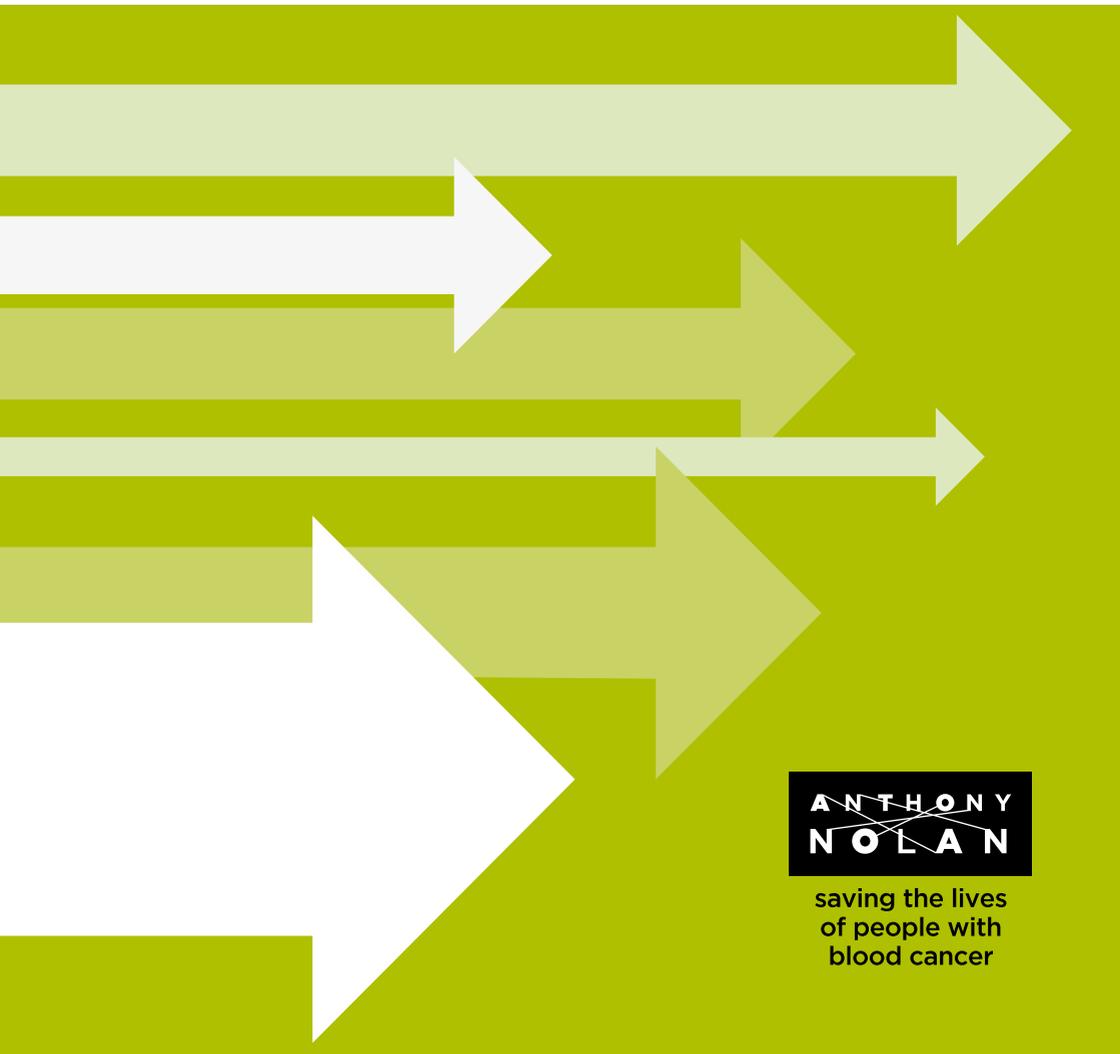


A YOUNG PERSON'S GUIDE TO THE **STEM CELL TRANSPLANT JOURNEY**



**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer



Produced with support from the Jack Petchey Foundation, in memory of John Petchey.

© Anthony Nolan 2017

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.

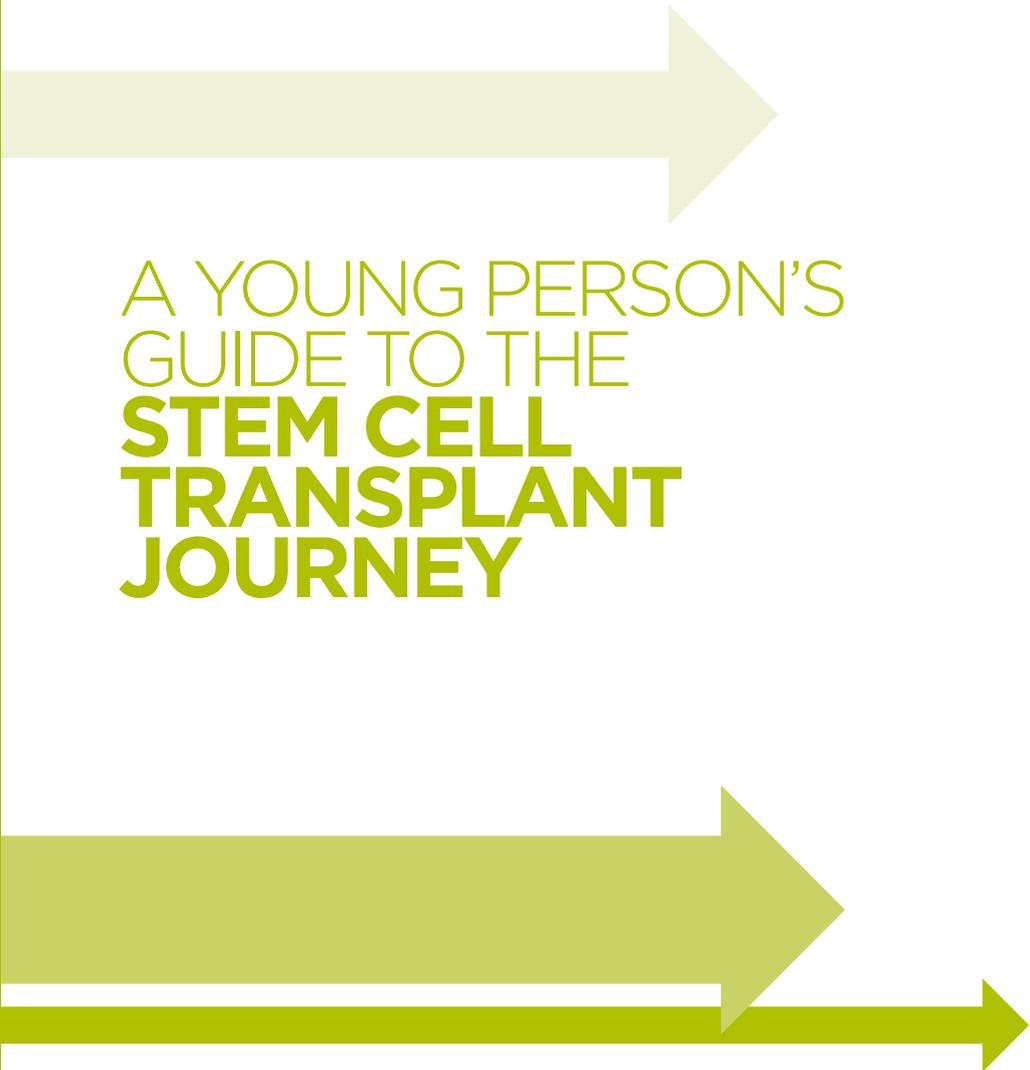
If you have any questions or comments about this resource, or would like information on the evidence used to produce it, please email: patientinfo@anthoynolan.org

The information contained in this booklet is correct at the time of going to print (June 2017). We plan to review this publication within three years. For updates or the latest information, visit anthoynolan.org

Anthony Nolan is a registered charity No 803716/SC038827

This publication was reviewed by: Rachael Hough, Consultant in Haematology & Stem Cell Transplantation, University College London Hospitals; Filippo Oliviero, Adolescent Bone Marrow Transplant Clinical Nurse Specialist, University College London Hospitals; Hayley Leonard, Anthony Nolan Lead Nurse; Anthony Nolan Patient and Family Panel.

