

HELPING YOUR CHILD THROUGH THEIR STEM CELL TRANSPLANT



ANTHONY
NOLAN

saving the lives
of people with
blood cancer



HELPING YOUR CHILD THROUGH THEIR STEM CELL TRANSPLANT

© Anthony Nolan 2020

All rights reserved. No part of this publication may be reproduced or transmitted without permission in writing from Anthony Nolan.

All trademarks and brand names referred to are acknowledged as belonging to their respective owners.

If you have any questions or comments about this resource, or would like information on the evidence used to produce it, please email: patientinfo@anthodynolan.org

The information contained in this booklet is correct at the time of going to print (August 2020). We plan to review this publication within three years. For updates or the latest information, visit anthodynolan.org

Anthony Nolan is a registered charity, No 803716/SC038827

This publication was reviewed by:
Dr Helen Broome, Clinical Psychologist, Stem Cell Transplant Team, Royal Hospital for Children, Queen Elizabeth University Hospital, Glasgow; Emma Briggs, Class Teacher, St Martin de Porres Catholic Primary School, Luton; Julie Kay, Home and Hospital Teacher (retired), Ethos PRU, Kirklees; Anthony Nolan Patients and Family Panel.

Author: Jonathan Kay

Editors: Tom Bishop, Anya Muir Wood

Design: Jamie Cross, Horacio Herrera-Richmond

Illustration: Spencer Wilson



saving the lives
of people with
blood cancer

ANTHONY NOLAN
PATIENT SERVICES

WHAT'S IN THIS BOOKLET?

We've produced this booklet for anybody with 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 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'RE HERE FOR YOU

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 are 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@anthonymolan.org or on 0303 303 0303

CONTENTS

Key facts	7
Talking to your child	8
Understanding stem cell transplants	10
Preparing for transplant	14
Pre-transplant treatment	22
Transplant day	24
Staying in isolation	26
Side effects	28
Preparing for their return home	33
Hospital visits	38
Keeping track of their recovery	42
Your child's education	44
Looking after your family's mental health	46
Caring for yourself	51
Recommended resources and sources of help	53
Getting support	55

KEY FACTS

- Your child needs a stem cell transplant to treat their blood cancer or blood disorder. The cells will be donated by a family member or unrelated donor with a matching tissue type.
- After their transplant, your child will spend a few weeks in protective isolation. 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 all aid 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.
- Talk to your child about what's going to happen. You can decide how much you want to tell them, but encourage them to ask questions and check in with them to see how they're coping.
- Take time to acknowledge your own needs. Caring for your child will be difficult at times, but you need to make sure you're looking after yourself as well.

TALKING TO YOUR CHILD

You may have just been told your child needs a stem cell transplant to treat their blood cancer or blood disorder. No doubt you will have many thoughts running through your head right now. You might feel relieved at the thought of a possible cure or effective treatment, but also worried about what your child will go through and how you will all cope. This might feel very overwhelming right now, but at Anthony Nolan we're here for you every step of the way.

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 and you will need time to digest all the facts before making your mind up. Your child's medical team will talk you through all the possible options and highlight any advantages and disadvantages. It can be a lot to take in, so write down as much information as you need. Don't be afraid to ask questions more than once if you haven't fully understood. It's an extremely stressful time for you and the team will understand.

'We found the more we asked the more we were told. I don't think they wanted to worry us unless we had something to worry about.'

Alex, whose son Samuel had a stem cell transplant.

Only you can decide what to tell your child about their situation. Some parents are very open and honest, while others prefer to shield them as much as possible by telling them very little. You can decide how much you want to tell them, but encourage them to ask questions and check in with them to see how they're coping. You know your child better than anybody and what's best for them. This is why we won't tell you what you should or shouldn't say to them.

This booklet is intended as an aid to your discussions with them by informing you of what is likely to happen. It will hopefully give you the confidence to answer any difficult questions they might ask about their transplant. Where it does make suggestions, please only use them if you think they're appropriate and helpful.

'We didn't even know what a transplant was. We didn't know whether to be happy or sad, worried or excited.'

