eating.



Have a bath or shower and put on clean clothes.



Clean your teeth after eating.



Don't let pets lick you and wash your hands after touching them.



Eating after your transplant

When you first come home you might still be using your feeding tube – but hopefully it won't be for much longer.

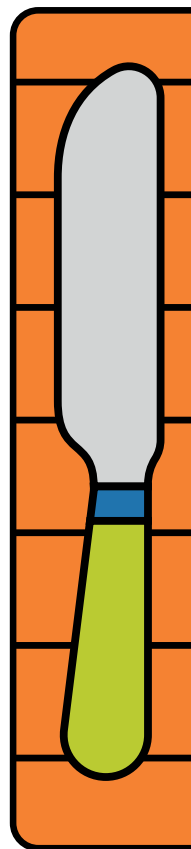
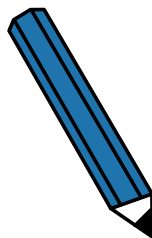
When your tube is removed, the food and drink you have is very important. It will help you get fit and strong again.

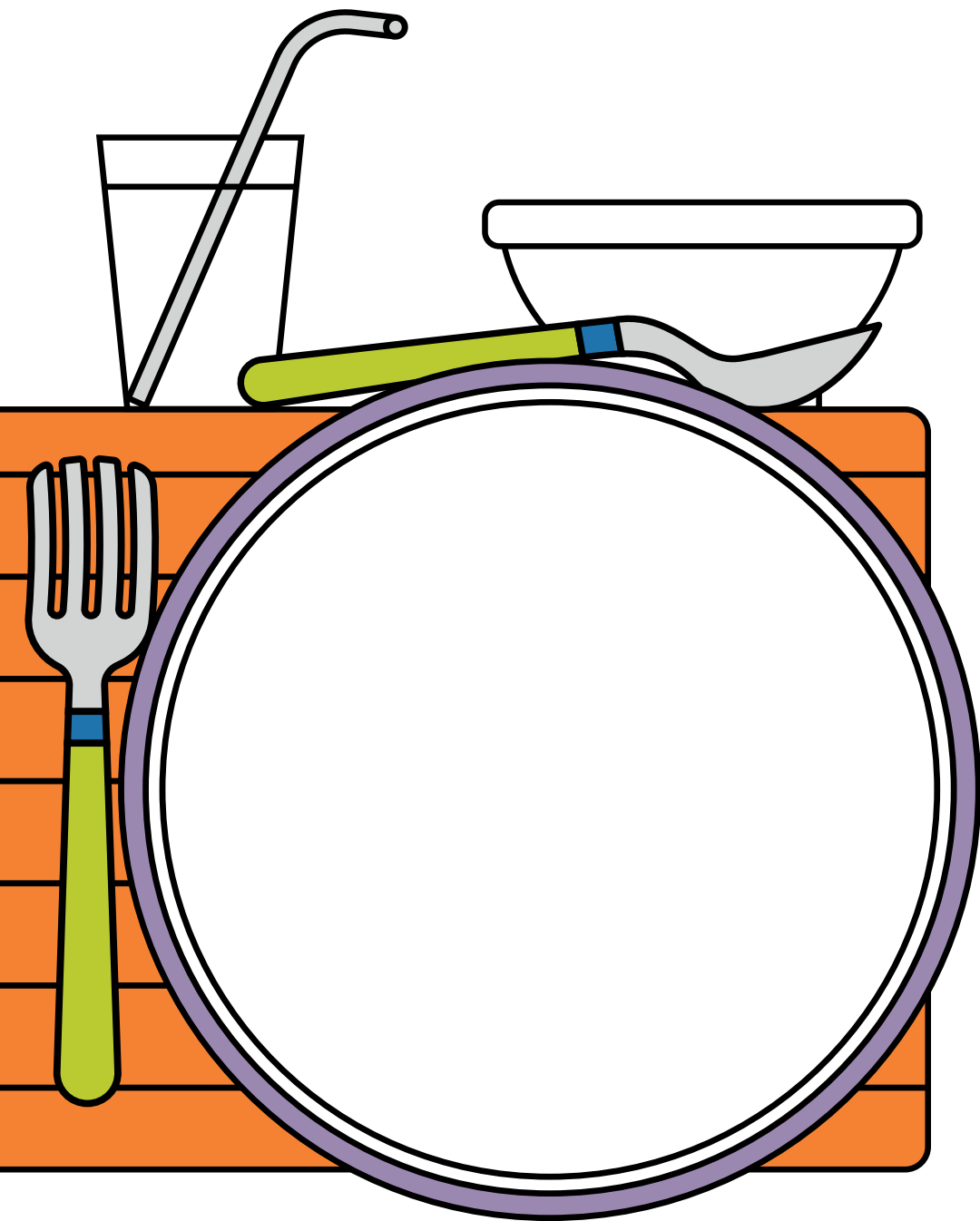
You might not be able to eat everything you like. This is because some types of food have more germs in them, and they might make you poorly.