1230PA/0717



A YOUNG PERSON'S GUIDE TO THE **STEM CELL TRANSPLANT JOURNEY**



saving the lives
of people with
blood cancer

ANTHONY NOLAN
PATIENT SERVICES

At Anthony Nolan we take great care to provide up to date and accurate facts about stem cell transplants. We hope the information here will help you to look after yourself.

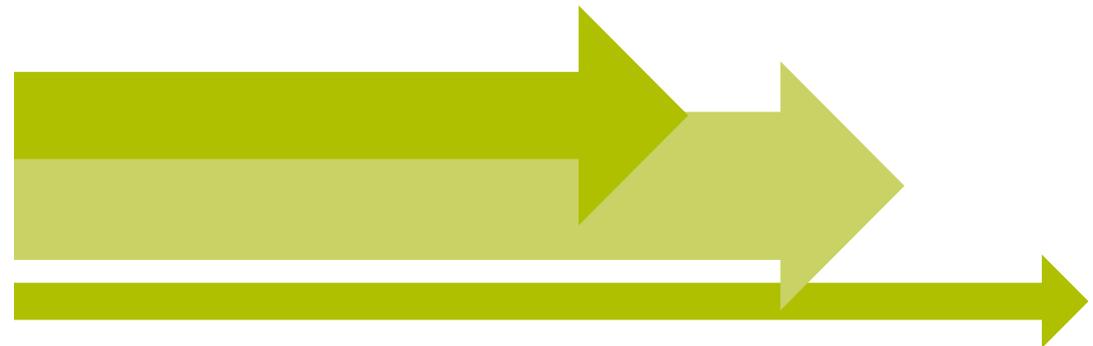
Each transplant centre will do things differently, so this booklet is just a general guide and isn't intended to replace advice from your doctor and transplant team.

Please speak to your transplant team for more details about your own situation, as they will be able to give you personalised, specific advice.

If you'd like to order more copies of this guide please get in touch:
patientinfo@anthonymolan.org

CONTENTS

When you get the news	6
Planning ahead	10
The bigger issues	16
Meet your transplant team	18
What happens next?	22
Side effects	30
Effects on your life	36
Taking control of your recovery	40
Getting back to your life	46
Dealing with your feelings	54
Glossary of terms	62
Other useful information	69



WHEN YOU GET THE NEWS

'A stem cell transplant could now be your best option...'

If you have started reading this booklet, chances are you have been told something along those lines by your doctor.

You may be feeling relieved because a potential new cure has become a possibility, or you could be anxious and worried because it might mean that a recent course of treatment has not worked. This could be the start of a long, turbulent and life-changing journey. So take a few deep breaths and try to stay calm.

Over the next few weeks you will be given lots of information about stem cell transplants. It can be a lot to take in all at once so make sure you take notes, keep a diary and jot down any questions you have. That way you can ask your medical team when you next see them. At the end of the day, remember that because you are over 16, you have the right to decide if a transplant is the best choice for you. If you would like to read up on some transplant basics, see our booklet, *The Little Guide for Transplant Patients*, or check out our website at anthonymolan.org/patientinfo

This booklet has been designed to provide teenagers and young adults like you with the information and support needed at every stage of the stem cell transplant journey. It will cover all aspects, from how your donor is found, right the way through to coping with long term side effects and helping you return to education or work.

You may wish to read it all in one go, or you may find it easier to only read the chapters that are relevant to you as you progress on your journey. We will tell you what to expect, who will look after you and how your body might respond to the process. We hope this information will also help you to cope with how you are feeling and how to return to a more normal way of life, in education or at work. We'll also share the stories of some of our patients with you to help you know that you are not alone on this journey.

HOW CAN ANTHONY NOLAN HELP ME?

We are the UK's pioneering blood cancer charity. We run a register full of willing volunteers who are ready to donate their stem cells (or bone marrow) to someone in need of a transplant. We are the ones that help to look for a matching donor and then co-ordinate the transplant cells arriving at hospital.

However, our responsibility does not end there. We employ Clinical Nurse Specialists to support you throughout your long term recovery and provide information services for you and your loved ones about all aspects of your treatment.

Away from the clinic, we conduct cutting edge scientific research to improve the matching process, so that more lives can be saved. We are also researching the causes of post-transplant side effects, such as graft versus host disease (GvHD), so that there will be better treatment options for everyone in the future.

If you would like to know more about the work that we do, check out our website at **anthonymolan.org** or the Anthony Nolan YouTube page, where you'll find videos that explain how we work and introduce some of the amazing donors and fundraisers who make it all possible.

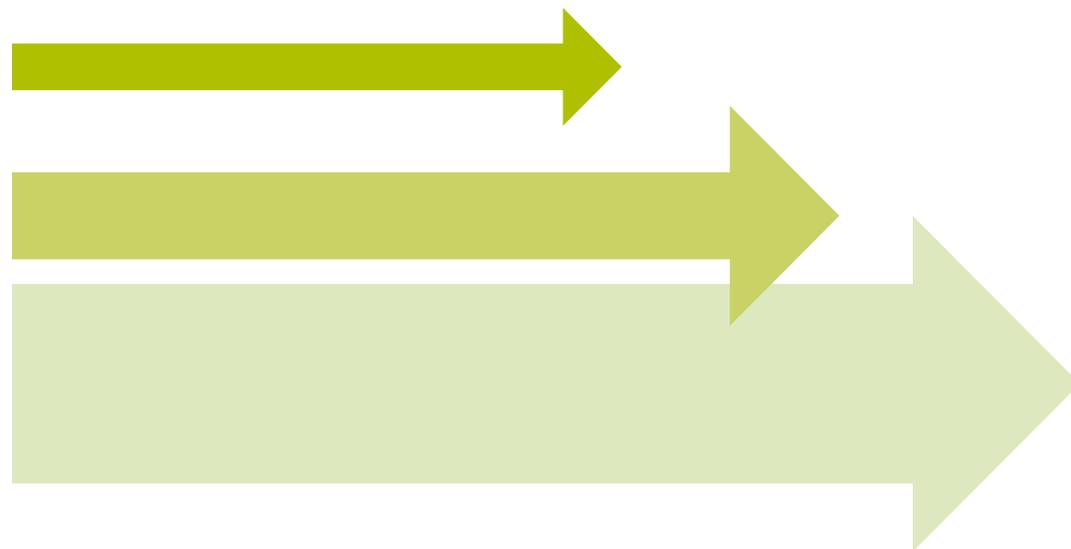
GETTING THE INFORMATION YOU NEED

At this point one thing is for certain, you will have lots of unanswered questions and there is nothing wrong with that, at all!

If you have a question about any aspect of your transplant, it is best to ask your medical team because they can give personalised advice that is specific to you. Talking to people, especially about your body and your feelings, can be difficult and might make you feel nervous. But don't worry, it is perfectly normal. Here are some things that might help:

- Plan the questions you want to have answered before you start.
- There is no such thing as a stupid question and you can never have too many questions.
- There is nothing wrong with asking people to speak more clearly, to repeat something or to explain something in a different way.
- Don't be afraid to say you do not understand. The only person that matters is you, and the people you are talking to are there to help you.
- Feel free to note things down at medical appointments or get someone else to do it for you. There can be lots to remember and it's important that you don't miss out on anything.

Finding out information about your transplant can be empowering and help to build your confidence to tackle the situation head on. However, it is really important to get your information from sources that you can trust, especially when searching online. For a start, we would recommend our own website, but we have also put together a list of other websites in our glossary section that we recommend.



PLANNING AHEAD

In this section, we'll look at what you can do to prepare for your stem cell transplant. It will help you to feel more in control of your situation and hopefully help with any unexpected surprises.

GET YOUR DIARY READY

It is important to consider any major appointments that you might have in your calendar, such as holidays, a gap year or the start of a new academic year. Your stay in hospital generally lasts for around six to eight weeks, followed by regular visits to outpatients for up to three months. It varies from person to person, but it could be up to six months before you start to feel more like yourself again.

