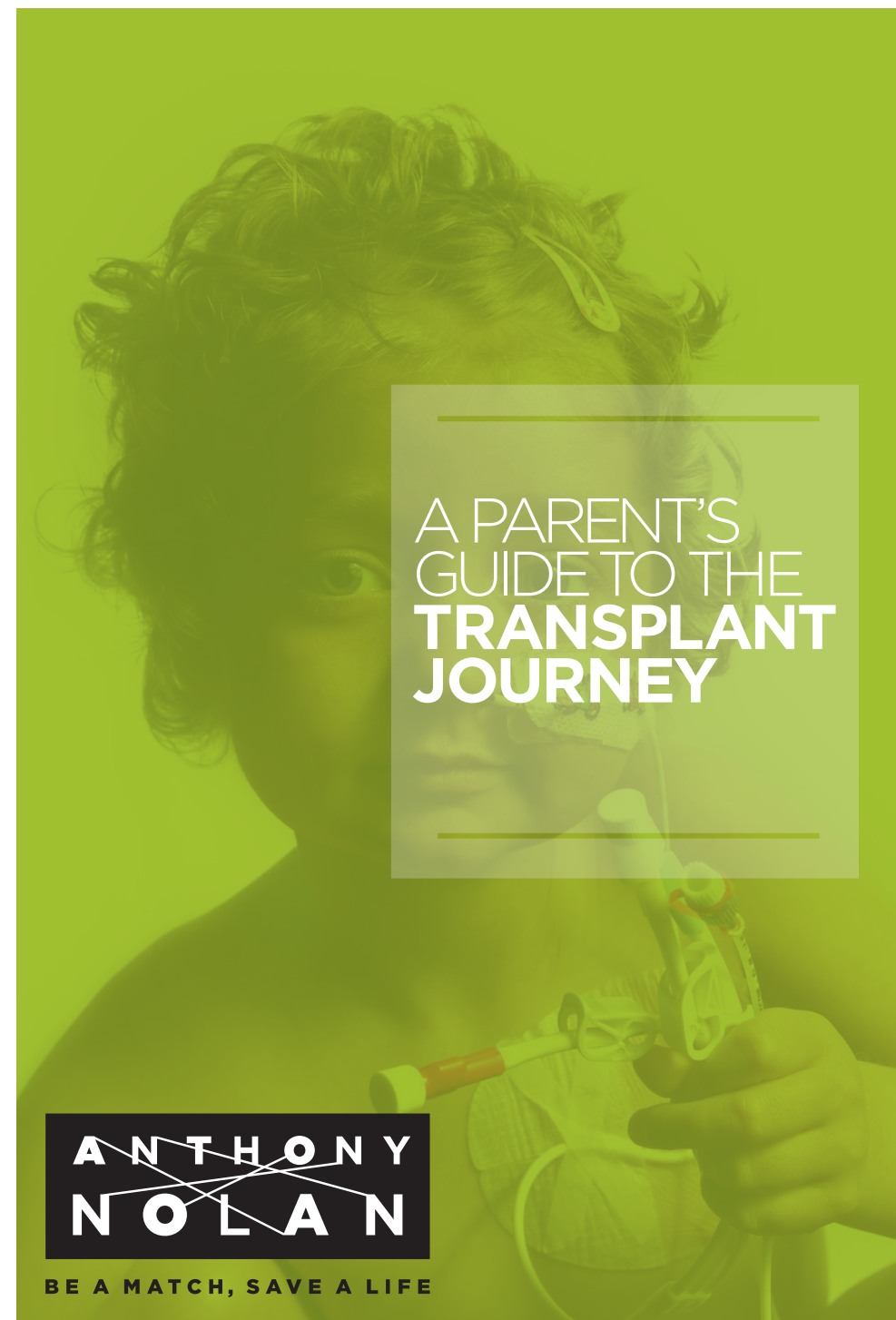


‘AFTER EVERYTHING
ESME HAS BEEN
THROUGH, SHE TAKES
OUR BREATH AWAY.
WE’VE MADE IT,
STRONGER AND MORE
FEISTY THAN EVER!’

Naomi Clayson, Esme’s mum



www.anthonynolan.org
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A PARENT'S GUIDE TO THE **TRANSPLANT JOURNEY**

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

Steph Mullin, Harry’s mum

LET’S INTRODUCE OURSELVES

We’re Anthony Nolan, the UK’s pioneering blood cancer charity. We run a register full of willing volunteers ready to donate their stem cells (or bone marrow) to someone in need of a transplant. We also connect with millions of donors all over the world.