Lee, whose daughter Rebecca had a stem cell transplant.

UNDERSTANDING STEM CELL TRANSPLANTS

WHY DOES MY CHILD NEED A TRANSPLANT?

Our blood is made up of different cell types including red blood cells for carrying oxygen, platelets to help blood clot and white blood cells that fight infections. They all originally come from stem cells that live in the spongy tissue inside our bones called bone marrow. Stem cells are our body's building blocks. As they divide and mature, they develop into other types of blood cells.

Our blood stem cells need to produce exactly the right amount of each type of blood cell. If your child has a blood cancer or blood disorder, there's likely to be a problem with this carefully-controlled process. Their body will either not make enough blood cells or produce large numbers of immature blood cells that can't do their job properly. These cells also 'clog up' the bone marrow, which stops other blood cells doing their job too. This can lead to symptoms such as extreme tiredness, regular infections, pain or swelling.

WHAT IS A STEM CELL TRANSPLANT?

Stem cell transplants are a possible treatment for children and adults who have a blood cancer or blood disorder. However, other options, such as radiotherapy or chemotherapy, may be considered first. Your child may have already been given these treatments and a transplant is now being considered because unfortunately, they haven't worked. Your child's consultant will talk to you about the best option for them.

If the transplant goes ahead, your child will receive their new stem cells from a willing donor. When the stem cells enter their blood, they will move 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.

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.

FINDING A MATCH

When your child needs an allogeneic transplant, they will need a donor whose tissue type matches their own. The search will begin with someone at the hospital taking a small blood sample from your child. This will be used to determine their tissue type. If they have any 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. Usually, wider family and friends will not be tested, as it's very unlikely they will be a match.

If that is unsuccessful, the hospital or transplant centre will contact Anthony Nolan. We will search all the possible donors in the UK to find the best match. If necessary, we will look for possible donors on registries from across the world. We can also check for cord blood matches in our cord bank.

WHAT WE LOOK FOR

Matching is based on our human leukocyte antigen (HLA) tissue type. Our HLA is part of what makes us all unique – our individual genetic characteristics.

Our HLA type is made up of hundreds of genes, of which five are important when finding a match*. Each one has two different versions (called alleles) making 10 in total. We inherit one version from our mother and one from our father. When it comes to matching with a donor, if nine match up it's called a 9/10 match. If all 10 match it's a 10/10 match.

The team at Anthony Nolan will try to find the best possible match, because it gives your child's body the best possible chance of accepting their donor's stem cells.

We also test to see if your child is positive for cytomegalovirus (or CMV for short) – a very common virus that often has no side effects. Ideally, we want to find a donor who tests the same for this virus as your child does. There is now growing evidence that when a patient and donor have matched CMV status, it helps improve transplant success.

Finally, we consider the donor's age too. This is because our latest research has confirmed that transplants are generally more successful when younger donors are selected.

For more information on the different types of stem cell transplant and how we find a match, visit anththonolan.org/understanding

* You may hear the term 12/12 being used as well. This is because recent research has shown the importance of a 6th HLA gene when matching donors to patients. However, the principle is the same: when it comes to finding a match, the higher the better.

PREPARING FOR TRANSPLANT

Once a potential donor has been found for your child, it will take some time to organise the collection and delivery of their stem cells. During this time, the medical team will make sure your child is ready for their transplant as well. Now is also a good time for you to prepare yourself for the challenges that lie ahead by putting some practical plans in place.

Many parents worry about who will look after everyone else while their child is in hospital. You will probably need the support of friends and family, so have the confidence to ask them. You might find people are more than happy to help, but are unsure how to. By asking for specific things – like driving you to appointments, housework or picking up your children from school – you will get the help that you need most.

PRE-TRANSPLANT CHECKS

Your child will have some 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.

- A bone marrow biopsy and/or CT-PET scan to confirm their condition is stable.
- Electrocardiogram (ECG) to check the rhythm and electrical activity of their heart.

- 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.
- They will also need to visit the dentist. Problems with their teeth or gums could become a source of infection after transplant, so it's important to go for a check-up.

