

# Helping your child through their stem cell transplant



**ANTHONY  
NOLAN**

saving the lives of  
people with  
blood cancer



Patient Information Forum

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**ANTHONY NOLAN**  
PATIENT SERVICES

# What's in this booklet?

We've produced this booklet for anyone caring for a child who needs a stem cell transplant (sometimes also called a bone marrow transplant). It will help you understand why they need one, what will happen to them and how to look after them as they recover. It will also help you answer any questions your child might have about what they're going through.

This booklet is a supplement to our three children's activity books: **Going to hospital for my stem cell transplant, Having my stem cell transplant and Coming home after my stem cell transplant.**

Depending on their age it might be better to read the children's books together with your child, but some older children might prefer to read them on their own first.

These booklets have been written with guidance from the parents of some of our remarkable patients, as well as healthcare and teaching professionals. They have shared their experiences with us to help you see that other people have come through similar difficulties. 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**.

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# Key facts and top tips



- Your child needs a stem cell transplant to treat their blood cancer or blood disorder. Stem cells will be donated by a family member or unrelated donor with a matching tissue type.

- Your child will spend a few weeks in protective isolation after their transplant. This is to reduce the risk of infection while their new stem cells rebuild their immune system.



- It will take time for your child to fully recover. They could still be quite ill and at a high risk of picking up an infection when they return home. Setting some ground rules for everyone to stick to will help reduce the risk.



- Regular exercise, sleeping well and eating healthily will help your child's recovery.





- Every child has a right to an education and your child's will continue during their treatment. A hospital teacher will visit regularly to continue their school work.

- This will be an emotional time for your child and family. Keep talking together about how you're feeling and encourage everyone to ask questions. There is support available for you all.



- Take time to acknowledge and look after your own needs. You can support your child best if you're looking after yourself as well.

# Talking to your child





It can feel overwhelming to find out that your child needs a stem cell transplant. You might be experiencing lots of different, conflicting feelings – relief, worry, confusion. There’s a lot to find out, process and go through. Anthony Nolan will be there every step of the way, for you, your child, and your loved ones.

## **‘How much should I tell my child?’**

Only you can decide what to tell your child about their transplant. Some parents are very open and honest, while others prefer to shield them as much as possible by telling them very little. It will entirely depend on your personal circumstances. There is no right or wrong answer.



***Because Sofia was only two and then four when she had her transplants, it was difficult to explain to her what was happening. We said she had poorly blood and she needed somebody to give her some better blood. We used to use all kinds of special words to help her understand what was happening. ‘Jelly belly’ for ultrasound, ‘donut ride’ for the MRI and ‘magic sleep’ when she was having an operation.***

**Claire, whose daughter Sofia, pictured left, had two stem cell transplants to treat congenital amegakaryocytic thrombocytopenia (CAMT)**

**Top tip:** However much you decide to tell your child, do check how they are feeling and encourage them to ask questions.

You know your child best. This is why we won't tell you what you should or shouldn't say to them. But it's important that they have lots of opportunities to share what's on their mind. They will probably be experiencing lots of the complex and conflicting feelings that you are too, no matter how much they know.

This booklet will hopefully help with any discussions or tricky questions. We hope it builds your knowledge and confidence. Please only use any suggestions we offer if you think they are appropriate and helpful.



**Rupert who had a stem cell transplant to treat myelodysplasia with monosomy 7, pictured with his mum, Holly.**

# Understanding stem cell transplants

## Why does my child need a transplant?

Your child might need a stem cell transplant to treat a blood cancer or blood disorder.

Our blood cells are made from stem cells that live in our bone marrow. If the process of making blood cells goes wrong, you can develop a blood cancer or blood disorder. A stem cell transplant can replace the damaged stem cells with healthy ones, so more healthy blood cells can be made.

You can find out more about stem cells at [anthonynolan.org/StemCell](https://www.anthonynolan.org/StemCell)

**Important:** You will need to give your consent for the transplant if your child is under the age of 16. This is obviously a big decision. You will need time to find out all the facts and process them before making your mind up.

Your child's medical team will talk you through all the possible options and explain the benefits and risks. Please ask as many questions as you need to, however big or small you think they may be. There is no silly question, and you can ask for any information to be repeated. Try and write down your questions and the answers you're given. There can be a lot to remember.



***I was keen to know as much as I could about stem cell transplants, but you can't possibly remember it all. And you don't need to. You naturally grow more in your knowledge. But don't be afraid to ask the same questions again and again if you forget the answer or don't understand something.***

Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)

## What is a stem cell transplant?

Your child may have already had other treatments before a stem cell transplant. They might have had chemotherapy or radiotherapy. A transplant may now be considered because, unfortunately, other treatments haven't worked. Your child's medical team will talk to you about the best option for them.

There are two main types of stem cell transplant. They are different because the stem cells are collected from different sources:

- If your child has an **autologous** (or autograft) transplant, they receive their own stem cells that are collected before treatment begins.
- If they have an **allogeneic** (or allograft) transplant, they receive stem cells from somebody else. This might be a sibling or parent, or it could be an unrelated or cord blood stem cell donation.

When your child's new stem cells enter their blood, they will travel to the bone marrow and start producing new blood cells. Over time, this leads to the development of a new immune system that can recognise and remove any remaining abnormal cells. It will also protect them against things like bacteria and viruses that can cause infections.

You can read more about what happens during a stem cell transplant in our **Transplant day** chapter on page 30.

**Important:** There are some possible side effects and long-term complications of having a stem cell transplant. It's important to know about these before your child begins their transplant journey. You can read more about this on page 38.

## Finding a donor

When your child needs an allogeneic transplant, they will need a donor whose tissue type matches their own. You can read more about how a donor is found at: [anthohnolan.org/FindingADonor](https://anthohnolan.org/FindingADonor)

This is what is likely to happen:

1. Someone at the hospital will take a small blood sample from your child. This will be used to determine their tissue type.
2. If your child has any biological brothers or sisters, they will be tested next as they have the best chance of being a perfect match. This is because they share the same parents.
3. Usually wider family and friends will not be tested as it's very unlikely they will be a match.
4. If there is no related donor match, the hospital or transplant centre will contact Anthony Nolan.
5. Anthony Nolan (that's us) will search all the possible donors in the UK to find the best match.
6. If necessary, we will look for possible donors on registries from across the world.
7. If there is still no match found, we can check for cord blood matches in our cord bank. Find out more about cord blood transplants at: [anthohnolan.org/CordTransplant](https://anthohnolan.org/CordTransplant)

# Key facts about finding a matching donor

- 1.** Matching is based on our **human leukocyte antigen (HLA)** tissue type.
- 2.** Our HLA type is made up of hundreds of genes, of which **six** are important when finding a match. Each one has two different versions (called alleles) making **12** in total. We inherit one version from our mother and one from our father.
- 3.** The best donor will be a **12/12** match. Your child's medical team, and the team at Anthony Nolan, will try to find the best possible match. This gives your child's body the best possible chance of accepting their donor's stem cells.
- 4.** Your child will also be tested for **cytomegalovirus (CMV)**. The result will either be positive or negative. CMV is a very common virus that often has no side effects. Ideally, we want to find a donor who has the same result for this virus as your child. There is growing evidence that a matching CMV status helps improve transplant success.
- 5.** We also consider the **donor's age**. Research confirms that transplants are generally more successful when younger donors are selected.  
  