We research, we fundraise, we support and with a lot of hard work, we can cure.

As you’re reading this guide, you may have just found out that your child needs a transplant. This is the start of a long, turbulent, life-changing journey. We could tell you all about what happens next, but we think that parents just like you could explain the story far better.

That’s why we’ve enlisted the help of the mums and dads who have walked this road before. These are their words: their joy, their frustration and their best tips on how to get from day zero to day 100 and beyond.

If you’d like more support or information on anything in this guide, chat to our Patient Experience team on **patientinfo@anthonymolan.org** or **0303 303 0303**.

GOING THROUGH A TRANSPLANT WITH YOUR CHILD WILL CHANGE YOUR LIFE FOREVER.

LET'S INTRODUCE THE PARENTS

Helen and Phil Dunnington Waters

Peter was ten years old when he had a transplant for severe aplastic anaemia in 2012.

Jane Campbell

Sarah had a transplant for acute lymphoblastic leukaemia back in 2006 when she was 12 years old.

Rob and Nicola France

Jackson had a transplant for his juvenile myelomonocytic leukaemia (JMML) in 2009 when he was four years old.

Steph and Steve Mullin

Harry was just 11 months when he had a transplant for his hemophagocytic lymphohistiocytosis (HLH) in 2005.

Alex Gonzalez

In 2007, when Samuel was ten months he had a transplant for Wiskott-Aldrich syndrome, the same disease that Anthony Nolan himself had.

Naomi Clayson

Esme has had two transplants for JMML, one in 2011 when she was three years old and the other six months later in 2012.

Carla and Lee Batten

Rebecca was 21 when she was diagnosed with acute lymphoblastic leukaemia in 2011. She had her transplant the following year.

Lou Hannard

Alex had a chronic granulomatous disorder for which he received his transplant in 2011 when he was nine years old.

Richard and Amy Hardyman

At 11 months, Kieran was diagnosed with monosomy 7 syndrome for which he received a transplant in 2012.

‘WE DIDN’T EVEN KNOW
WHAT A TRANSPLANT
WAS. WE DIDN’T KNOW
WHETHER TO BE HAPPY
OR SAD, WORRIED
OR EXCITED.’

Lee Batten, Rebecca’s dad

HEARING THE NEWS

Hearing that your child needs a transplant could make you feel all manner of emotions, from fear to relief. This will depend on many things, including the treatment your child has already had.

Some parents are thankful that a potential cure is finally an option for their child. For others, “all hell breaks loose” as they try to absorb all this new and complicated information in the first few days.

Since you’ll receive a lot of information during this time, keep a diary and jot down any questions and observations you have. That way you can ask your medical team when you next see them.

Before you consent to the team going ahead, they’ll take you through all the known risks associated with having a transplant. This is an opportunity to ensure you have all the answers you need. If your child is 16 or over they can give consent themselves. But it’s up to you and the team to make sure they fully understand what’s involved.

‘DURING THIS JOURNEY,
KEEP A DIARY. TRUST
ME, IT REALLY HELPS.’

Steph Mullin, Harry's mum

THE PREPARATION

Now the initial conversations have happened, the team will carry out a very thorough medical screening that checks how your child's heart, lungs, liver and kidneys are working.

Once your child is ready to start the treatment, he or she will probably have a 'central line' fitted into a large vein in their chest. This makes it easy for the team to give your child their transplant, blood products and other drugs, without having to give them lots of injections.

This will stay in place for a few months but it shouldn't stop your child from doing their normal activities. Your team will give you plenty of advice about how to keep the line clean and prevent any infections once you're back home.

Your child will have treatment to prepare them for their transplant. This is called 'conditioning'. This involves chemotherapy and sometimes radiotherapy, depending on the reason they're having a transplant. This is used to suppress their immune system and prepare a space in the bone marrow for the new cells to be accepted by your child's body.

The conditioning will make your child very poorly, so this will be a tough time. Your transplant team will do absolutely everything to minimise the side-effects and keep your child comfortable and content.

ALL PARENTS FEEL DIFFERENTLY ABOUT HOW MUCH THEY WANT TO KNOW DURING THIS JOURNEY.

FINDING THE ANSWERS

'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 Gonzalez, Samuel's mum

When discussing the facts with your medical team, you may want to only know the vital details so you're not overwhelmed. Or perhaps you'd rather have all the 'ifs and maybes'.

However much or however little, you must communicate your wishes clearly to your team.