There's nothing to worry about if they don't have every test listed here – their consultant will decide which checks are necessary for the transplant to go ahead.

PLAN A VISIT

Find out if it's possible to visit one of the isolation units before your stay. It will help you visualise 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 their 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. Our booklet *Preparing for hospital isolation* has further information and advice.

PACKING THEIR HOSPITAL BAG

There might not be much time between your child being diagnosed and the start of their hospital treatment. This can be a very intense and hectic time, so it might be better to pack a hospital bag in preparation. Here's a handy list of things you might want to pack. Your child has been asked to write their own list in their activity booklet, but you might find these suggestions more practical.

If you get a chance, tell a family member or friend where you keep your spare 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 button-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 the hospital room can get very warm.
- Plenty of sleepwear, 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.

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.
- 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.

Things to keep them 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.

LONG-TERM IMPACT

There are some potential long-term consequences of stem cell transplant that, as parents, you may want to consider for your child before treatment starts. Obviously, their immediate health and wellbeing needs to be your primary concern right now, but these issues could have an impact on the choices they make in later life. You will always be able to discuss the options with the medical team before making any decisions.

Will it affect their development as they grow up?

The conditioning therapy (see page 10 of *Having My Stem Cell Transplant*) your child has before their transplant could affect the rate at which they grow and delay the onset of puberty. Their height and weight will be monitored at regular intervals in follow up clinics in the years post-transplant. This is done to 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 as part of their conditioning therapy.

Will it affect their fertility?

Although many child patients are able to have children in later life, your child's treatment could make it difficult for them to conceive naturally when they're older. Even if they encounter problems, steps can be taken now to help them in the future. Reproductive tissue can be collected and frozen from girls to be used as part of fertility treatment in later life. It's also possible to do this for boys, however research is still ongoing to work out how it can be used to conceive.

Unfortunately, depending on your situation, the medical team may decide that treatment must begin straight away and options to preserve fertility might not be possible.

Will there be any other long-term complications?

There's 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.

More information on other late effects, which could affect some stem cell transplant recipients, is available on our website: anthonymolan.org/late-effects.

PRE-TRANSPLANT TREATMENT

CENTRAL LINE

Shortly before treatment is due to start, your child will be fitted with a central line. It's a thin tube that goes through the skin near their collarbone and into the vein that flows into their heart. It might sound scary, but it allows the nurses and doctors to take blood samples, deliver treatments and the stem cells themselves without using a needle every time. It will be fitted under general anaesthetic at the hospital and your child may need to stay in overnight to check that everything is ok.

Central lines can be a source of infection if they aren't kept clean. The medical team will advise you on 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

Before the transplant happens, your child will stay in hospital for a course of treatment called conditioning therapy. It will last for a week or two 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.

The 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 (or 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 26** for more details). This is distressing for most parents and can leave them feeling helpless. Most side effects only last a few weeks and the medical team will be on hand to treat the symptoms. It's better to focus on the importance of this treatment though, and how it will benefit your child in the long term.

It's very likely that conditioning therapy will lead to your child losing their hair over the next few weeks. This can make children self-conscious of their appearance, so it's better to address the situation early – so they can get used to the idea. They will be given the option to wear a wig at the hospital if they want, but they may need to wear a hat or head scarf to protect their skin from the cold or direct sun. The *Having my stem cell transplant* activity book introduces these ideas to your child and shows them that it's something that affects everyone.

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 anti-histamine 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 in the same way as 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 your hard work and emotion has gone into making this day possible.

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 two to three 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 it has started.

During this time, your child might need blood and platelet transfusions a few times a week. This is to help 'top up' their red blood cells, which may also be low. It's a normal part of recovery and doesn't mean the transplant isn't working. However, if you have concerns, you should talk to the medical team.

STAYING IN ISOLATION

Your child will be moved into their own protective isolation room on the day of their transplant, if not before.

It will take some time for their new stem cells to start making new blood cells, including white blood cells that fight infections. This means they're at a higher risk of becoming unwell. The isolation room is specially designed to create a germ-free environment, where the risk of picking up an infection is very low.