You can find out lots more about the different types of stem cell transplant and finding a donor match at: [anthonynolan.org/Understanding](https://www.anthonynolan.org/Understanding)





**Diane and Derek Lambert, with their son Calum who had a stem cell transplant**

# Preparing for transplant

Finding out that a potential donor has been found for your child can feel a huge relief. Your child's medical team, or Anthony Nolan, will now be busy organising the stem cell donation and delivery process. They will also be making sure your child is ready for their transplant. This is a good time for you to prepare yourself, too. We give some tips over the following pages for things you can organise and plans you can put in place.



## Pre-transplant checks

Your child will have a number of medical checks to make sure they're fit and healthy enough to have their transplant. Most of them will be carried out at the hospital. They will probably have:

- a **bone marrow biopsy** and/or **CT-PET** scan to confirm their condition is stable
- an **electrocardiogram (ECG)** to check the rhythm and electrical activity of their heart
- an **echocardiogram (ECHO)** to look at their heart and nearby blood vessels
- **lung function tests** to measure the capacity of their lungs
- **blood tests** to check how many blood cells they have and to test their liver function
- **EDTA blood test** to assess how well their kidneys are working
- a **dentist** appointment as problems with teeth or gums could become a source of infection after transplant, so it's important to have a check-up.

There's nothing to worry about if your child doesn't have every test listed here. Their medical team will decide which checks are necessary for the transplant to go ahead.

## Asking for help from family and friends

Most of your time will be taken up either looking after your child or thinking about your child. The last thing you need is to worry about what you're having for dinner, when you last put a wash on, or who is picking your other children up from school.

**Ask for specific help.** Ask someone to do your washing up, batch cook some meals, or take your other child to their friend's birthday party. People will be more than happy to help – they'll want to feel useful! We have more suggestions on page 72.



***If people offer to cook you a meal, take them up on it. Your child might not be able to eat it but an easy dinner for yourself is so welcome when life is already complicated enough.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

## Plan a visit before transplant day

It can be a great idea to try and visit one of the isolation units you will stay in. It will help you picture what it will be like and make sure there are no unnecessary surprises. It might be a good idea to take your child along too, if you think it could settle any nerves.

Take time to ask the questions that are important to you. Find out how often you will be able to visit and the arrangements for staying overnight with your child.



***We visited the hospital multiple times before transplant because there were so many appointments which helped us get used to travelling to the hospital. We also had a brief visit to the unit where we'd be living which was helpful.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

## Financial support

You might be able to apply for financial grants from some charities, the government, or other organisations. Speak to your child's medical team to see what might be available for you. It's best to apply for grants as early as possible as they can take a while to process.

## Packing your child's hospital bag

There might not be much time between your child being diagnosed and the start of their hospital treatment. It might be best to pack a hospital bag in preparation.

Here's a handy list of things you might want to pack. We've left some space for you to write your own list, too.

Your child has been asked to write a list in their **Going to hospital for my stem cell transplant** activity booklet but you might find these suggestions more practical!



If you get chance, tell a family member or friend where you keep your clothes and other items that you might want brought into hospital later.

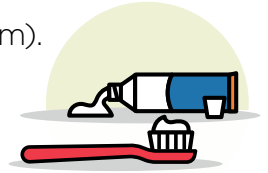
## What to wear

- Comfortable clothes for both you and your child.
- Zipped or buttoned-up clothes – they're easier to put on and take off when your child has their central line attached.
- Vests, T-shirts and shorts because hospital rooms can get very warm.
- Plenty of pyjamas, a dressing gown, slippers and socks.



## Things for the bathroom

- Wash bags – moisturisers, lip balm and hand cream can help relieve post-transplant dry skin.
- Mild shampoo and shower gel for sensitive skin.
- Spare loo rolls and tissues.
- Your child's glasses (if they need them).
- Soft toothbrushes and toothpaste.



## Your list

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## Practical items

- Strong flavoured snacks – your child's treatment might leave a nasty taste in their mouth, so things like mints can help.
- Plain food – if they're struggling with nausea, snacks like shortbread or crackers might be easier to stomach. Bring snacks in small packets to reduce waste if your child has a low appetite.
- Cordials and fizzy water – they will need to drink lots of fluid, and plain water can get a bit boring!
- Ice pops/lollies – another good way of taking in fluid, and they can help soothe mouth or gum pain (it might be easier for visitors to bring them in).
- Eye masks and ear plugs to help you both sleep.
- A night light or torch in case you want to read when your child is asleep.



***If you have a young child going through transplant then hand puppets can be great for 'human-like' social interaction during isolation. And as they are clothed-based, they can be washed easily too.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**



## Things to keep your child busy

- Mobile phone – check if the hospital has Wi-Fi for your phone and other devices, or if your contract will cover your data use.
- Laptop or electronic tablet with pre-downloaded films, TV shows, apps and games.
- Headphones, chargers and an extra-long cable that will reach the bed.
- A notebook, pens, books and magazines.
- Jigsaws, puzzles, board games or other crafts and hobbies.



# Pre-transplant treatment

Your child will need to have some treatment before their transplant. They will need to have a **central line** fitted and **conditioning therapy**.

## Central line

A central line is a thin tube that goes through the skin near the collarbone and into the vein that flows into the heart. It allows the nurses and doctors to take blood samples, deliver treatments and the stem cells themselves without using a needle every time.

This might sound scary but it will be fitted under general anaesthetic at the hospital so your child won't feel a thing. They might need to stay in overnight to check that everything is OK.

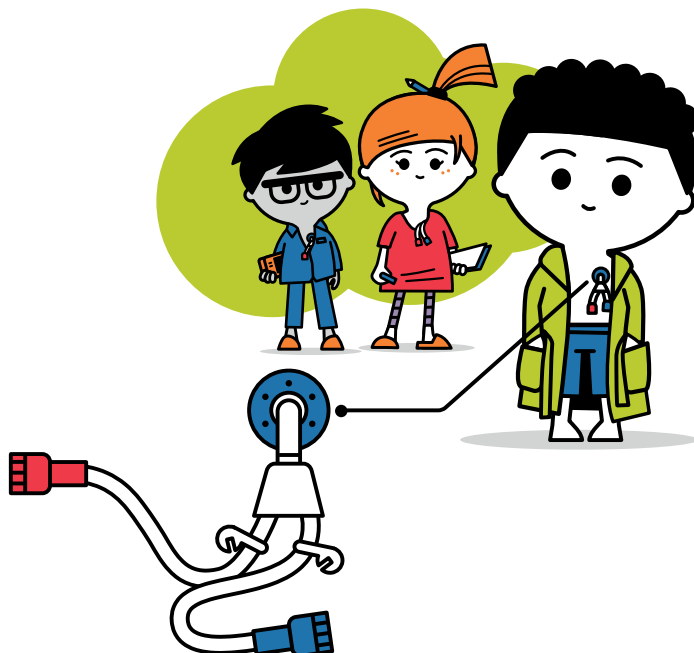


***The children took to their 'wiggles', as we called them, quite well. We always had some tape on them to stop them moving around too much. You get nervous to begin with and worry if they'll be pulled out, but over time you are more relaxed. We even had tickling/wrestling fights, and the children would do a roly poly with them in!***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

## Keeping a central line clean:

- Central lines can be a **source of infection** if they aren't kept clean. Your child's medical team will tell you how to do this but in general, **the ends shouldn't be touched**, and the lines need to be **kept dry at all times**.
- This means your child will have to take **shallow baths and won't be allowed to go swimming**.
- The line will also be cleaned and **flushed regularly by a nurse** at the hospital.
- In your child's activity book, we have asked them to find out how to keep their line clean. Talking to them about what they can and can't do will help reinforce the importance of keeping it clean.