If your team tells you that they don't know what may happen tomorrow, most of the time it's because they honestly don't. Transplants can be very unpredictable and there is a lot of waiting involved. We know this is extremely frustrating.

Your medical team understands that this is a challenging time. Just because they explained something to you yesterday doesn't mean you can't ask the same question today. Or tomorrow or the day after, for that matter.

We also have reliable information about transplants on our website at **www.anthonynolan.org**.

'We 'Googled' our son's condition and because it is so rare, the stuff we read was really scary. It was all about the treatment of adults and it didn't seem relevant so we ended up even more confused.'

Richard Hardyman, Kieran's dad

‘I USED TO WATCH
MY BOY LOOKING
AROUND HIS ROOM
AT THE PICTURES OF
THE WORLD OUTSIDE.’

Rob France, Jackson’s Dad

STAYING IN HOSPITAL

Many parents find it really helpful to take a tour of the transplant centre before their child’s treatment. It may help to settle those pre-transplant jitters, plus it’ll help you plan what your family would like to take with you.

If your child is old enough, encourage them to take part in making a list of the things they’d like with them during their stay. You might be surprised by what they choose and by the things you hadn’t realised were important to them.

Many centres let you decorate your child’s room. This is a great comfort and it feels good to take control over something. Pictures of friends and family, special pillows and blankets, favourite toys and books bring along anything familiar and comforting.

Be sure you bring things you can wipe clean or wash, including loose fitting clothes and plenty of spare pyjamas.

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

Nicola France, Jackson’s mum

PARENTS SPEAK OF A SPECIAL CLOSENESS, A SHARED JOURNEY AND A DEEPER LOVE.

STAYING IN HOSPITAL CONTINUED

Despite this struggle for control as a parent, it's important to be involved in every single decision made. If your child is old enough, it is equally important that they can do something every day that helps them have some control. This could simply be deciding the order in which they take their tablets or choosing what they'd like to eat that day.

As strange as it may seem now, many parents have fond memories of their time in hospital with their child. When times are tough this may not be the case. But there will be many days when your child is well and you are spending long days alone together.

Parents speak of a special closeness, a shared journey and a deeper love and trust after going through something that nobody else can understand.

We hope that through this difficult time, you'll find joy in small moments and come out of the other side, feeling stronger as a family.

‘IT WAS NICE TO TALK TO
ANOTHER DAD WHILE I
WAS WAITING FOR THE
KETTLE TO BOIL.’

Steve Mullin, Harry’s dad

TAKING CARE OF YOURSELF

Remember, you’ll need to take care of yourself too. We know this is the last thing you’ll be worried about, but feeling tense and sleep deprived won’t help. You’ll be able to support your family the most when you’re relaxed and adequately supported yourself.

Time for yourself

It’s vital to find a small amount of time for yourself, allowing you to remain healthy, focussed and in control. For some this will be easy, but for many, it may take a while to get used to leaving the bedside or cot for more than a few minutes.

Rob France, Jackson’s dad, used to go out for a run once a day. Taking a break is crucial, so make sure you take these opportunities.

Time with other parents

Meeting and chatting to others on the ward isn’t for everyone, but some find comfort from bumping into other parents who are in similar situations.

Lou Hannard, Alex’s mum, became close friends with another mum on the same ward. They’d text each other in the evening and meet up for coffee once the kids were asleep.

‘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 Campbell, Sarah’s mum

SOMETIMES JUST KNOWING THAT HELP IS AVAILABLE CAN BE ENOUGH.

TAKING CARE OF
YOURSELF CONTINUED

Time with staff

Some parents become friendly with the staff on the ward, and are able to chat to them on a personal and professional level. The nurses and social workers are very experienced in supporting families going through these tough times.

Other support

Psychological support services vary from one centre to the next. Ask your team what's available for you and your family. Even if you don't feel like you need additional support right now, there may be a time when you will. We've listed supportive organisations you can contact at the back of this guide.

Your faith

Religion can play an important role for some families. You don't have to be a practicing member of a faith to talk to someone from the hospital chaplaincy team, nor does your child have to be really poorly for them to visit.

They often see people just as a listening ear – someone separate from the direct care-givers in the hospital. Speak to the staff on your ward if you'd like them to come and visit.

'There were a few times when things didn't look good for Kieran and there was nothing more we could do as parents apart from put our faith in God.'

Amy Hardyman, Kieran's mum

**MORE CHILDREN
THAN EVER
RECEIVE
LIFESAVING
TRANSPLANTS
THAT OFFER
HOPE OF A CURE.**

IMAGINING THE WORST

When you first find out that your child is gravely ill and may need a transplant you'll feel it all: numb, angry, confused, desperate. You may even worry that they'll die. Every parent we speak to admits that they were forced to imagine this dreadful prospect.