In the first few weeks, restrictions will be put in place to limit the spread of germs into the room. The rules vary in each hospital, so please check what you can and can't do, with the hospital staff. In general, restrictions involve wearing protective clothing, washing hands with sanitiser and keeping surfaces and items clean. As their carer, you can always stay with them in their room, 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.

'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.

To help your child understand the importance of these rules, the *Having my stem cell transplant* activity book asks them to design some safety signs that could be displayed in the hospital. Talking to them about their ideas and making some suggestions is a good way to reinforce these rules and improve their understanding.

Your child's isolation room will be their home from home, so it's a good idea to make it feel as familiar as possible. They will be able to take in their own possessions and items such as electronic tablets to help occupy their time. You might also want to get some pictures of family, friends or even pets to put up too, so they feel more connected to the outside world.

'We felt it was really important to make it his space – not just a hospital room.'

Nicola, whose son **Jackson** had a stem cell transplant.

Our *Preparing for Hospital Isolation* booklet contains more information on staying in isolation and suggests ways to cope during what can be a difficult time.

SIDE EFFECTS

The conditioning therapy and transplant are both physically and emotionally demanding. Unfortunately, they will cause some side effects that can be difficult to cope with.

As a parent, it can be heartbreaking to watch your child go through illness like this. Although you might feel completely helpless at times, just being there to support your child will give them comfort like nobody else can. It will help them feel safe and secure during this challenging time.

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.

Nausea and vomiting

Many children are either sick or feel sick for a week or two after their transplant for a variety of reasons including 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.

Sore mouth

Chemotherapy can damage the cells in the mucosal lining of the mouth and throat, causing painful ulcers to form. If this occurs, 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.

It's also important to practice good oral hygiene after transplant. Using a soft toothbrush might help your child if they have sore gums. Ice lollies can help numb the pain and are a good way of taking on extra fluid.

Diarrhoea

As with nausea, diarrhoea can have many different causes. If it happens for a long time it can affect how we absorb vitamins and minerals from our food, leading to weight loss. 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 medical staff will make things better for them.

WEIGHT LOSS AND FEEDING TUBES

The medical team may decide to give your child a feeding tube to avoid unnecessary sickness and diarrhoea. It's nothing to be concerned about and many children have them after transplant to prevent weight loss. 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

When 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 the medical team. They will be able to give you specific information about your child's situation.

GRAFT VERSUS HOST DISEASE (GvHD)

After the transplant, the donor's stem cells will form a new immune system for your child. It will keep their body safe from infections caused by bacteria and viruses. However, there will be small differences between their immune system and other cells in their body. As a result, the immune cells 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. 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.

More information and support on how to manage GvHD is available in our *Essential Guide to GvHD* booklet.

PREPARING FOR THEIR RETURN HOME

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 enjoy.

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. More information on the causes of fatigue and how to come to terms with it is available in our *Managing Fatigue After a Stem Cell Transplant* booklet and audio guide.

OTHER SIDE EFFECTS

Some children will develop other complications such as liver and kidney problems, but they are less common.

More information is available in our guide
The Seven Steps: The Next Steps.

Many parents experience a wide range of emotions when their child is well enough to return home. It's a big milestone in their recovery and it should be a time of celebration for everyone. However, the prospect of taking on the day-to-day responsibility of looking after them can make it a daunting and stressful time too.

'In hindsight, the hospital stay and transplant were the easy bits!'

Naomi, whose daughter **Esme** had a stem cell transplant.

At this stage, your child will still be vulnerable to infections and at times could be very poorly. Instinctively you might want to wrap them in cotton wool forever so they're always safe, but this is often impractical. 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 whole family to enjoy life too.

Many of the things you will need to consider focus on infection control, but eating healthily and exercising regularly are important too. It's a good idea to put a plan in place before your child comes home. Setting your own ground rules, that everyone agrees to follow, will give you control of your situation. You can decide on the level of stringency you're comfortable with. Bear in mind though,

that it's impossible to remove all risk and your child may become ill at some point. It won't have been because of anything you did wrong – unfortunately sometimes it just happens.

To help get your plans in place, we have highlighted some of the important areas to think about. You should also talk things through with your child, so they understand the importance of them too.