## Conditioning therapy

Your child will stay in hospital for a course of treatment called conditioning therapy before their transplant. It will last for 1-2 weeks and consist of **chemotherapy** and possibly **radiotherapy** too. Both treatments get rid of any abnormal blood cells causing your child's condition. They also prepare your child's bone marrow so it can receive their donor's stem cells and allow a new immune system to develop.

Chemotherapy could be given as a tablet but will more likely be delivered as a liquid through their central line. If they also have radiotherapy, it will be given at the hospital by a radiographer.

There are two types of conditioning therapy: **full intensity (myeloablative)** and **reduced intensity conditioning (RIC)**. The consultant will consider many factors when deciding the best option for your child, including their general health and the type of blood cancer or blood disorder they have.

Unfortunately, conditioning therapy causes side effects that will make your child poorly (see page 38). This can be distressing for the family and can leave you feeling helpless. Most side effects only last a few weeks and the medical team will be on hand to treat the symptoms.

It's likely that conditioning therapy will lead to your child losing their hair. They may feel self-conscious of their appearance so it's better to address the situation early so you are all prepared. It might also help if your child gets their hair cut shorter before treatment so they get used to the change. They will be given the option to wear a wig at the hospital but they may need to wear a hat or head scarf to protect their skin from the cold or direct sunlight.



*Sofia had a week of intense chemo to wipe out her own bone marrow completely. That was the most difficult bit for me because she didn't seem poorly at the time, so we had to make her poorly to make her better. It was intense, it was difficult to put her through that.*

Claire, whose daughter Sofia (below) had two stem cell transplants to treat congenital amegakaryocytic thrombocytopenia (CAMT)



Your child's activity book **Having my stem cell transplant** talks about losing their hair. You can encourage them to draw a wig or design a new haircut to make it less scary.



# Transplant day



Your child's stem cell transplant normally happens the day after conditioning therapy finishes. People often call it '**day zero**'.

On the day, a nurse will check your child is feeling well and may give them an antihistamine or a small dose of steroids. This helps prevent an allergic reaction to the new stem cells.

The stem cells will be passed as a fluid through your child's central line, like a blood transfusion. It can take between 30 minutes and a few hours. The transplant isn't painful.

Although it might seem like a quick, low-key event, today is a new beginning that can be celebrated. A lot of hard work and emotion has gone into making this day possible.



***Transplant day itself is a bit of an anti-climax. You've had so much intensive prep and the stakes are high, but the process looks similar to a blood transfusion. However, if you manage to get a peak through your isolation room window and see the bag of cells arrive, that can bring a tear to your eye.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

The new stem cells then travel in the bloodstream to the bone marrow. Once there, they attach themselves and start to produce new blood cells that will form your child's new immune system. This is called **engraftment**.

Engraftment normally takes around 2-3 weeks but it can sometimes take longer. The first sign of engraftment is often an increase in your child's white blood cell count. The medical team will test their blood regularly, so they know when engraftment has started.

Your child might need blood and platelet transfusions a few times a week during engraftment. This is to help 'top up' their red blood cells which may be low. It's a normal part of recovery and doesn't mean the transplant isn't working.

**Remember:** If you're worried about anything, or don't understand something, at any time during your child's treatment and recovery, please do speak to their medical team.

You can read more about what's happens on the day of your child's stem cell transplant at **[anthonynolan.org/TransplantDay](https://anthonynolan.org/TransplantDay)**





Zara who had a stem cell transplant to treat acute myeloid leukaemia (AML)

# Staying in isolation

Isolation is an important but tough part of the stem cell transplant process.

Your child will be at a higher risk of infection and becoming unwell after their transplant. It takes some time for their new stem cells to start making new blood cells, including white blood cells which fight infections.

Your child will be moved into their own protective isolation room on the day of their transplant, if not before. This room is specially designed to create a germ-free environment, where the risk of picking up an infection is very low.



***Be prepared for long days in hospital and to be bored. Have a plan for this. Take up knitting, reading, colouring, running, anything to give you something else to focus on. Try to stay positive, even when this seems impossible. Take each day one at a time and talk to anyone who will listen - partner, parents, friends.***

**Dave, whose son Theo had a stem cell transplant to treat acute lymphoblastic leukaemia (ALL)**

## Sticking to the rules

Restrictions will be put in place in the first few weeks after transplant to limit the spread of germs into the room. The rules vary from hospital to hospital so please check what you can and can't do with the hospital staff.

In general, they involve wearing protective clothing, washing your hands with sanitiser and keeping surfaces and items clean.

You can stay with your child in their room as their main carer, but other family members, including their siblings, may not be allowed in.

When your child's blood counts increase and they start to get stronger, these rules may be relaxed but the decision will be taken by the hospital staff.



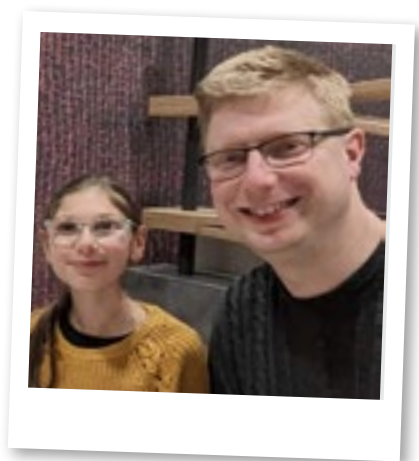
## Make it homely

Your child's isolation room will be their new home for a while, so it's a good idea to make it feel as familiar as possible. They will be able to take in their things such as books, games, and electronic tablets to help occupy their time. You might also want to put up some pictures of family, friends or even pets so their room feels more homely and they feel more connected to the outside world.



***Try to keep some routines from home, even if they're small or slightly different. For us, Charlie's bedtime always involved reading a book before saying a little prayer, so we carried this on in hospital when we could.***

Minou, whose children Charlie and Zoe (pictured below with her dad), had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)



You might also be able to bring in your child's duvet cover but check with their medical team. This will have to be clean and will likely be washed on the hospital ward.