FEELING COMFORTABLE

Unfortunately, you will have to spend a lot of time in hospital as you wait for your immune system to recover after a transplant, so it's important that you feel comfortable. It's a good idea to organise a visit to the hospital or transplant centre where you'll be treated, so you can get used to your surroundings.

Your hospital room might start to feel like your second home, so you should make that space your own. You can normally bring in familiar home comforts that you would like to have around you, such as photographs and posters, so do check with your team.

PACK YOUR BAG

Depending on your medical condition, the time between being diagnosed and going into hospital can be very short. This period of time can be very intense and you might have a lot of things to think about, so we've put together a list of things that you (or your parents) might want to pack for your stay. Also, if you get the chance, tell a family member or friend where you keep any spare clothes or other items that you might want brought into hospital at a later date.

'Because you are getting so much information about your health, and with everything else that's going on, you forget to bring something simple like a bowl!'
Kate, had a transplant in 2015

PACK YOUR BAG

Practical stuff

- photos and other personal possessions
- cutlery and crockery
- cups, glasses and water bottles
- strong flavoured snacks – your treatments might leave a nasty taste in your mouth, so things like mints will help
- cordials and fizzy water – you will have to drink a lot of fluid and plain water could get a bit boring
- spare cash
- ice pops/lollies – another good way of taking in fluid, and they can help soothe any pain in your mouth and gums

Stuff to wear

- comfortable clothes – you won't need your entire wardrobe, and your family will probably be able to wash and return your clothes in between visits
- zipped or button up clothes – you might spend a lot of time attached to a medication line so clothes that you can take on and off easily are ideal
- vests, T-shirts and shorts – your room might get hot at times
- plenty of sleepwear and a dressing gown
- slippers and socks

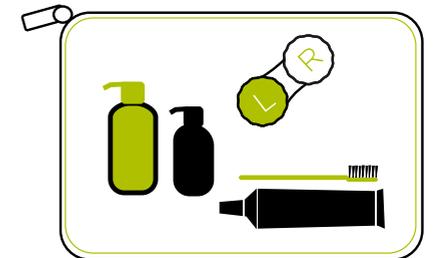


Stuff for the bathroom

- wash bag – moisturisers and hand cream can help relieve any dry skin you might experience following your transplant
- spare loo roll
- contact lenses/glasses
- soft toothbrushes and toothpaste

Stuff to keep you 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
- headphones
- chargers
- books and magazines
- MP3 player/electronic tablet – if you have one, it will enable you to play games, watch movies, listen to the radio, read or communicate with friends and family on social media
- crafts or other hobbies
- stationery and notebook(s)
- deck of cards
- jigsaw(s)
- board games – preferably travel sized
- DVD box sets – lose yourself in your favourite TV show or set up membership to a streaming service to help pass the time



DENTIST

Worrying about the state of your teeth might not be high on your list of priorities right now, but it's important to have a dental check up. If you know of any work that needs doing, it should be done before you start treatment because there will be a risk of infection once your treatment starts. Your hospital team will usually organise this for you.

DIET

Once you've had your chemotherapy you will probably have to follow what's known as a 'clean diet' which doesn't contain foods rich in bacteria, such as yoghurts and some cheeses. This reduces the chance of picking up an infection from food while your immune system is recovering. The guidelines vary between transplant centres but the dietician in your team will be able to support you.

HAIR LOSS

You may already be aware of this but when you have your chemotherapy it's very likely that you will lose your hair. However it will grow back after treatment, normally after a couple of months. This can be very upsetting for both men and women, but schemes such as **The Teenage Cancer Trust's Hair 4 U** provide real hair wigs, free of charge, to patients like you. Your nurse or youth support worker should be able to give you the details that are specific to your hospital for this.

Some people take this opportunity to go wild and experiment with hairstyles that they have never dared to try before. If you have long hair you might want to try out some shorter styles before treatment starts. Your hair may not all fall out at once, so you could decide to shave your head before it starts. You'll be advised to keep your head covered with a hat, scarf or even a wig if you prefer, to prevent losing heat in the winter and getting sunburnt in the summer.

THE BIGGER ISSUES

The issues raised here have potential long term consequences. It's important to think about them early so that you can plan ahead for your future. They could be a source of stress and worry, so you might like to talk to someone who's close to you about them.

You will always be able to discuss your options with your transplant team before you make any decisions. You can also find out more information on all of these topics in our handbook *The Seven Steps: The Next Steps*, or contact the Anthony Nolan Patient Services team.

YOUR FERTILITY

It is highly likely that the chemotherapy associated with a stem cell transplant means that you would not be able to have children without some kind of assistance. That does not mean that you will not be able to have children in later life. You may be offered the chance to visit a fertility clinic before your treatment starts.

EARLY MENOPAUSE

The menopause normally affects women in their late forties or early fifties and describes the changes that occur when their menstrual cycle stops. Although it may not be on your mind right now, the chemotherapy and radiotherapy associated with your transplant is likely to damage your ovaries. This can result in your body going through the menopause earlier than you might have expected.

The Daisy Network is a charity that supports women who have experienced premature menopause (see 'Other useful information' on page 70).

MEET YOUR TRANSPLANT TEAM

During your transplant journey you will be at the centre of a large transplant team that is responsible for giving you the best possible care. They will all be experts in their field and can help you with anything you might need.

It can sometimes be difficult to keep track of everybody's name and remember what they do, so we have put together this handy list overleaf for you to refer to. Feel free to write down the name and contact details of the people in your team next to their job title. You can then refer to it whenever you need to.

There's also a useful summary of their job titles in 'Glossary of terms' on page 62, in case you need to check something.

'At least if this information is written down, your parents can find it if they need it at 2 o'clock in the morning and you can't really explain who you need to phone.'

Georgina, had a transplant in 2014

JOB TITLE	CONTACT NO.	NAME
Clinical Specialist Nurse (CNS)		
Community nurse		
Consultant		
Counsellor		
Dietician		
General Practitioner (GP)		
Haematologist		
Palliative care team		
Physiotherapist		
Psychologist		
Radiographer		
Social worker		
Youth support worker		

WHAT HAPPENS NEXT?

FINDING A MATCH

For a transplant to take place, you need to have a donor whose 'tissue type' matches yours. Matching is done based on your human leukocyte antigen (HLA) tissue type. Your HLA is what makes you 'you' - it's your individual genetic characteristics. Your hospital will arrange for you to have blood tests to determine your HLA type (it may have been done already).

Your HLA type is made up of five genes. Each one of these has two different versions (called alleles) making 10 in total. You inherit one version from your mother and one from your father. When it comes to matching you with a donor, if nine of these genes match up it's called a 9/10 match. If all 10 match then you've got yourself a 10/10 match. It's important that your doctors find the best possible match because this will give your body the best possible chance of accepting your donor's stem cells - this is called 'engraftment'.

For more information on this process, see our guidebook *The Little Guide for Transplant Patients*.

If you have any brothers or sisters who are willing to be your donor, they will be tested first as they have the best chance of being a really good match for you. If a sibling donor is not an option for you, then Anthony Nolan will search its register and other international registries to try to find you a match. If a sibling or unrelated donor is unavailable, you may be offered an umbilical cord blood transplant or a haploidentical transplant using stem cells from a family member whose tissue type or HLA is half matched to yours depending on your situation. For more information about the five different types of transplant, see our website at anthonymolan.org/transplanttypes

CENTRAL VENOUS CATHETER (CVC)

Before, during and after your transplant you will need lots of medication and supportive therapies, as well as other treatments, such as your chemotherapy. To make this as straightforward as possible, you will be fitted with a Central Venous Catheter (sometimes called a 'Hickman line'). This is a thin tube that goes through the skin near your collarbone and into the big vein that leads into your heart. Alternatively you may have a PICC (Peripherally Inserted Central

Catheter) line which is inserted into your upper arm. Both devices enable the ward nurses and doctors to take blood samples, deliver treatments and the stem cells themselves without using a needle every time.