Some parents were even told to prepare for the worst by their medical team on more than one occasion, only for their child to make an unexpected recovery.

Transplantation has made giant steps forward in recent years, but it remains a complex, unpredictable procedure. The overall success rate for transplants in children is far higher than for adults, but unfortunately not all children survive.

However, every day more and more children receive lifesaving transplants that offer the chance of a cure.

There is lots of support available to you and your family, so speak to your hospital team. There are also other organisations who are on hand to help, which we've listed at the end of our guide. Or you can visit our online community and share your experiences with other parents going through the same thing at www.anthonynolan.org/transplantcommunity

‘BE AS HONEST AS
POSSIBLE WITH THEM –
8-YEAR-OLDS CAN
TAKE IN MORE THAN
WE THINK.’

Lou Hannard, Alex’s mum

YOUR RELATIONSHIPS

Your child

Try to give your child an honest impression of what the weeks ahead may be like. It might feel hard, but you know your child better than anyone else, so you’ll instinctively know how to explain this to them. You could also use books or pictures to help them understand and prepare.

Ask them what they already know, so you can clear up any scary misunderstandings they may have formed. Starting an honest conversation will let your child know they can ask more questions.

There are online resources where they can communicate with other young people going through the same experience. See the other organisations listed at the back of this guide.

During this time, you may notice that your child’s behaviour changes. It’s tempting to ignore this and put it down to the situation, but do try to keep a normal approach to discipline, as tricky as that may sound. This will help them develop a sense of normality and security.

Some children may be concerned about you, and how you’re feeling too. To put their mind at ease, explain what your routine will be and where you’ll be staying.

‘When Peter’s dad said the parent’s accommodation was a bit ‘spooky’ he didn’t want me to stay there!’

Helen Dunnington Waters, Peter’s mum

MANAGING RELATIONSHIPS WITH YOUR CHILDREN CAN BE A LITTLE COMPLICATED.

YOUR RELATIONSHIPS CONTINUED

Your other children

If you have other children, managing relationships with them can be a little difficult. They will almost certainly be experiencing many of the same emotions that you'll be going through.

Although very resilient, children don't like change. They may feel resentment towards their poorly brother or sister for taking you away from them. Some parents say that professional support can help. Your hospital may have a support group for siblings, so talk to your team. Other sources of support are at the end of our guide.

Keep all channels of communication with your other children open.

You may feel that you have no empathy left to give but they need to feel loved by you. Try to find a bit of dedicated time to make them feel the centre of attention.

'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 France, Jackson's mum

‘YOU ARE A DAD FIRST
AND FOREMOST AND
YOU FORGET ABOUT
BEING A HUSBAND.’

Steve Mullin, Harry's dad

YOUR RELATIONSHIPS CONTINUED

Your partner

When it comes to keeping a relationship strong, there's no magic formula. Our parents say you just get through it, a day at a time. You can rebalance your relationships when you're back home and things feel more like normal.

Whether you're with a partner or not, this time can be very isolating. You may find sharing your thoughts with other parents helpful, and the Anthony Nolan transplant community is just one place where support can be found.

Your family and friends

This journey often feels like you've left the rest of the world behind and you're on Planet Transplant. But back on earth your friends will be desperate to hear from you. They mean well, but sometimes the calls and texts are overwhelming.

Have a communications plan. Let everybody know how and when you'll be updating them, so they're less likely to inundate you with messages.

If you have a large group of friends, choose a key communicator who can pass on news to the rest of your network. This means you don't have the same conversation ten times.

Social media makes communicating easy, too. Some parents keep a blog throughout their stay in hospital and although diaries are difficult to keep up, they can become a wonderful memory of the journey once travelled.

MAINTAINING RELATIONSHIPS WITH SCHOOL AND WORK IS VITAL.

YOUR RELATIONSHIPS CONTINUED

Your child's school

'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 Dunnington Waters, Peter's dad

It may be the last thing on your mind, but keeping your child's school updated will help. Not only could the school offer you another avenue of support, they'll also take your lead on how to inform children and parents about the situation.

The experience of parents is varied when it comes to schools, but they always welcome direction from you and if they can help, they nearly always do.

Your work

Like schools, parents have a variety of experiences with their employers. Many have great support with paid leave, while a few struggle and have to give up work to care for their child.