It can be tricky to keep a child happy, entertained and positive when they have to stay in one room for a long period of time. It can be tricky for *adults* to stay happy, entertained and positive!

Hopefully you'll have made a good list above full of things to keep you and your child busy. But it can also help to go over the rules and why they are important. This can help with their understanding and them feeling more in control.

In their **Having my stem cell transplant booklet**, we ask your child to design some safety signs that could be displayed in the hospital. This can make isolation even seem fun!



You can read more about the isolation period at: **[anthonymolan.org/Isolation](http://anthonymolan.org/Isolation)** or in our booklet: **Preparing for hospital isolation**

# Side effects



Rupert in hospital during his treatment for myelodysplasia with monosomy 7

It is likely that your child will experience some side effects after their conditioning therapy and stem cell transplant. Some side effects happen early on, and some might not for a while after.

We have summarised some of the most common side effects your child could experience here. It's unlikely that your child will experience all of them, but they might have to cope with more than one at once, especially during early recovery.



***Side effects are inevitable. Make sure you don't assume any initial side effects are signs regarding your child's future. It can be easy to get caught up in them but there are so many ups and downs. It's common.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

## **Nausea and vomiting**

Many children are either sick or feel sick for a week or two after their transplant. This can be due to their conditioning therapy, an infection or the medication they're taking.

Changes to their diet or anti-sickness drugs can be given to relieve the symptoms. Sipping water or isotonic drinks will help keep your child hydrated and replace lost salts and sugars that cells need to stay healthy.

## **Diarrhoea**

Diarrhoea (runny poo) can affect how we absorb vitamins and minerals from our food, leading to weight loss, if it happens for a long time. Medication is available to relieve diarrhoea but changes to your child's diet may also be needed.

Diarrhoea can be upsetting and embarrassing for a young child to experience. They may need reassuring that it isn't their fault and that their medical team will make things better for them.

## **Sore mouth**

Chemotherapy can damage the cells in the mucosal lining of the mouth and throat, causing painful ulcers.

Your child could find it very difficult to swallow certain types of food. Softer foods like mashed potato and soup could be easier to eat. Ice lollies can help numb the pain and are a good way of taking on extra fluid.

It's important for your child to brush their teeth to keep their mouth healthy, even if it's sore. Using a soft toothbrush might help.





Dylan, who had a stem cell transplant to treat AML, enjoying some time with his sisters.



***Many of the drugs make them feel weird and can affect their mouths making eating difficult. You may need to help them with choosing from the available menu as some foods will be difficult to eat or swallow because of their texture.***

Dave, whose son Theo had a stem cell transplant to treat acute lymphoblastic leukaemia (ALL)

## Weight loss and feeding tubes

Your child's medical team may decide to give them a feeding tube if they're struggling to eat. Many children have them after transplant to prevent weight loss, so it's nothing to be concerned about.

Their food (nutrition) will be delivered as a liquid directly into their body. A dietician will decide on the best formula of nutrition to use depending on your child's condition and general health. The tube will probably stay in for a few weeks or until their condition improves.

There are two types of feeding tubes:

### Enteral nutrition

Nutrition is passed through a small tube directly into your child's stomach. This will most likely be inserted through their nose and down their throat. It will be fitted while your child is awake and doesn't require an anaesthetic. Some children get nervous about it being fitted but it won't hurt at all. They may experience some discomfort after it's fitted, which soon passes.

### Parenteral nutrition

Nutrition is delivered directly into the bloodstream through your child's central line. It will be given by a nurse who will then clean the line to reduce the risk of infection. This option is often used if your child finds it difficult to keep any food or drink down due to problems with their digestive tract.

If you have any questions about feeding tubes, please talk to your child's medical team. They will be able to give you specific information about your child's situation.

You can read more information about feeding tubes and diet after a stem cell transplant at:

**[anthonynolan.org/Diet](https://www.anthonynolan.org/Diet)**

## Graft versus host disease (GvHD)

Your child's new stem cells will create a new immune system for them. There will be small differences between their new immune system and existing cells in their body. This means that their new immune system may harm some of these cells because it sees them as 'different'. This is called GvHD.

Some GvHD can be a good thing because it means the new immune system is working and can remove any remaining or returning disease. However, too much GvHD can cause unwanted complications and side effects. It's difficult to predict who will get GvHD and the parts of the body it will affect.



***Zara started complaining of a lot of tummy pain and bleeding in her poos. The doctors did some tests and confirmed that she had gut GvHD. She's six months post-transplant now and she's still having treatment for the GvHD. She's just come off the really high-dose steroids and she's still having ECP (extracorporeal photopheresis).***

**Taruna, whose daughter Zara had a stem cell transplant to treat acute myeloid leukaemia (AML)**

Medication can be given to control the immune system and reduce the effects of GvHD. This is why your child will be monitored regularly for any changes to their symptoms.

You can read more about GvHD at:

**[anthynolan.org/GvHD](http://anthynolan.org/GvHD)** or in our booklet:

**Essential guide to graft versus host disease (GvHD).**

# Fatigue

Many children experience fatigue after their transplant. It's more than just feeling tired. Your child could often have very little energy, to the point where they struggle to get out of bed. They may also find it difficult to concentrate and have little motivation to do the things they like.

Fatigue can be a short-term effect caused by the conditioning therapy that improves after a few months. However, some people still experience it more than a year after transplant.

There may be times in your child's recovery when fatigue is unavoidable, but you can manage the situation so they can make the best of the energy they have.

You can read more about fatigue at: [anthonymolan.org/\*\*Fatigue\*\*](https://anthonymolan.org/Fatigue) or in our booklet: **Managing fatigue after a stem cell transplant**

It can be upsetting to watch your child deal with side effects. You can feel helpless and overwhelmed at times. Just being there for your child is the best thing you can do. You're the best person to comfort them and help them feel safe and secure.



Mason who had a stem cell transplant to treat JMML

## **Long-term impact**

There are some potential long-term consequences of stem cell transplant. It's important for you to have conversations about these consequences with your child's medical team as soon as possible.

Your child's immediate health and wellbeing is your primary concern, but these issues could have an impact on the choices they make in later life.

## **Will a transplant affect their development as they grow up?**

Conditioning therapy (see page 28) can affect your child's growth and delay puberty starting.

Their height and weight will be checked regularly in follow-up clinics in the years following transplant. This will help decide if medical intervention, such as hormone therapy, is needed.

The impact on their development could be greater if they also had total body irradiation (TBI) as part of their conditioning therapy.

## Will it affect their fertility?

Your child's treatment could make it difficult for them to get pregnant, or get someone else pregnant, when they're older. This will depend on things such as your child's age and the type of conditioning therapy they have. You can read lots more about this at:

[anthonymolan.org/Fertility](https://anthonymolan.org/Fertility)

Your child's fertility can be surreal and overwhelming to think about. It's understandable to have complex feelings about it. This is why it's important to ask all the questions you have to your child's medical team.

There are options for preserving your child's fertility, including:

- collecting and freezing sperm
- collecting and freezing eggs or ovarian tissue
- collecting testicular tissue, though this is an experimental treatment with no evidence of success.