After your transplant your CVC can be at risk of causing infection, so it will be removed as soon as it's no longer needed, normally a few weeks after the transplant. Removing it is normally done at the outpatient clinic using a local anaesthetic - you may need a stitch or two to help the wound heal. Many people see its removal as a positive early step in their recovery.

CONDITIONING THERAPY

To give your new stem cells the best chance of rebuilding your immune system, you must first undergo treatment known as conditioning therapy. It is usually a five- to 10-day course of chemotherapy, sometimes in combination with high doses of radiotherapy called total body irradiation (TBI). This gets rid of any abnormal cells and provides your new stem cells with plenty of space in your bone marrow to engraft and grow into a new immune system.

THE TRANSPLANT

Your transplant normally takes place the day after the conditioning therapy has finished (called 'Day 0'). The transplant itself involves having the donor stem cells or bone marrow passed as a fluid through a thin tube into your bloodstream, a bit like having a blood transfusion. The transplant isn't painful and you'll be awake the whole time.

'The transplant process on my end was almost underwhelming - 20 minutes, just like a normal infusion! It's bizarre that this bag of magic that looks unassuming is so incredible. It's amazing to think of everything that's gone into developing it, and the luck that that bag represents.'

Jacob, had a transplant when he was 19

STAYING IN HOSPITAL

You'll probably be in hospital for about four to six weeks, and after your transplant you'll need to spend some time in something known as 'protective isolation'. You'll usually be in a single hospital room with precautions taken to reduce your risk of getting an infection. Spending lots of time in your room by yourself can be a tricky time for some people, especially if you are feeling poorly.

'I was in hospital for six weeks and during that time, to get myself through, I would set myself targets.'

Kate, had a transplant in 2015

For more information about how to cope during this time read our *Dealing With Isolation* booklet.

Your family and friends will be able to visit you during this time, so it's a good idea to check the hospital's visiting times. Parking for visitors is sometimes expensive and hard to find, so make sure they check your hospital's website in advance. The hospital you are being treated at could be far from home, which could cause concern for you and your family. However your transplant team will be on hand to offer support to everyone. It might also be possible for a member of your family to stay with you overnight.

Anthony Nolan grants can help contribute toward these costs. You can find out more about our grants by visiting our website at **anthonymolan.org** or asking your transplant team. More information is available in the money section on page 50.

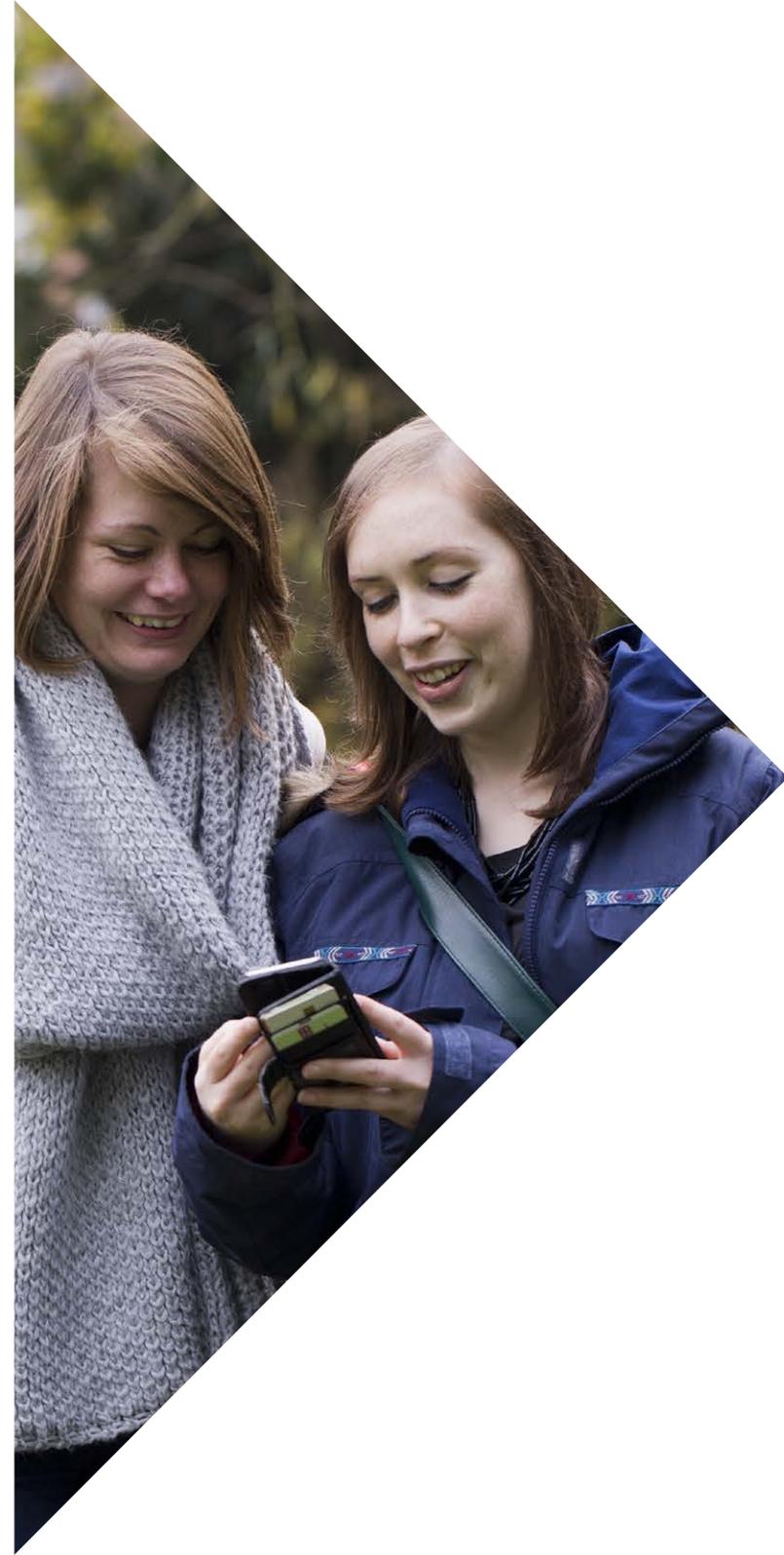
'One of the major shocks for my parents was the travelling - how much travelling they would have to do to the hospitals, how much time, how much it would cost.'

Georgie, had a transplant in 2015

PREPARING TO RETURN HOME

By the time you are well enough and ready to go home, you might be feeling a bit overwhelmed and feeling lots of different emotions all at once. Many patients are relieved and excited about going home, but others worry about coping without the support they received in hospital (your parents may worry about this as well).

You may not have realised it, but you have already spent a few weeks getting used to being a transplant recipient and the regular medical checks that need to happen. You are probably more aware of your body already and how to spot



the signs of any side effects of your treatment – so try not to worry. Your team will only be happy for you to go home once they are sure you are safe and ready to do so.

THE ESSENTIALS

It's important that you feel prepared to go home. Your nurse will come to see you and your family before you leave hospital for a 'going home' talk, when they will provide you with:

- Contact numbers for your transplant team, including out-of-hours contacts/hotline numbers.
- Information about looking after your CVC.
- Advice about nutrition, your diet and some gentle physical exercise you can do at home.
- Information on what to do if there's a sudden increase in your temperature (see 'short term side effects' on page 31 for more details).
- Your medication and information on how to take it.
- The times of your first appointments in outpatients.

LIFE AT HOME

You might find that you are not as independent as you were before your transplant and that you have to rely on the help of your parents or family more than you were expecting. If you have recently moved out of the family home and into your own place, this could be particularly frustrating.

If your parents go a little over the top, remember that they have been worried and frustrated about not being able to help you until now. This will not last forever and as you recover you will begin to regain your independence.

'My mum would wipe down every door handle when I first came out of hospital but after a while she realised that I was completely fine.'

Kate, had a transplant in 2015

Although being well enough to return home is a significant milestone in your recovery, the day-to-day reality of being at home can be challenging for some people. Many patients we talk to were surprised about how isolated they felt during this time because they were often in the house alone.