Think of the things you like to eat and either write them in a list or draw some pictures on the plate. When you next see your nurse, you can talk to them about which are the best to eat to help you get better. They might suggest some new ones too.

Your food will also need to be cooked properly and made in a clean kitchen to stop germs spreading. The hospital staff will tell your grown-ups how to do this.

You just need to remember to wash your hands before eating.





Feeling tired

It's OK to feel tired at times. You've been through a lot and your body is still getting used to your new stem cells. You might need to have regular naps to top up your energy levels throughout the day.

It probably sounds strange but sometimes the best way to feel less tired is to do some exercise. It doesn't have to be for a long time, even a little bit of exercise will help your recovery.





To avoid getting an infection, you might not be able to play with your friends in the park just yet. But there's lots of other fun activities you can do for exercise.

- ★ Go for a walk with your family
- ★ Play in your garden
- ★ Dance to your favourite music
- ★ Online exercise or yoga videos
- ★ Create an obstacle course in your house



Returning to school

You won't be ready to go back to school just yet. Going to school every day can be very tiring while you're still recovering. First you will need some time at home to get stronger after your transplant.

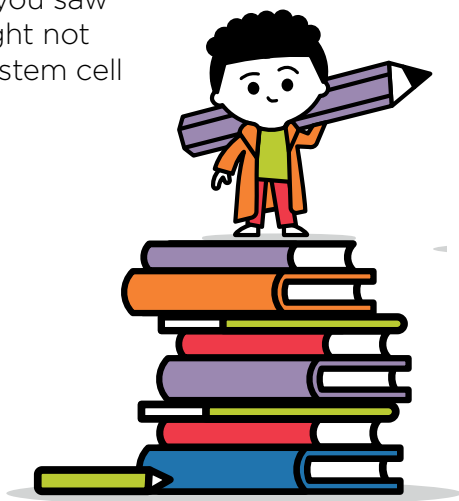
Instead, a teacher should come to your home. They will talk to your school teacher so you can do the same work as your friends back at school. They will also listen to you read.

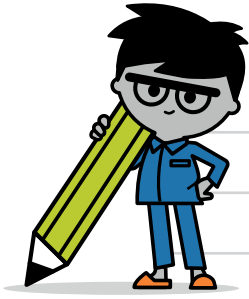
Your family and doctor will decide when you're well enough to start school again. At first, you will probably only do a few days each week or go in for half days. As you get stronger, you will start to spend longer there.

It will have been a long time since you saw some of your classmates. They might not understand what it's like to have a stem cell transplant or how you're feeling.

Like you did earlier, you can write or draw some pictures to explain what's happened and how your friends can help you at school. Maybe they could carry your bag for you or make sure you're always looked after.

You could also use this space to write down any worries you have about going back to school.





A series of horizontal lines for writing, starting from the top right of the page and extending down to the bottom right, where the girl is sitting.

When you've finished, ask your grown-up to check it and they can talk to your teacher about it.



Your recovery star chart

You have done such a good job trying to stay healthy. This star chart will help you look after yourself as your recovery continues.



Eat well

Try to finish all your food, whenever you can.

Drinking liquids

Try to drink lots of water every day.

Wash your hands

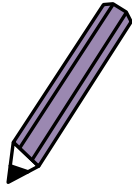
You need to make sure your hands are clean after going to the toilet and before eating.

Take your medication

Remember to take your medicine everyday - it will help you feel better.

Exercise

Running, jumping, playing and anything that makes your heart beat faster.



Every time you do something good,
draw or stick a star next to the activity.

My moments

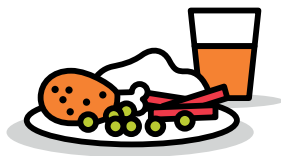


During your recovery, there will be lots of events and moments that are good to remember to show you how well you're doing. On this page, you can write down your important moments and say how it made you feel. We've written some examples here.