The type of fertility preservation chosen will depend on many things, including whether your child has gone through puberty.

**Important:** Unfortunately, fertility preservation may not be possible at all. This is likely if your child needs to start treatment quickly, so there is little time to preserve their fertility. But it is still important to have conversations about their fertility with your child's medical team. Ask any questions and express any worries that you have.

## **Are there any other long-term complications?**

There is an increased risk of your child developing cancer in later life because of the conditioning therapy they have before their transplant. They will be invited to be screened for certain cancers and encouraged to check for any changes to their body regularly.

You can read more about possible late effects of a stem cell transplant at: [\*\*anthonynolan.org/LateEffects\*\*](https://www.anthonynolan.org/LateEffects)





Zara who had a stem cell transplant to treat acute myeloid leukaemia (AML)

# Preparing for their return home

You might feel lots of different emotions when your child is well enough to come home after their transplant.

It's a big milestone in their recovery and it should be a time of celebration. However, the prospect of taking on the day-to-day responsibility of looking after them can make it a daunting and stressful time too. This is totally normal.

Your child will still be vulnerable to infections, and at times could be very poorly, at this point in their recovery. You might want to wrap them in cotton wool forever so they're always safe. But it's about finding the right balance. You will need to be careful at times, but you need to be relaxed enough to allow your child, and the whole family, to enjoy life too.

This can feel overwhelming but we, and your child's medical team, are here to help. We've highlighted some areas below that are important to think about when putting a plan in place before your child comes home from hospital. They include:

- making your home a safe space, focusing on infection control
- your child's diet and food hygiene at home
- the importance of exercise
- tips for going out safely, while still having fun!



Ava who had a stem cell transplant to treat severe aplastic anaemia



***We were given day and overnight trials before we were officially discharged. This really helped our family get used to being together again, and helped us get used to new routines.***

Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)

## Your home

Your child will spend most of their time at home during their early recovery. It's important to keep things at home as normal as possible, while also making things safe.

Make sure you:

- regularly clean, vacuum and wipe surfaces with **anti-bacterial spray**
- clean surfaces in the kitchen **before and after preparing and cooking food**
- clean the **bathroom** often
- encourage everyone living at home to wash their hands regularly, especially after going to the bathroom and eating.

It's lovely for friends and family to come and visit. Here are some top tips for making sure these visits stay safe:

- Make sure people visiting understand the importance of infection control and what the risks are. Education is important and can help you feel understood.
- If someone is feeling unwell, even if they're just a bit snotty or have a cough, they should delay their visit. Video calls are still a great alternative.
- Have the confidence to put your foot down if you need to. It's your home, your family, and you're in control.

If you have a **pet**, your child should:

- definitely still play with them!
- help to take them for walks, if appropriate, as it's a great way to exercise
- avoid being licked
- wash their hands after touching them
- not clean up a pet's poo – they get a free pass from that job!

You can read more about infection control after a stem cell transplant at: [anthonynolan.org/Infection](https://www.anthonynolan.org/Infection)



## Food

Your child's dietary needs will change over time. You should initially focus on **preventing weight loss** and finding foods they can **eat easily**, and **enjoy!**

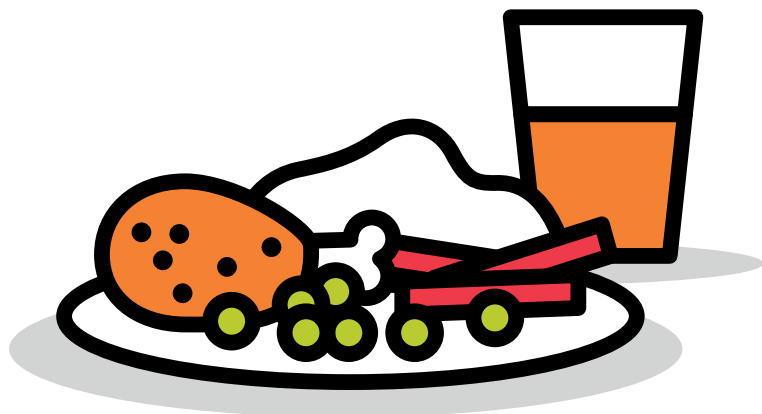
Read more about diet after a stem cell transplant at: [anthonymolan.org/Diet](https://anthonymolan.org/Diet)

As your child's recovery progresses, you can start to make their diet healthier. This will help their body repair and create new cells. Their medical team will guide you on the types of foods your child should eat.



***I believe that feeding my child the right nutrition allowed his body to be strong. Teddy would have always needed chemotherapy and a bone marrow transplant to cure him, but by fuelling his body with the right nutrition his recovery has been so much better. The body is a healing machine.***

Sarah, whose son Teddy had a stem cell transplant to treat acute myeloid leukaemia (AML)



It's important to be careful with the way you clean, store, prepare and cook food. It's impossible to remove all bacteria from food, but these food hygiene tips will help:

- Always **wash your hands and kitchenware**. Wipe down surfaces with disinfectant and **change dishcloths regularly**.
- Buy food in **smaller portioned containers**. They remain open for less time before being used up. It's also better to avoid **leftovers or re-heated food**, too.
- Stick to 'best before' and 'used by' food labels. **Never use anything that's out of date**.
- Only eat in restaurants or get takeaways from places you're familiar with and you know **have good hygiene standards**.
- **Wash all fruit and vegetables** before eating them.
- Make sure food is **cooked and heated properly**.
- **Avoid drinking tap water**. You'll be advised whether to use either bottled or boiled water.

You can read Children's Cancer and Leukaemia Group's booklet: **Helping your child to eat well during cancer treatment** for more information and tips. You can find this booklet at: [cclg.org.uk/publications/all-publications](https://www.cclg.org.uk/publications/all-publications)

## Going out

Leaving the house can be great for your child's wellbeing, but it comes with a higher infection risk.

- Avoid public transport and large crowds as much as possible.
- Your child will get tired more quickly. They might need more rests or extra time to do things.
- Encourage your child to wear a face covering when they're out of the house.

## Exercise

Keeping active is an important part of your child's recovery. It helps with fatigue, rebuilding strength and improving their balance. They don't have to join any clubs. Exercise can include free, simple, fun things, like:

- going for a walk in the countryside or to a local park
- dancing to their favourite music in the house
- games like hide and seek, obstacle courses or treasure hunts
- online videos of children's yoga, stretches or other meditation-based techniques.

Activities like visiting local playgrounds and joining sports clubs are possible but are better suited for later in their recovery. Your child can also start swimming once their central line is removed. If you have any questions about physical activity, please talk to a member of your child's medical team.



**Remember:** Your child may still pick up an infection or otherwise become unwell, despite your best efforts to protect them. If this happens, it isn't your fault so please try to not feel guilty.