This time will pass much more quickly if you break each day down into small, manageable chunks, and set yourself goals for what you would like to achieve. For example, you might decide that you are going for a 30-minute walk or do a craft that you enjoy for an hour or so. Doing a small amount of exercise each day will also help reduce the effects of fatigue. Our *Dealing With Isolation* booklet has ideas to help you during this time.

TESTS, TESTS, TESTS

Just like during your hospital stay, your transplant team will check up on you regularly to make sure your new immune system is working properly and to monitor any side effects.

At first, you will have blood tests a couple of times a week, as well as a more thorough examination of your health in the outpatient clinic. You may also see other specialists from time-to-time depending on the side effects you are experiencing. Just remember to plan ahead when considering your travel arrangements. Although it can be difficult to get to and park at hospitals (depending on where you live), it is very important to attend these appointments to aid your recovery.

'At home I have a folder with all of my blood counts, every week for the last three years in it.'

Kate, had a transplant in 2015

As time passes, the appointments will become less frequent. This might make you feel quite alone but help is always available, should you need it. Eventually you'll get to the point that you only need an annual check up; but that is normally after at least a couple of years. Always remember that you can get in touch with your transplant team or the Anthony Nolan Patient Services team if you have concerns.

SIDE EFFECTS

Having a transplant is a very intensive treatment that will have a big physical and emotional impact on your life. Side effects vary from person to person and can be short term or long term. This unpredictability can sometimes make people feel worried. The side effects you experience can be caused by either the conditioning therapy you have before the transplant or the effect of the transplant itself.

We've listed some of the main side effects after transplant. This might seem a bit overwhelming, but don't forget that these are potential side effects - it doesn't mean that you will definitely experience them. Depending on how these complications affect you, your transplant team will always be close by to give you the treatment and support you need.

SHORT TERM SIDE EFFECTS

Nausea and vomiting

It is fairly common to feel and be sick after your transplant as a result of your treatment, your medication, a possible infection or graft versus host disease (GvHD) - see 'Long term side effects' on page 33). Nausea normally only lasts a week or two for most people, and can be controlled using drugs called anti-emetics. If you struggle with nausea for longer than this, you should have a chat with your transplant team because they might need to change your medication.

Diarrhoea

As with nausea, diarrhoea can have many different causes (including GvHD). If diarrhoea occurs for a long time, it can affect how you absorb vitamins and minerals from your food. Without a bit of specialist nutritional advice you could lose weight quite quickly, so it is important to let your care team know.

Sore mouth

Chemotherapy damages the cells that make the mucosal lining of your mouth. The skin can break down, which can cause painful ulcers to form inside your mouth and throat. This normally occurs about a week after treatment and will clear up in a week or two with medication and good mouth hygiene.

Infections

You'll be at an increased risk of getting an infection as your immune system recovers, which can take up to a year. Infections are caused by viruses, bacteria and fungi. They can happen anywhere in your body but the most common ones are likely to be caused by your central venous catheter (CVC), your respiratory system or your gut. For more information on infections, see our guide *Life After Transplant: An Essential Guide to Dealing With Infections*.

The essentials

It's very important to be able to spot the signs of an infection as early as possible to stop it from becoming too severe. If you have any of the following symptoms, contact your transplant team right away:

- If your temperature is higher than 38°C or it rises suddenly, it is likely that you have an infection of some sort. Keep a thermometer (in good working order) at home and take your temperature regularly, especially if you are feeling unwell, have chills, a fever or feel you do not want to eat or drink.
- If you have diarrhoea, frequent or painful urination, blood in your urine or stools or abdominal pain and cramps.
- If you have severe fatigue, bleeding, coughing, shortness of breath, chest pain or severe headaches.

Your long term recovery can be seriously delayed if infections are left untreated – so do not worry about reporting what turns out to be a false alarm, and do not think you are wasting people's time. It is always better to be safe than sorry.

Kidney problems

There are a number of reasons why your kidneys might not be working properly after a transplant. Sometimes this can be related to your medication, an infection, or simply dehydration. Mild kidney problems are common, but occasionally it might be necessary for you to go into hospital for treatment. This usually involves making

adjustments to your medications and sometimes you might need extra fluids through a drip if you've become dehydrated.

Bleeding

You might experience new bruising or bleeding at times, including a persistent nosebleed or blood in your urine or stools. There can be many possible reasons for bleeding, so contact your transplant team immediately so they can investigate the problem. It could be that your platelet count is low, which means your hospital will arrange a platelet transfusion for you.

Mood

You have gone through an awful lot in the last few months, so it's not surprising that it might start to take its toll on you. It's very common for you to feel a bit down or anxious during the early stages of your recovery, so ask your transplant team for some help. They will be monitoring you closely to offer you treatment to help with your mood at this time. For more information see page 54 for our chapter on 'Dealing with your feelings'.

TTP

Thrombotic thrombocytopenic purpura (TTP) is a rare condition that causes small clots to form in your blood following your transplant. This means you have less platelets available to do their normal job of helping your blood to clot following an injury. TTP can cause fever or headaches, and you might find that you bruise easily. It is associated with certain medications. If you ever need to talk about a particular problem you are having, contact either your transplant team directly or the Anthony Nolan Patient Services team by calling **0303 303 0303** or emailing patientinfo@anthonymolan.org

LONG TERM SIDE EFFECTS

Graft versus host disease (GvHD)

When you've had a stem cell transplant, there are still small differences between your new immune system and other cells in your body. As a result, your growing immune system may harm some of the cells in your body because it sees them as 'different'. This is called graft versus host disease (GvHD). It can affect different parts of your body

but commonly affects your skin, gut and liver in the early stages after your transplant, and can affect any part of the body later on. It can be short or long term, mild or severe. Your transplant team will be monitoring you closely for signs of GvHD and will offer you treatment that can help. Find out more by reading our booklet *Life After Transplant: The Essential Guide to Graft versus Host Disease*. For more information on the long term effects of a transplant, visit anthonymolan.org or read our booklet *The Seven Steps: The Next Steps*.

Infection

As we said earlier, you will be at risk of picking up infections for as long as you have a weakened immune system – and your immune system is likely to be dampened down by medication in order to control any GvHD symptoms you may have. This means that you will also have a long term risk of infection. This is one of the trickiest balances that your team has to make, so it's important to tell them when you get new or different symptoms so they can tweak your medications quickly.

Fatigue

When we talk about fatigue, we don't just mean feeling tired after working hard. Fatigue is when you find it difficult to concentrate and have no energy, even after lots of rest and a good night's sleep. Fatigue can be a short term effect of your treatment that improves after a few months – but some patients can still experience it more than a year after their transplant.

As surprising as it sounds, gentle exercise has been shown to help reduce treatment-related fatigue and improve your strength and energy levels. It's important to keep things in balance; your energy levels are likely to go up and down. The secret is to not overdo it on a good day but even more importantly, try to do just a little bit on what might feel like a bad day – even if it's just getting up, getting dressed and walking around the house. You will really feel the benefit of doing something, no matter how small.

You can find lots of suggestions and tips from other people who've had a transplant in our booklet *Managing Fatigue After a Bone Marrow or Stem Cell Transplant*, including tips on balancing your energy levels and being active. You will also find tips on getting a good night's sleep on page 43.

OTHER THINGS TO LOOK OUT FOR

As your recovery continues, you will have check-ups once or twice a year. This will include monitoring for late effects of treatment and health screening. You may also be referred to other healthcare professionals who can give you specialist treatment, such as dermatologists or gynaecologists. During your transplant your immune system is replaced by your donor's immune system, which means you lose the immunity you had from vaccinations when you were younger (such as measles and TB). Your transplant team and GP will schedule and deliver your new vaccinations to you; normally this happens at least two years after your transplant. Our booklet *The Seven Steps: The Next Steps* has further information about these longer term issues.

WHAT TO DO IF SIDE EFFECTS DEVELOP

It's far too easy to put something off until another day. We've all had little niggles that we should have had checked out by a doctor or dentist, only for them to be forgotten about in our hectic and busy lives. Unfortunately, if complications arise after your transplant, they are unlikely to disappear by themselves and will only get worse if left untreated.