The main thing is to talk to your employer at the earliest opportunity. Keep up regular communication so they know you haven't disappeared indefinitely. This way they'll be more inclined to support you at a time when you really need them.

Be sure to find out about your rights to leave and flexible working. If you have a social worker, you can ask them, or find out more at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).

‘IN HINDSIGHT, THE HOSPITAL STAY AND TRANSPLANT WERE THE EASY BITS!’

Naomi Clayson, Esme's mum

GOING HOME

Going home can be a daunting prospect, particularly after a long stay in hospital. Your child has been in safe hands, under regular supervision and although you may have been responsible for some of your child's care, suddenly it's all down to you.

You should be aware of the potential problems your child may encounter in those first days and weeks at home. It can be worrying, but your medical team will only allow your child home if they believe they're well enough and ready.

There are a few practical things you can do in the days leading up to your child's return home:

- Consider your GP. They won't be the main point of contact for your child, but you could still let them know. Share as much information as you can. This can include the exact treatment your child has had and what side-effects you'll be looking out for.
- Prepare your house. This is important to minimise the risk of infection. Don't worry though, your nursing team will tell you everything you need to know.
- Register for home tutor allowance. If your child is old enough, this can be arranged by your school and County Council. Additional home support may be available if they're unable to return to school for a longer period than expected.
- Inform the school. Keep your child's school informed of progress so they can make suitable arrangements to accommodate your child's return, whenever that may be. There may be a teacher working at the hospital who can help sort out home tuition and liaise with their school.
- Plan childcare. If you need to return to work, ensure you have someone at home.

**EVENTUALLY, YOU
AND YOUR FAMILY
WILL FEEL LIKE
YOU'VE FOUND A
'NEW NORMAL'.**

GOING HOME CONTINUED

When you finally get home, one of the hardest things will be managing both your own and your child's expectations of how challenging this new chapter can be.

'Home' sometimes feels like "back to normal", but the healing process can take many months. It takes time for your child to recover their energy levels and the physical and psychological strength to engage in their usual everyday activities.

Keep your transplant team fully informed regarding your child's progress. You could also let your GP know. This way they can refer you to other services which can help to rehabilitate your child. For example, they may need to see a physiotherapist or a dietitian.

While you establish a new routine at home, you'll still be expected to attend regular hospital appointments. The joy at finally getting home is often dampened by the disappointment of not being free of hospitals for quite some time. But you'll get there in the end.

It's important to be vigilant when monitoring your child for side-effects. Your medical team will have equipped you with all the information you need to spot any changes, so you'll know exactly what to look for.

‘THE TRANSPLANT WAS
TOUGH, GOING HOME
WAS EVEN HARDER.
BUT EVERY DAY WE
GET A BIT STRONGER.’

Carla Batten, Rebecca's mum

LIFE AFTER TRANSPLANT

With time and support, family life can return to what we call the ‘new normal’. You’ll have been on a journey of anxious waiting, long hospital stays, extreme highs and profound lows, and now you’re moving forward into a new chapter of your lives together.

Families often celebrate certain milestones after a transplant such as the 100 days or one year anniversary. These are good opportunities to thank those who offered practical or emotional support while you were in hospital with your child.

Other people chose to fundraise for charity or their hospital, while some decide to put everything behind them and move forward as quickly as possible. Everyone is different: just do what feels right for your family.

Going through a transplant with your child will change your life forever. It’s an incredibly tough, emotional experience, but the love and trust you’ll feel at the end is incomparable to anything you’ll have felt before.

Hold onto this hope when you’re going through the low moments. We know you can do it. And we’re with you every step of the way.

Organisations who can help

Children with Cancer

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

www.childrenwithcancer.org.uk

Children's Cancer and Leukaemia Group (CCLG)

The national association of healthcare professionals involved in the treatment and care of children and young teenagers with cancer, offering support and information.

0116 249 4460

www.cclg.org.uk

CLIC Sargent

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

0300 3300 0803

www.clicsargent.org.uk

Contact a Family

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.

0808 808 3555

www.cafamily.org.uk

Direct Gov

Information about your employment and benefit rights.

www.gov.uk

Genetic Disorders UK

Support for people affected by genetic disorders and their families.

0800 980 4800

www.geneticdisordersuk.org

Rainbow Trust

Support for families of children with life threatening illnesses.

www.rainbowtrust.org.uk

Teenage Cancer Trust

Support to improve the lives of teenagers and young adults with cancer.

020 7612 0370

www.teenagecancertrust.org

Visit our website for a list of other organisations who can help.