***Everything had to be clean - really clean. We weren't even allowed to hammer a nail into the wall because the dust could cause a problem. He had to drink huge amounts of water but he wasn't allowed to drink tap water or bottled/mineral water. All his water had to be boiled and then cooled. We weren't allowed to go on holiday or see/stay with friends. Eventually Rupert was allowed one friend at a time to come and visit, but they had to be well. Rupert was also still feeling rubbish a lot of the time. However, we were home. We had our own beds, clothes, washing machine, iron, food in the fridge, cooker, and most importantly - we were together as a family.***

Holly, whose son Rupert had a stem cell transplant to treat myelodysplasia with monosomy 7



# Hospital visits after transplant



Rupert being visited in hospital by his brother Hector

Your child will have check-ups at the hospital after their transplant. These appointments are to make sure their new immune system is working properly and to treat any side effects.

Every child's recovery is different, which means they may need to see different members of hospital staff at different times. In general, you'll visit the hospital less and less over time.

## **Regular check-ups**

Your child will have one or two check-ups with their medical team every week during their early recovery. They will:

- assess your child's general health
- look for signs of infections or GvHD
- check on other side effects and possibly alter their medication
- test their blood to count their blood cells, and check their liver and kidneys are working well – your child may need a blood transfusion if their counts are low
- answer any questions or concerns you might have.

Some of these things might be carried out at home by a visiting community nurse.

## **Being referred to specialists**

Your child may be referred to specialist doctors who are experts in one treatment or part of the body. This often happens if they have GvHD that affects certain organs.

## Central line removal

Your child's central line is at risk of causing infection, so it will be removed when it's not needed. This is normally a few months after transplant. Removing it is normally done at the hospital using a local anaesthetic. It's another key moment in their recovery that can be celebrated!

## Donor lymphocyte infusion (DLI)

A DLI is a bit like a 'top up' blood transfusion that uses blood cells from their original donor. When the donor's T cells (a type of white blood cell) enter your child's blood stream, it starts an immune response. This should remove any remaining or returning abnormal cell causing their condition.

Not all patients will need a DLI. They're sometimes used when patients relapse, but they can be planned in the pre-transplant phase of treatment. Needing a DLI doesn't necessarily mean that the transplant has failed.

You can read more about DLIs at:

**[anthohnolan.org/DLI](http://anthohnolan.org/DLI)**

## Hospital readmission

Unfortunately, there are likely to be some setbacks during recovery and your child might need to spend some time back in hospital. This doesn't mean the transplant hasn't worked – it's a natural part of recovery that cannot always be avoided.



***There were plenty of hospital readmissions for both kids. It was frustrating but served a good purpose – to keep them safe while they were still recovering.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

Infection is common reason to be admitted back into hospital. You will need to know how to spot the early signs of an infection so your child can be treated as soon as possible:

- A temperature higher than 38°C or a temperature that rises or falls suddenly. Keep a thermometer (in good working order) at home and take their temperature regularly, especially if they're feeling unwell. Some painkillers and steroids can mask changes in temperature, so look out for other symptoms too.
- Chills, a fever, or no appetite for food or drink.
- Diarrhoea (runny poo) , frequent or painful weeing, blood in their wee or poo, or tummy pain and cramps.
- Severe tiredness, bleeding, coughing, shortness of breath, chest pain, or headaches.

**Important:** Please tell your child's medical team as soon as possible if you think your child may have an infection. You should have been given the details of someone on the medical team to contact. Don't worry if it turns out to be a false alarm. It's always better to have any concerns checked out as soon as they happen.

You can also visit your GP, but if things happen very quickly, you should go straight to A&E. It's also good to have a pre-packed hospital bag, just in case you need to grab it at short notice.



# Keeping track of their recovery

There's a lot to remember when your child goes through a stem cell transplant. You'll have to be aware of admin things like hospital appointments, medications and contact details, and more medical things like your child's diet and exercise advice, possible side effects and infection symptoms.

Keeping track of all these things can be a huge help, practically and mentally. It will allow you to see when things are not quite right so you can seek help, but it will also highlight when things are going well and the progress you have all made.



***We had a white board where we could keep track of medication and tick things off.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

We want to make this as easy as possible for all our patients and their carers. This is why we created **My Transplant Tracker**, our first mobile phone app. It allows you to record all aspects of recovery and set goals that you can work towards.

**My Transplant Tracker** can be downloaded for free from the Apple and Google Play stores – just search for ‘My Transplant Tracker’. You can find out more about the app at [anthonymolan.org/MyTransplantTracker](https://anthonymolan.org/MyTransplantTracker)



Your child can be involved with tracking their recovery in their **Coming home after my stem cell transplant** activity booklet. Hopefully engaging with their star chart will make recovery a bit more fun.



For some children, and their families, the Transplant Tracker app will come in handy



# Your child's education

Every child has a right to an education, and your child will continue to receive theirs during their recovery. A hospital teacher will introduce structured learning into their daily routine once they are well enough. These lessons will be gentle at first. They may simply listen to your child read. As your child gets stronger, lessons will become a bit more involved.

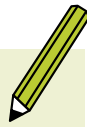
A tutor will be arranged to continue their schooling at home once they leave hospital. The hospital teacher will talk to your child's teachers at school to make sure they're being taught the same topics as their classmates. This will make the return to school easier.

You, or another family member, might be able to help with some teaching, too. If you talk to their teacher, they might be able to give you some work you can do together.

## Returning to school

This is a big milestone in your child's recovery! It signifies the return to a 'new normal' for them and your family.

You may need to be mindful of how your child feels about their return. It's probably been a long time since they saw their friends or teachers, which could make them anxious or nervous. They could be worried about how people are going react.



Your child's booklet **Coming home after my stem cell transplant** encourages them to talk their feelings with you. It also asks them to think about how they will talk about their recovery when they are at school.

Going back to school will have an impact on your child's energy levels and it's recommended that they have a phased return. This might mean they only go for a few half-days a week at first, and then build up gradually until they can attend full time.



***We had plenty of discussions with the school beforehand and a letter was sent out to parents. This explained our children's health issues and reiterated to parents to keep their children off school if they were poorly. Our community nurse also visited the school to show staff how to deal with a central line and feeding tube. This was really comforting and helpful for everyone.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

## Extra support

Your child's school may not have a good understanding of stem cell transplants and the impact it can have on a child's long-term recovery. This could lead to teachers having unrealistic expectations of your child's energy levels and ability to concentrate in class.

It's a good idea to regularly update the school on your child's progress, both before and after their return. This can help them to understand a bit better.

If you think your child would benefit from extra support, ask for the school's help. Often schools are more than happy to help wherever they can, but they may need your direction on how to do it. You could even give them this booklet to help their understanding.

You can read more about returning to education at:

**[anthonynolan.org/ReturningToEducation](https://anthonynolan.org/ReturningToEducation)**

# Looking after your family's mental health

Your child's transplant will probably be one of the most challenging experiences that you and your family ever face.

There is no right or wrong way to feel about what you're going through. Everyone's transplant journey is unique. There will be highs and lows that impact on your mental health. It's important to be prepared for them by knowing where to get support when you need it.