Before you leave hospital, your transplant team will make you aware of symptoms to look for if something starts to go wrong. If you have any of these symptoms, or if you don't feel like your usual self, it's time to get checked out. You should have been given the contact details of a doctor or nurse that you can talk to about any problems you are having. You could also visit your GP, but if symptoms develop very quickly, you should go straight to A&E.

Don't worry about reporting something that turns out to be a false alarm – nobody will be upset with you because of it. It is more important that concerns are raised so that if treatment is needed, it can be given as quickly as possible.

EFFECTS ON YOUR LIFE

SOCIAL LIFE

We don't want to say you can never go out and enjoy yourself in the same way as your friends can – but your medical condition will have a bearing on elements of your social life. You might find that you can't do everything that you'd like to do all the time. However it's important to still enjoy life, so don't restrict yourself too much either; it's all a balancing act. If you find that you are not able to see as much of your friends as you would like, we have some information about managing your friendships in the 'Dealing with your feelings' section on page 54.

Even though you might not feel very healthy right now, if you can lead as balanced a life as possible it will help aid your recovery. For more information about living a healthier lifestyle see page 40 for advice on taking control of your recovery.

GOING OUT

Everybody likes to go out, whether socialising with friends, going to the cinema or a full-on night out. If you have not been able to see much of your friends recently, you might feel you have some lost time to make up for. But it is important to not overdo it, especially with alcohol. Hangovers are nasty at the best of times, so try to avoid them.

You might also find that you tire easy – and that you still feel tired the following day. Try to plan your social life accordingly and if there is a particular event you would really like to be a part of, give yourself plenty of time to recover.

DRUGS AND SMOKING

If you are a smoker or use recreational drugs, it's important that you are honest with your transplant team about what you take and how often. Nobody will judge you and you can talk to them in complete confidentiality. Your parents will not be told.

Although we won't tell you that you should stop these activities, if you continue to use them it could reduce the effectiveness of your medication, your ability to fight infections and ultimately delay your recovery. Also if you continue to smoke after your transplant, you have a higher than normal risk of developing heart problems and cancer. It is a good idea to at least consider cutting back, stopping smoking or using drugs completely in the short term.

If you would like any advice on drugs or smoking, ask your transplant team for details of services and organisations that can help you.

SEX

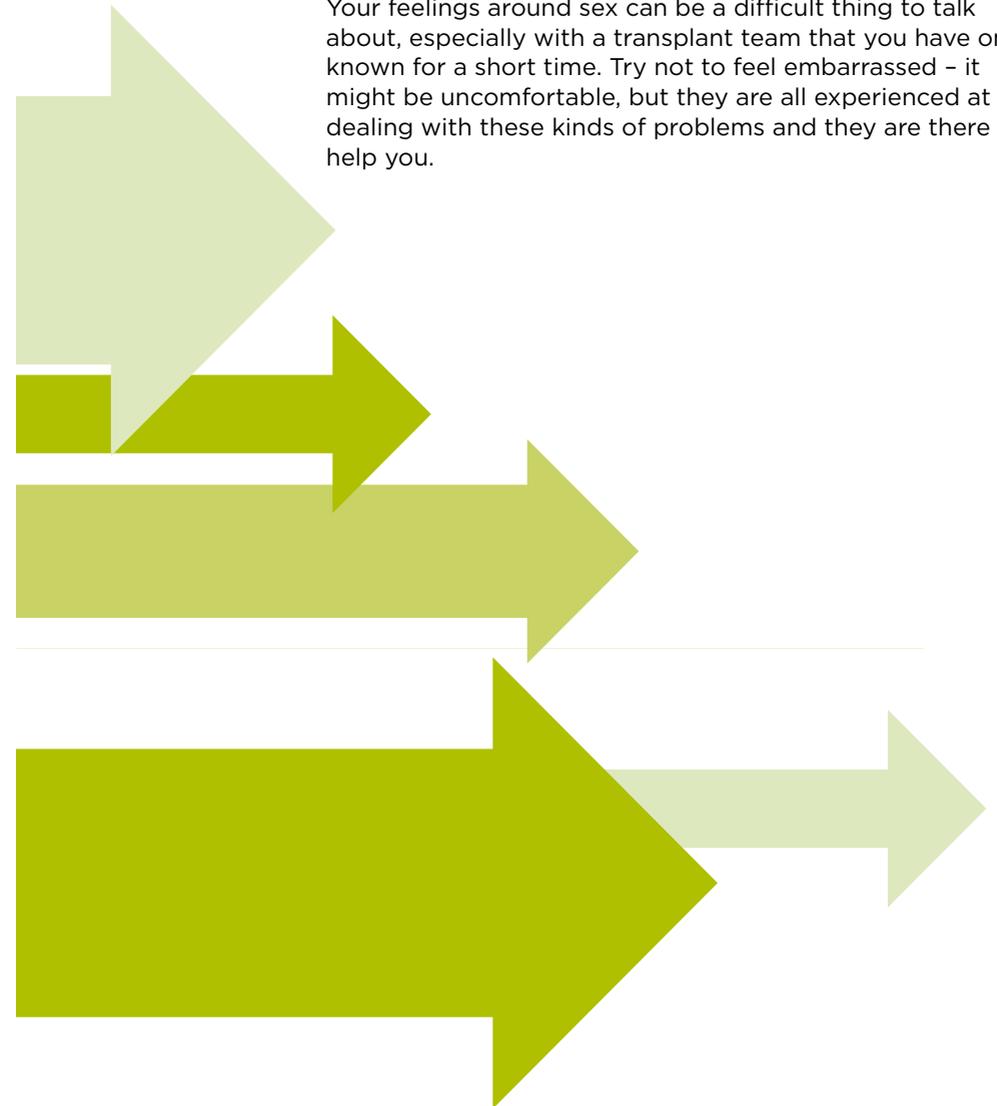
Whether you are in a sexual relationship or not, your stem cell transplant could have an impact on your feelings towards sex and your enjoyment of it.

Both young men and women can find it physically more difficult to have sex after their transplant. Men sometimes find it more difficult to sustain an erection and can experience pain during ejaculation. Women may experience vaginal dryness and pain or discomfort during sex. They may also go through the menopause earlier than expected due to the conditioning treatment they had before their transplant (see 'long term side effects' on page 33 for more details). You may be referred to a urology or gynaecology expert for specialist treatment to help you with these symptoms. For more information, see our guidebook *The Seven Steps, The Next Steps*.

During your recovery, you might feel like sex is the last thing on your mind. Your body may go through a number of physical changes that could affect your confidence and make you concerned about how you look in the eyes of other people. If you are in a physical relationship with someone, try to talk to them about how you are feeling. This will help them understand your new situation and relieve your concerns about how they will react to having less intimacy. It is important to remember that these feelings will not last forever and, as your recovery progresses; your interest in sex is likely to return.

If you are in a relationship, it is important that you practice safe sex and always use a condom, even if you or your partner is taking the contraceptive pill. This is because the chemotherapy drugs you have been taking could be passed on to your partner during sex. This also applies to oral sex.

Your feelings around sex can be a difficult thing to talk about, especially with a transplant team that you have only known for a short time. Try not to feel embarrassed - it might be uncomfortable, but they are all experienced at dealing with these kinds of problems and they are there to help you.



TAKING CONTROL OF YOUR RECOVERY

'The more in control you feel as a person, the more positive an experience it is.'

Kate, had a transplant in 2015

Being away from the security of the hospital can make some people feel anxious. But if you've gone home, that means you are doing well and it's important to start taking control of your recovery.

Although you will still have to visit the hospital for check-ups on a regular basis, you are now at the point where you can start to manage aspects of your daily routine. Think of this as one of the first steps in returning to having more freedom in your life.

In talking to our patients, they highlighted the difficulty of keeping track of everything they had to remember, from taking their medication and their appointments, to monitoring their sleep patterns. If you record all your medical data in one diary or app, it will enable you to set yourself short term and long term goals for all aspects of your recovery. This might be as simple as making sure you take your medication for a week without forgetting or going for slightly longer walks each day, the choice is up to you.

'I think it's really important to constantly have some kind of goal, even if it's just to get out of bed that day.'