Returned home

This is a very special day. You will get to see all your family together, sleep in your own bed and play with all your toys again.

Even if you need to go back into hospital a few times afterwards, that's OK.



Feeding tube removed

You're now ready to eat normal food again. You might need to still be careful with what you eat but your grown-up will help you choose.

Central line removed

Now that you don't need as many medicines, you don't need your central line either. Your doctor will take it out at the hospital, but it won't hurt. You might be able to go swimming again too.



Your hair starts to grow back

You might want to try a few different hair styles as it gets longer?



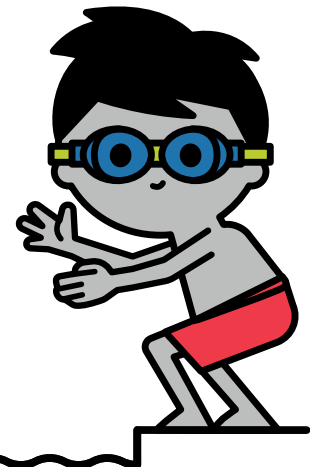
Returned to school

This is another big day for children who have had a transplant. Did you enjoy seeing all your friends again?

Some other moments that are important to you could be:

- ★ having friends around
- ★ eating out at a restaurant
- ★ your first trip to the playground
- ★ walking to the shops for the first time

Can you think of any other special moments you want to celebrate?



Word search

Can you find the following words in the grid above? They could be spelt horizontally, vertically or diagonally, even forwards or backwards!

Doctor – They'll continue to check everything is OK as you recover from your transplant

Community nurse – They'll visit your house and clean your central line and feeding tubes

Blood test – Done at the hospital to see how many blood cells you have

Medicine – You will need to take medicine every day to help stop you feeling unwell

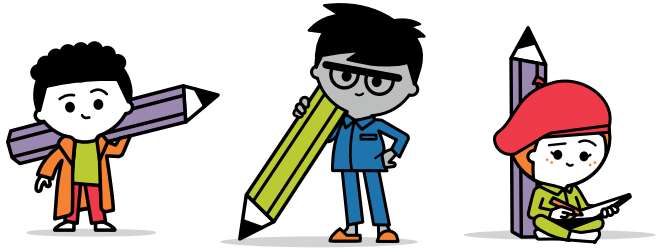
Pharmacy – Where your grown-up will collect your medicines from

Recovery – The time after your stem cell transplant

Exercise – Running, jumping, playing and anything that makes your heart beat faster

Germs – They are too small to see but can cause infections that make you poorly

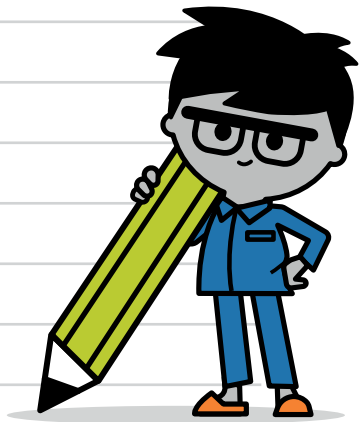
Home teacher – They'll teach you at your house until you're ready to go back to school



F W I R B U G W E G B E N F C
 R A D E E E B N O P E X V H T
 G E O R B H I N M Z C E U U S
 B B C L I C C D X A P R P A E
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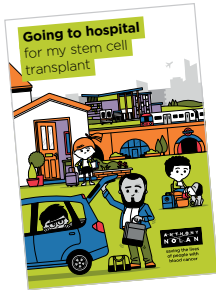
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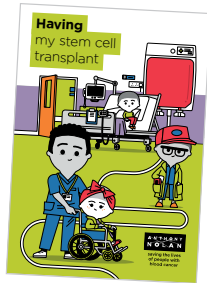


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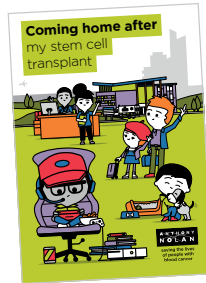
It will help them understand why they need a transplant, what will happen to them and how to look after themselves as they recover.



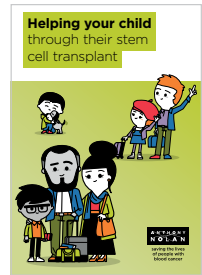
Going to hospital
for my stem
cell transplant



Having
my stem cell
transplant



Coming home
after my stem
cell transplant



Helping your child
through their stem
cell transplant



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