You can read more about this, and find more support, in the 'Mind' section at [anthonymolan.org/Recovery](https://anthonymolan.org/Recovery) or in our booklet: **Your mental health and stem cell transplant.**



***Both Rupert and I tried to make things light-hearted and see the funny side of things - like when he had jaundice and called himself a 'yellow banana alien', we laughed! Funnily enough, Rupert says he remembers the good things in hospital, the funny times and the amazing doctors and nurses. Families in hospital support each other, too. You can share tips - what worked for you, what didn't. Simple things.***

**Holly, whose son Rupert had a stem cell transplant to treat myelodysplasia with monosomy 7**

## Supporting your child

How your child is feeling and coping mentally with their transplant will likely change throughout their treatment and recovery. It will also depend on their age and ultimately their personality and environment.



***Their personality and temperament were indications of how well they coped emotionally during and after transplant. Letters from home and school, as well as videos really helped them feel connected to family and friends.***

**Rachelle, whose children Emma and James both had stem cell transplants**

You know your child best and will be the best person to spot the signs of them struggling. Try to not project your own feelings on to your child. Let them feel however they are they feeling – good or bad.

Your child's medical team will monitor their mental health in the same way as their physical health. Your child should have access to a play therapist and/or a child psychologist, but this will vary between hospitals.



***We had an amazing community play worker that came over regularly. She gave the children a great hour of fun and also gave me a valued, listening ear. She really helped to bridge that personal and clinical gap.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

It's important for you to monitor your child's mood and spot any changes when they come home. Are there times when they don't act like their usual self? It could be that they just need some loving reassurance or distraction. However, there could be times when it's appropriate to seek professional support. Have the confidence to ask for extra help, either from your GP or someone at the hospital. They will be able to refer you to right person. The charities Young Lives vs Cancer, Macmillan and Maggie's can also provide advice and support.

## **Supporting yourself**

Your child is your priority. You'll put their needs first. But you'll feel able to support them much better if you're looking after yourself, too. There are lots of people who can support you and your family. Please take advantage of them, whether you feel like you're struggling or not.

We've given some tips in this section, but if you're struggling, please talk to your GP or someone in your child's medical team. They will be able to refer you for some talking therapy.

### **Telephone Emotional Support Service (TESS)**

TESS is our emotional support service provided by Working 2 Wellbeing. You can have free sessions with trained professionals who have years of experience supporting people who have had a stem cell transplant and their families. Find out more at:

**[anthonymolan.org/TESS](http://anthonymolan.org/TESS)**



***I'm having therapy. For me, it wasn't suitable during the transplant process, because it felt like too much. But now we're further along, I'm able to focus on my recovery. Therapy helps, and I also focus a lot on my own nutrition as well as Teddy's. Good sleep helps, so does the Headspace app and I also do freewriting. I use these things whenever I need them. Different things work for different people.***

**Sarah, whose son Teddy had a stem cell transplant to treat acute myeloid leukaemia (AML) In person**

Maggie's and Macmillan provide purpose-built centres at some hospitals. They offer free emotional, practical, and financial support to people looking after someone having cancer treatment. Your hospital or local charities may run support groups that you can attend, too.

Even simply talking to other parents on the ward about what you're all going through will give you support. It can be comforting to know you're not alone during this difficult time.

## **Online**

You can share whatever's on your mind on our Patients and Families Forum: [anthonymolan.org/Forum](https://anthonymolan.org/Forum)

The Macmillan forum also has a page dedicated to parents of children with cancer: [community.macmillan.org.uk](https://community.macmillan.org.uk)

## Supporting your child's siblings

This can be a worrying and confusing time for any of your child's brothers and sisters. They might feel:

- anxious about their brother or sister being unwell
- unsettled by any changes in routine
- left out if there is more attention on their brother or sister
- confused if they don't understand their brother or sister's diagnosis, or what a stem cell transplant is.

These feelings could be particularly strong if they donated their own stem cells. They may feel guilty or responsible – especially when their sibling looks unwell. If they were unable to donate, they could be feeling disappointed, frustrated or even angry that they were not able to help.

Don't be too surprised if there is a change in their behaviour. They might become more needy and want more of your attention. It could also lead to more challenging or disruptive behaviour. Although this can be difficult, try to remember it's their natural reaction to a very stressful situation. Be aware of their feelings and talk to them about what's on their mind.



To make sure they feel involved, you could:

- Regularly check in with them about what's going on and encourage them to ask questions. They might not have the confidence to say they don't understand aspects of their sibling's treatment.
- Ask them to draw pictures or other crafts to help decorate their sibling's hospital room.
- Record video messages and take photos to show their sibling when you visit.
- When their sibling is back home let them take part in activities like preparing meals, cleaning or exercise. It will help them feel part of the recovery.

We've recommended some books on page 76 which may be helpful to read with your other children, if appropriate.



***My little highlight of the hospital day was to get outside, go for a quick coffee, go to the supermarket and buy something. I even managed to go out for a glass of wine with the mum next door to me. It was warm and we sat in the pub outside and pretended we were on holiday.***

**Holly, whose son Rupert had a stem cell transplant to treat myelodysplasia with monosomy 7**

## Accepting help

If people offer to help but you don't know what to say, these suggestions might come in useful:

**Childcare** – Could someone take charge of the school run or be on standby in case there's an emergency?

**Pets** – Ask if they wouldn't mind popping in to feed your pets or taking them for a walk.

**Batch cooking** – Having a freezer full of prepared meals comes in handy when you don't have time or energy to cook yourself.

**Housework** – Making sure your house is clean can help reduce the risk of spreading infections.

## Work and finances

Your child's stem cell transplant is also likely to have a big impact on your financial situation and you will likely need to take time off work to look after them. Depending on where you work, you may be able to take a period of paid leave. It's advisable to talk to someone in your HR department as soon as possible to see how they can support you during this time.

You may be able to access certain benefits provided by the government such as Carer's Allowance.

You can read more of our information about financial support, including how to access an Anthony Nolan Grant, at: [anthonynolan.org/ManagingFinances](https://www.anthonynolan.org/ManagingFinances)

# Caring for yourself

Your child will understandably be nervous about what they're going through. They will look to you for support and reassurance that nobody else can give them. So, you need to make sure you're looking after yourself both physically and mentally. It's OK to allow yourself some 'me' time.

This might be simply phoning a friend for a chat or re-starting a forgotten hobby. It will reinvigorate you and give you fresh energy to tackle the challenges ahead.



***Even little chats mean a lot. You'll probably feel socially overwhelmed but connection is good for the soul. Don't put pressure on yourself to be on peak social form but just enjoy the company. Go easy on yourself.***

**Minou, whose children Charlie and Zoe had stem cell transplants to treat familial monosomy 7 and myelodysplastic syndromes (MDS)**

Alongside eating healthily and sleeping well, try to get a support network of friends and family in place to help you when you need it. Make sure there are people you can talk to about your situation and how you're coping, or who can take your mind off things. Don't feel guilty about laughing and forgetting about your stresses for a short time.

# Recommended resources

## Books and booklets

### **Olly the Brave**

[mollyolly.co.uk/olly-the-brave-pack](http://mollyolly.co.uk/olly-the-brave-pack)

Charity Molly Ollys has produced six books for children who have a life-threatening illness. They are sensitively written and cover topics like chemotherapy, having a central line, and going back to school.