Georgie, had her transplant in 2015

MEDICAL APPOINTMENTS

After your transplant, you will still have to visit your hospital outpatient department on a regular basis. This is to check that everything is recovering as it should be, that you have not picked up any infections and that any side effects you may have are being properly controlled.

MEDICAL DATA

Your medical team will regularly count the different types of cell that make up your blood and other factors to check that your new immune system is working properly. These results

are recorded every time you visit the hospital. You will be able to monitor your progress by looking at:

- White blood cell count – the cells that make up your immune system and fight infections.
- Haemoglobin – carries oxygen around your body, it is found in red blood cells.
- Platelets – help the blood to clot following an injury.
- Immunosuppression – the amount of ciclosporin, mycophenolate, tacrolimus or other drugs used to dampen your immune system currently in your blood.
- Chimerism – the amount of bone marrow and blood cells that come from your donor compared to your own. The ideal = 100% donor.
- Temperature – acts as an early sign that you might have an infection.
- Blood pressure – transplant patients have an increased risk of high blood pressure.
- Kidney and liver tests.

CENTRAL VENOUS CATHETER (CVC)

Your CVC can be a potential source of infection so it is important that you look after it. When you visit the hospital it will be checked, cleaned and flushed weekly to stop it becoming blocked. Your doctors will remove it as soon as it is safe to do so.

MEDICATION

We know that trying to remember to take all of your medications at the right time is not always easy. Changes in your medication can happen frequently and getting used to the changes can be hard. Put reminders in your diary to make sure you don't miss any.

'I feel like I have to be my own stock taker at home. This is how many drugs I have got and this how long it's going to last me.'

Georgie, had a transplant in 2015

EXERCISE

Exercise may feel like the last thing you want to do, but it can help to reduce fatigue and improve your physical strength. It is important to not overdo it as your fitness, endurance and muscle strength will have reduced during your treatment. Set yourself small goals and build up gradually over time. You should ask to speak to a physiotherapist at your transplant centre so they can give you some specific advice about how much exercise you can safely do, especially if your blood results are still going up and down a bit.

SLEEP

Having a good night's sleep will help your recovery, but you might find it difficult to sleep at times. By recording your sleep pattern you will be able to look back on when these problems occur. This will help your transplant team to spot patterns and identify ways in which they can help.

Sleeping tips:

- Avoid alcohol, caffeine and nicotine for approximately four hours before sleep as they all act as stimulants.
- Stop using devices that emit stimulating 'blue light' – such as mobile phones and laptops – one hour before you go to bed.
- Make your bedroom quiet and relaxing, and keep it at a comfortable, cool temperature.
- Establish a relaxing pre-sleep routine, such as reading a book or listening to a podcast.
- Stick to a regular sleeping pattern – if you fall asleep and wake up at the same time each day, your body's natural sleep cycle will be more settled.
- Only go to bed if you feel tired – if sleep doesn't come, try something relaxing to take your mind off things.

FOOD AND WEIGHT

After your transplant, you might find that your attitude to food changes. Your appetite might not be what it once was and food might smell and taste differently to you. Don't worry – this doesn't last forever.

Many people lose weight during this time – but your body actually needs more nutrients than usual, to help your cells renew and repair. To help this happen, eat little and often, and focus on food that you really enjoy.

'If I knew I was gaining weight after my transplant that would have been helpful to me.'

Georgina, had a transplant in 2014

FLUIDS

It is very important that you keep yourself hydrated at all times to aid your recovery. Your transplant team (and family) will remind you of this fact on a regular basis. It might be easier to drink smaller amounts more regularly. Try to have a water bottle with you at all times – using flavoured cordials can make drinking large volumes more bearable.

'I have to make sure I am drinking at least three litres of water a day.'

Jabraan, had a transplant in 2016

PHYSICAL WELLBEING

Being able to accurately recall when you experienced certain side effects and how strong they were can help your team tailor your medication accordingly. Get in the habit of recording any symptom or change you experience, when it happened and how bad it was, perhaps using a 1-10 scale.

MENTAL WELLBEING

Recovering from a stem cell transplant will probably be the hardest thing you ever have to do. There will be days when you are physically and mentally drained – but there will be good days when you feel like you're on top of the world.

There are great benefits to recording your state of mind in a diary or app. You can gain a sense of progress in your recovery – and it can also highlight when you need extra support from friends, family or a professional counsellor. For more information see page 54 for our section on 'Dealing with your feelings.'



GETTING BACK TO YOUR LIFE

Just like when you left hospital, your return to school, university or place of work is a big step in your recovery. This can feel exciting but also daunting, especially if you've been away for a long time. However, making preparations for your return will really help. Although it might be tough, it's really important that you tell your tutors or employer about your condition so that they can support your needs. At the end of the day, if you don't tell them, it's very difficult for them to help you.

RETURNING TO EDUCATION

Starting your education following your stem cell transplant does not necessarily mean you have to begin full time education straight away. Your transplant team will help you decide when it is OK for you to return. Your recovery is a gradual process, so ease yourself into it slowly. You may be able to do some work at home or attend part time. Try to build up your workload slowly over time, so that you don't feel overwhelmed.

BREAK THE ICE

You might not have been able to see your close friends very often during your recovery, either because you were too far away or because they weren't sure what to say. It is also possible that your appearance has changed since you were in school or college. To make yourself feel more comfortable, you could organise to go out with them for a catch up before you return to school or college or, if you don't feel up to that, invite them to your home for a chat. Take this opportunity to tell them as much (or as little) about what you are going through as you feel comfortable with. They might have questions about things they are unsure about as well so give them our *Supporting Your Friend Through a Bone Marrow or Stem Cell Transplant* booklet to read.

'I wanted to make going back to school as easy as possible. I did not want to walk back in on my first day and have random people asking me lots of questions.'
Kate, had a transplant in 2015

TALK TO YOUR TUTORS

Before you return to your studies, it is a good idea to get in contact with your tutors to let them know how you have been getting on. Although they will know why you had to take time off, they may not be aware of your needs during your recovery. This is the perfect opportunity to think about what could be done to make your return easier. It's important that they know there could be times when you have to attend medical appointments or feel too unwell to study. You may want your tutor to talk to your classmates about what has been going on, so that you don't get overwhelmed by everyone asking you the same questions. If you prefer you could ask your parent, guardian or friend to go along with you.

'I was lucky with my teachers in that they would send me work every single week, check on my progress, ask my friends or get my friends to give me stuff. I was really interactive with them.'

Kate, had a transplant in 2015

MOVING AWAY

If you are about to start university or are returning to your studies after your transplant, then potentially living a long way from home can provide its own set of challenges. Make sure that you have a good support network in place and that the people you are living with know who to contact in the event of an emergency. You should also try to move your hospital appointments to a local hospital and register with a GP that has access to your clinical records.

BULLIES

It's a horrible thing to have to talk about, but some people might use what you have been going through to make fun of you. If this happens, talk to an adult you can trust and get help – you should not have to put up with this alone. Although it's not an excuse, some people react this way because they are nervous and do not understand your situation. You might want your teacher to talk to your classmates about what you have gone through before you return. The **Teenage Cancer Trust** can arrange for an expert

to come into your school to do this. For more information, visit **teenagecancertrust.org**

EXAMS!

This is probably the last thing you want to think about as you prepare for your return to education. However, it might ease your mind to know that you can apply for certain access arrangements that could make your life a little easier when it comes to exams. This can include having somebody write for you, or being given additional breaks.

You might also decide to apply for a 'special consideration' for your exams. This means the examiner will consider your individual situation and the time you've had away from your studies when marking your exam sheet. You will need to talk to your tutors for the details of your specific college/university.

RETURNING TO WORK

Let's make one thing clear from the beginning: it is illegal for your employer to discriminate against you because of a medical condition. You are protected from losing your job unfairly under the Equality Act 2010 – the **gov.uk** website has full details.

Under the Act, your employer should also be willing to make 'reasonable adjustments' to help you upon your return to work. This includes allowing you to have time off work to attend hospital appointments and regular breaks during your working day. Give your line manager, employer and HR department our booklet, *Work and Stem Cell Transplants: An in-depth Guide for Employers* so they can understand more about your stem cell transplant and recovery, and they can start to prepare for your return.