'The transplant was tough, going home was even harder. But every day we get a bit stronger.'

Carla, whose daughter **Rebecca** had a stem cell transplant.

YOUR HOME

This is where your child will spend most of their time during their early recovery, it's also where you will have the most control. Regularly cleaning, vacuuming and wiping surfaces with anti-bacterial spray will all help reduce the chance of infection spreading. This is particularly important in the kitchen before and after food is prepared and in the bathroom.

When people come to visit you will need to make sure they understand the importance of infection control. If they are feeling under the weather at all, they should delay their visit until they're feeling better. It might not seem like a big concern to them, but passing on a bug or virus to your child could have a huge impact on their

wellbeing. Have the confidence to put your foot down if you need to and explain how important it is.

You shouldn't be too concerned if you have a pet. Interacting with pets is a great source of joy for many children and taking them for walks is a good way to exercise too. However, you do need to be careful. Your child should always avoid being licked and wash their hands after touching them.

FOOD

Your child's dietary needs will change over time. Once their feeding tube has been removed, the focus needs to be on preventing weight loss and finding foods they can eat easily. During this time, their body needs more energy and nutrients to repair and create new cells. As their recovery progresses, you can start to make their diet healthier, which will help in the long term. The medical team will guide you on the types of foods your child should eat.

It's impossible to remove all bacteria from food, but being careful with the way you clean, store, prepare and cook food reduces the risk of infection. The following tips are a good start to improving and maintaining food hygiene:

- 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 'use 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.
- Drink bottled water rather than tap water.

The Cancer and Leukaemia Group's (CCLG) booklet: *Helping Your Child To Eat*, contains information and handy tips about your child's diet after cancer treatment.

GOING OUT

Visiting busy places and travelling on public transport both increase the risk of catching infections from other people. If possible, these activities should both be kept to a minimum. You might also find your child tires easily, so try to plan your outings accordingly. They might need more rests, or you might need to allow more time to do things while you're out and about.

EXERCISE

Keeping active is a key part of your child's recovery that will benefit them both physically and mentally. It helps to combat fatigue, rebuild strength and improve their balance. You don't have to introduce anything specific, like organised sport, there are plenty of fun things you can do together.

You may want to consider the following

- Going for a walk in the countryside or to a local park.
- Dancing to their favourite music in the house.
- Organise 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 sports are possible, but are better suited for later in their recovery. Your child can also start swimming again once their central line is removed. If you have any concerns regarding physical activity, please talk to a member of the medical team, they will be happy to help.

HOSPITAL VISITS

The medical team will continue to check on your child's recovery to make sure their new immune system is working properly and to treat any ongoing side effects. Every child's recovery is different, which means they may need to see different members of hospital staff at various times. In general, the number and frequency of these visits will decrease over time.

REGULAR CHECK-UPS

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

- assess your child's general health
- look for signs of infections or GvHD developing
- check on other side effects and possibly alter their medication
- test their blood to count their blood cells and check that 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.

Alternatively, some of these tasks might be carried out at home by a visiting community nurse.

Specialists

Alongside more general health checks, 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, 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 with a sticker in their *Coming home after my stem cell transplant* activity book.

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 they start 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.

For more information on DLIs, please visit our webpage anthohnolan.org/DLI or talk to your child's medical team.

HOSPITAL READMISSION

Unfortunately, there are likely to be some setbacks along the way 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.

One of the main reasons for needing to go back into hospital is to treat an infection. You will need to know how to spot the early signs of an infection so that 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, frequent or painful urination, blood in their urine or poo, or abdominal pain and cramps.
- Severe tiredness, bleeding, coughing, shortness of breath, chest pain or headaches.

You should have been given the contact details of someone on the medical team you can talk to. 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

Your entire family has been through a lot in recent months and it's now time to start getting back to a 'new normal'. There's a lot to remember - from hospital appointments and medications to healthy diets and exercise. However, if you can keep track of everything, it will really benefit your child's recovery and your own mental health. 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.

At Anthony Nolan, we wanted to make this process 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.