### **Anna loses her hair and Ruby's stem cell harvest and transplant**

[cclg.org.uk/publications/all-publications/](http://cclg.org.uk/publications/all-publications/)

Two story books from Children's Cancer and Leukaemia Group that tell the story of children who all lose their hair while having treatment for cancer, and a child having an autologous stem cell transplant (using her own stem cells).

### **Children and Young People with Cancer: A Parent's Guide and Helping your child to eat well during cancer treatment**

Two guides from Children's Cancer and Leukaemia Group that support parents with children going through cancer treatment. You can find lots of other booklets which may be helpful on their website.

## **My child has cancer. What now? A guide for parents and carers**

**[publications.younglivesvscancer.org.uk/products/what-now](https://publications.younglivesvscancer.org.uk/products/what-now)**

This is a guide from Young Lives vs Cancer for parents of children aged 0-15 who have just been diagnosed with cancer.

## **Apps**

### **Hospichill**

**[hospichill.net](https://hospichill.net)**

Helps you prepare for hospital and clinic appointments by teaching you relaxation skills.

### **Smiling Mind**

**[smilingmind.com.au/smiling-mind-app](https://smilingmind.com.au/smiling-mind-app)**

Developed by psychologists to give 10 minute daily mindfulness exercises.

### **Headspace**

**[headspace.com](https://headspace.com)**

Guided meditation to live a healthier, happier, more well-rested life.

# Getting support

## Anthony Nolan contact details

### Where can I get more information and support?

If you or a loved one is affected by a stem cell transplant, there are many ways we can support you:

#### Need to talk?

The Patient Services team at Anthony Nolan is here for you. Call us on **0303 303 0303** or email **[patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org)**

#### Get connected

Find support from other patients and their families by joining our Patient and Families Forum at **[anthonymolan.org/forum](https://anthonymolan.org/forum)**

#### Find information

Our website has lots of helpful information about what it's like to go through a transplant. Download or order our booklets for free, and find links to other places where you can get support at **[anthonymolan.org/patientinfo](https://anthonymolan.org/patientinfo)**

#### My child has cancer. What now? A guide for parents and carers

**[publications.younglivesvscancer.org.uk/products/what-now](https://publications.younglivesvscancer.org.uk/products/what-now)**

This is a guide from Young Lives vs Cancer for parents of children aged 0-15 who have just been diagnosed with cancer.

# Other organisations that can help

## **Blood Cancer UK**

**[bloodcancer.org.uk](http://bloodcancer.org.uk)**

**0808 2080 888**

Information about all types of blood cancer including leukaemia, lymphoma and myeloma.

## **British Association for Counselling and Psychotherapy**

**[bacp.co.uk](http://bacp.co.uk)**

**01455 88 33 00**

Information about counselling and therapists in your area.

## **Carers UK Advice**

**[carersuk.org](http://carersuk.org)**

**0808 808 7777**

Information and support for people looking after their loved ones.

## **Children With Cancer UK**

**[childrenwithcancer.org.uk](http://childrenwithcancer.org.uk)**

**0800 222 9000**

Provides information on childhood cancers, as well as practical support like fun days and holidays for children with cancer.

## **Citizens Advice**

**[citizensadvice.org.uk](http://citizensadvice.org.uk)**

**0800 144 8848** (England) **0800 702 2020** (Wales)

Advice on a wide range of issues, including financial and legal matters.

## **Contact**

**[contact.org.uk](http://contact.org.uk)**

**0808 808 3555**

Advice and support for parents of children with health problems or disabilities, including information on benefits and services you are entitled to. They also have local support centres.

## **Gene People**

**[genepeople.org.uk](http://genepeople.org.uk)**

**0800 987 8987**

Support for people affected by genetic disorders and their families.

## **GOV.UK**

**[gov.uk](http://gov.uk)**

Information about UK government services, including benefits, employment and money matters.

## **NHS Talking Therapies**

**[nhs.uk/talkingtherapies](http://nhs.uk/talkingtherapies)**

Enables patients to self-refer to NHS-funded counselling and therapy services available in their local area.



**Little Princess Trust**  
**littleprincesses.org.uk**

**01432 760060**

Provides real hair wigs, free of charge, to patients who have lost their hair due to cancer treatment or other illnesses.

**Macmillan Cancer Support**  
**macmillan.org.uk**

**0808 808 00 00**

Practical, financial and emotional support for people with cancer, their family and friends.

**Maggie's**  
**maggies.org**

**0300 123 1801**

A network of drop-in centres for cancer information and support. Includes an online support group.

**The Mental Health Foundation**  
**mentalhealth.org.uk**

Provides information on mental health, including mindfulness and mindfulness meditation.

**Mind**  
**mind.org.uk**

**0300 123 3393**

Mental health charity which offers information, advice and support to anyone going through stressful situations or experiencing a mental health problem.

## **NHS Choices**

**[nhs.uk](https://www.nhs.uk)**

**111 (999 in an emergency)**

Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

## **Rainbow Trust**

**[rainbowtrust.org.uk](https://www.rainbowtrust.org.uk)**

**01372 363438**

Support for families of children with life threatening illnesses.

## **Samaritans**

**[samaritans.org](https://www.samaritans.org)**

**116 123**

The Samaritans are available 24 hours a day to listen and provide help for any problem you would like to talk about.

## **Turn2us**

**[turn2us.org.uk](https://www.turn2us.org.uk)**

Provides help with accessing money that's available through benefits, grants and other support.

## **Young Lives vs Cancer**

**[younglivesvscancer.org.uk](https://www.younglivesvscancer.org.uk)**

**0300 303 5220**

Offers a range of services for children affected by cancer and their families, including a helpline for emotional support and practical advice.

**ANTHONY  
NOLAN**

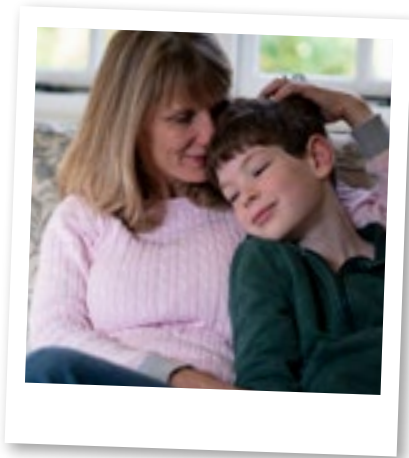
saving the lives  
of people with  
blood cancer

**ANTHONY NOLAN**  
PATIENT SERVICES



***People say, “Wow, you’re amazing,” but you have two options: you can think, “Oh, my poor baby, why has this happened?” or you can think: “Right, let’s get this done.***

Holly, whose son Rupert had a stem cell transplant to treat myelodysplasia with monosomy 7



Patient Information Forum

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[anthonymolan.org/patientinfo](https://anthonymolan.org/patientinfo)

[facebook.com/anthonymolanpatients](https://facebook.com/anthonymolanpatients)

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