It can be downloaded for free from the Apple and Google Play stores - just search for *My Transplant Tracker*. More information on the app is available from our webpage anthonymolan.org/mytransplantracker.

YOUR RECOVERY STAR CHART



Every time you do something you're proud of, draw or stick a star next to the activity or write down some details about what you did.

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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drinking liquids Try to drink lots of water every day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wash your hands You need to make sure your hands are clean after going to the toilet and before eating.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take your medication Remember to take your medicine every day - it will help you feel better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercise Running, jumping, playing and anything that makes your heart beat faster.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20 Anthony Nolan

Coming home after my stem cell transplant 21

We also wanted to get your child involved with tracking their recovery and make it fun too, so we have created their very own 'star chart' in the *Coming home after my stem cell transplant* activity book. Every time they do something good, such as wash their hands, do some exercise or get a good night's sleep, they can stick or draw a star onto their chart.

YOUR CHILD'S EDUCATION

Every child has a right to an education, and your child will continue to receive theirs during their recovery. Once they're well enough, a hospital teacher will introduce structured learning into their daily routine. These lessons will be gentle at first, they may simply listen to your child read. As your child gets stronger, the intensity and duration of these lessons will steadily increase.

When your child is well enough to leave hospital, a tutor will be arranged to continue their schooling at home. The hospital teacher will talk to your child's school teachers to ensure they're being taught the same topics as their classmates. This limits disruption and will make the return to school easier. It may be possible for you to help as well. If you talk to their teacher, they should be able to give you some work you can do together.

RETURNING TO SCHOOL

This is a big milestone in your child's recovery and should be celebrated. It signifies the return to a 'new normal' for them and your family. Your child can mark this moment in their activity book.

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 classmates or teachers, which could make them anxious or nervous. They could have concerns

about how people are going react to them. Their activity book encourages them to discuss their feelings with you and 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.

EXTRA SUPPORT

At first, the 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. To avoid this happening, it's a good idea to regularly update the school on your child's progress, both before and after their return. If you think your child would benefit from extra support, it's important to raise the issue and 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.

'Our school was great and sent a letter to every parent explaining the importance of keeping their child at home if they were unwell in order to minimise the infection risk to Peter.'

Phil, whose son **Peter** had a stem cell transplant.

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, because everybody'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.

If you would like more information about some of the subjects we talk about in this section, please see our *Your Mental Health and Stem Cell Transplant* booklet or our web section anthohnolan.org/mind.

SUPPORTING YOUR CHILD

While your child is in hospital, the medical team will monitor their mental health in the same way as their physical symptoms. The make-up of the team could vary from hospital to hospital, but your child should have access to a play therapist and/or a child psychologist. They will be able to support your child's mental health needs and answer your questions.

'Throughout both my children's transplants the play team were just amazing at keeping them engaged, and having fun when they were feeling well enough to.'

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

When your child returns home, they will not have immediate access to the same support. This means it's important for you to monitor your child's mood and spot any changes. 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, CLIC Sargent, Macmillan and Maggie's, can also provide advice and support.

SUPPORTING YOURSELF

It's easy to forget about your own mental health needs while caring for your child, but there will be times when you need help and support too. Feeling better equipped to cope with this stressful situation will help you support your child during this time.

In person

Purpose-built cancer centres, like those provided by Maggie's and Macmillan, offer free emotional, practical and financial support to people looking after someone undergoing 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.

'It was nice to talk to another dad while I was waiting for the kettle to boil.'

Steve, whose son **Harry** had a stem cell transplant.

Online

You can discuss a wide range of transplant-related topics on our Patients and Families Forum (anthonymolan.org/forum). The Macmillan forum (community.macmillan.org.uk) also has a page dedicated to parents of children with cancer.

Talking therapy – If you decide you need to talk to a trained therapist about anything, you can access them through your GP or your child's medical team.

'Once a week there was an hour set aside just for parents to go for coffee and chat. My daughter wanted to come but it was my time alone, away from the ward. That was so valuable to me.'

Jane, whose daughter **Sarah** had a stem cell transplant.

SUPPORTING THE REST OF YOUR FAMILY

Understandably, any child will worry about their brother or sister's transplant being successful. 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 this causes 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 might want to consider the following:

- 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.

CARING FOR YOURSELF

- 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.

Our illustrated storybook *Lucy and the Good Soldiers* helps to explain stem cell transplants to children. More advice on speaking to children about cancer is also available on the NHS and Macmillan websites.

'Having been left with their grandparents for long periods, we think it took our other children about 18 months to really get their personalities back.'

Nicola, whose son **Jackson** had a stem cell transplant.

Your child will understandably be nervous and even frightened about what they're going through. They will look to you for the support and reassurance that nobody else can give them. So, you need to make sure you're looking after yourself both physically and mentally during this time. 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.

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.

ACCEPTING HELP

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

Childcare – If you have other children who need looking after in case of an emergency.

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

RECOMMENDED RESOURCES

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 also apply for a grant from various charities including Macmillan, CLIC Sargent and our own Anthony Nolan grants. For more information, please see our *Managing your finances* webpage (anthonymolan.org/managing-your-finances) or visit the Citizen's Advice website (citizensadvice.org.uk).

BOOKLETS

Olly the Brave and the Wigglys

mollyolly.co.uk

A free pack consisting of a lion soft toy and story book. It has been produced to help young children (under 5) understand the concept of cancer and having a central line fitted.

Anna loses her hair

cclg.org.uk

A story book that tells the story of three children who all lose their hair while having treatment for cancer. It helps young children to understand what might happen.

Children and Young People with Cancer: A Parent's Guide

Helping your child to eat well during cancer treatment

Managing family life and cancer

cclg.org.uk

What now? A practical guide for parents and carers

clicsargent.org.uk

Practical information guides for parents and families of a child or young person with cancer.

GETTING SUPPORT

APPS

Hospichill

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

Stop, Breathe & Think

Helps your child to learn about feelings and how to manage them using short activities and guided meditations.

Smiling Mind

Developed by psychologists to give ten-minute daily mindfulness exercises.

Headspace

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

ANTHONY NOLAN CONTACT DETAILS

If you or a loved one is affected by a stem cell transplant, there are many ways Anthony Nolan 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**

Get connected

Find support from other patients and their families by joining our Patient and Families Forum at **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**

OTHER ORGANISATIONS THAT CAN HELP

Blood Cancer UK

bloodcancer.org.uk | 0808 169 5155

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

British Association for Counselling and Psychotherapy

itsgoodtotalk.org.uk | 01455 88 33 00

Information about counselling and therapists in your area.

Carers UK Advice

carersuk.org | 0808 808 7777

Information and support for people looking after their loved ones.

Children with Cancer

childrenwithcancer.org.uk | 020 7404 0808

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

Citizen's Advice

citizensadvice.org.uk | 03454 04 05 06

Advice on a wide range of issues, including financial and legal matters. Online advice is available at: adviceguide.org.uk

CLIC Sargent

clicsargent.org.uk | 0300 3300 0803

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

Contact a Family

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.

Genetic Disorders UK

geneticdisordersuk.org | 0800 987 8987

Support for people affected by genetic disorders and their families.

GOV.UK

gov.uk

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

Improving Access to Psychological Therapies (IAPT)

england.nhs.uk/mental-health/adults/iapt/

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 Centres

maggiescentres.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 | 111

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

Rainbow Trust

rainbowtrust.org.uk | Phone: 01372 363438

Support for families of children with life threatening illnesses.

Samaritans

samaritans.org | Helpline: 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 | 0808 802 2000

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

‘WE WERE JUST
SO RELIEVED
THERE WAS
SOMETHING THAT
COULD BE DONE.’

Steph, whose son **Harry** had a stem cell transplant.



Print sealed with Derprosa™
Matte Bacter Stop. Eliminates
99% of bacteria that comes
into contact with the film.

anthohnolan.org/patientinfo
facebook.com/anthohnolanpatients

patientinfo@anthohnolan.org
0303 303 0303

Reg Charity no 803716/SC038827
2110PA 08/20 DOC5076 Version 001 (0820)



saving the lives
of people with
blood cancer