It is a good idea to keep in contact with your employer during your recovery so you can update them on your progress. It might even be possible to arrange a 'phased' return, where you work part time or do a few tasks from home and then gradually build up your workload.

Even after you and your transplant team agree that it's a good time for you to return to work, it is still important to

regularly talk to your employer about how you are feeling. Your situation may change or you may find that you would benefit from other changes that you have not talked about previously.

For information about managing your return to work and finances, read our in-depth guide *Work and Finance: Before, During and After a Stem Cell Transplant*.

LOOKING FOR WORK

Some people find that a stem cell transplant is a life changing experience. This change in perspective sometimes leads to a change of career that they feel is new and exciting. If you have similar feelings, then take time to stop and think about exactly what it is that you want to do, and discuss your thoughts with your friends and family.

Remember that you have no obligation to tell a new employer about your medical situation. As long as you are qualified and physically able to do the job, it should not be a problem. If you see the 'disability confident' symbol in job adverts or an organisation's website you can be assured that they don't discriminate against disabled people when recruiting.

MONEY

If you've had to take a long period of time off work, this can lead to anxiety around money and being able to pay your bills. It is one of the main reasons why some people return to work earlier than they really should after their transplant. It is important to remember that there is money available to you during this time to help ease your financial worries.

Statutory Sick pay (SSP): You are able to claim SSP if you are in employment and off work for longer than four consecutive days. You can claim for up to 28 weeks and you will need to get a 'fit note' from your doctor or nurse in order to claim.

Occupational/company sick pay: You may be entitled to additional sick pay that is paid for by your employer. The details of your company's scheme will be written in your contract or staff handbook, if you have one. The amount of

money and the time in which you receive it will vary from company to company. It is not offered by all companies. Employment and Support Allowance (ESA): If you are not eligible for SSP or if your SSP is about to end, you may be able to claim ESA. You can apply for ESA if you are employed, self-employed or unemployed. It provides financial support when you are ill and personalised help so that you can work when you're able to.

A welfare advisor or social worker at your hospital should be able to help, or you may have a Macmillan Cancer Support or Maggie's Centre nearby - find out more at macmillan.org and maggiescentres.org

ANTHONY NOLAN GRANTS

Our grants are available to people affected by a transplant who have limited savings. Grants are typically under £150 and can help to meet a wide range of practical needs arising from their transplant. This might include paying for travel to get to your medical appointments, or new clothes if your treatment has caused you to lose weight, for example.

You can find more information about the grants by downloading the Anthony Nolan Grants Advice form from our website at anthonymolan.org

OTHER GRANTS

Macmillan Cancer Support and CLIC Sargent both offer grants to support young people, which you may be eligible for. The Turn2us charity also lists grants that you may wish to apply for - visit turn2us.org.uk or contact your local Citizen's Advice.

TRY SOMETHING NEW

You may decide that you would like to try something new after your transplant. This could be because your priorities in life have changed or it could just be that you want an excuse to get out of the house! Some people decide that they would like to give something back or help other people going through a similar situation. Here are a few suggestions of things you might like to try. Just remember, it's up to you what you do - but don't push yourself too far and overdo it.

Write a blog: Some people find it very therapeutic to write about their experiences, both good and bad, and enjoy sharing them with others. However some do not like the idea of putting their personal views on public display, so only share if you feel comfortable doing it. Online blogs can be set up and maintained for free using web platforms such as **wordpress.com**

Volunteer: Charities will always welcome people who would like to volunteer to help them. It can be very rewarding to support charities that are close to your heart – and volunteering looks great on your CV too. We'd love you to get involved with Anthony Nolan, and you can find out more information at **anthonymolan.org/volunteer**. You can also find lots of other volunteering opportunities all over the UK at **do-it.org**

Fundraising: Although you're probably not quite ready to run a marathon just yet, there are plenty of other things that you can do to raise money for a good cause. There are lots of ideas and tips on our website at **anthonymolan.org/fundraising**

British Transplant games: Held annually across the UK, the games consist of over 20 different events and transplant patients of all ages can compete. So if you fancy training for your big day and bringing home a gold medal, take a look at **britishtransplantgames.co.uk**. You can also register your interest to represent Anthony Nolan by emailing **patientinfo@anthonymolan.org**



DEALING WITH YOUR FEELINGS

It goes without saying that recovering from a stem cell transplant can be tough at times. You've probably already experienced a wide range of emotions including feeling scared, lonely and uncertain - but also positive feelings of happiness and joy when you feel things are going well. This rollercoaster of emotions, coupled with feeling ill and tired, can take its toll on you emotionally. This can affect how you interact with other people.

When you are feeling low or it seems like your worries are getting on top of you, it's important to reach out for support. You can talk to your transplant team or contact other organisations for help such as The Samaritans, mental wellbeing charities such as The Mix and Mind, or the Anthony Nolan Patient Services team. Contact details for these organisations can be found at the back of this guide.

In this section we'll look at how your transplant might change the relationship you have with your family and friends. We will also look at some coping mechanisms you can use to help you keep in control of your emotions when things get hard.

PARENTS

As a young person, your relationship with your parents can become strained. This is completely natural because you are starting to gain a sense of independence and rely on them less. Unfortunately, your parents are probably feeling the exact opposite right now because of your medical condition. Their natural response is to try to protect their child from any harm and to 'wrap them up in cotton wool'. They may go too far and become over-protective, perhaps nagging you to take your medicines or stopping you from going out in case you overdo it.

This can be a recipe for disaster, and you might find that you argue with them more often. Rows are usually caused by breakdowns in communication, so it is important to understand how to negotiate and compromise. Try to remember that even though they might be putting on a brave face, at times your parents are likely to be as stressed and worried as you are. This can make it more difficult to listen to you and to see your point of view. Your parents are not mind readers, so it's important that you can tell them

what you need and what you would like to happen without causing confrontation. However, this has to go both ways – so if they are insisting on something you don't agree with, try to see their point of view and suggest compromises.

SIBLINGS

Whether you are really close to your big sister or fight like cat and dog with your little brother, your transplant will have a big effect on your siblings. Hopefully it will make the bond between you even stronger – but it might be a source of some friction.

Your sibling might have been the person who donated stem cells for your transplant. They obviously did this because they wanted to help you but it can be a stressful situation for them too. All siblings worry if their brother or sister's transplant is going to be a success – but some of them feel guilty or even responsible if it is not. Our booklet *Donating to Your Relative* has been put together to help them work through these feelings.

Even if you did not receive your stem cells from your sibling, it will still be a really tough time for them too. They may be disappointed, frustrated or even angry that they were not able to be your donor. They may also feel unimportant and a little forgotten about if other family members focus on you and your recovery most of the time.

Don't be too surprised if this causes a change in their behaviour. They might not be too friendly around you, behave nastily or even decide not to come and visit you. Although this can be hard to take, try to understand that this is their natural reaction to a very stressful situation. Be aware of their feelings and try to involve them as much as you can. Let them know they are important to you and that you appreciate their support.

'My parents were worrying about me, and my sister was completely on her own. Then she got in her head that she had to be strong because she did not want them to worry about her.'

Kate, had a transplant in 2015

FRIENDS

It's likely you'll make new friends on your transplant journey. In hospital, charities such as Macmillan, CLIC Sargent and the Teenage Cancer Trust organise support groups that encourage patients to get to know each other (once you are well enough to attend). Friendships formed here can support you in ways that other friends and family might struggle with, because they are experiencing the same thing as you. For that reason, many people form deep, lifelong friendships during this time.

It can be difficult to keep in contact with your friends from back home while you're recovering from your transplant. Some friends will continue to make you laugh and help to support you, but others may find it more difficult. You might find that your relationship with some friends changes and becomes a little awkward. This is often because they are uncomfortable with the situation and worry about saying the wrong thing. If you notice this and feel comfortable doing it, try to encourage your friends to be open and to ask questions about things they don't understand.

'At first I did not want my friends to know, but now I understand that the community of people you are in is important too.'

Kate, had a transplant in 2015

Seeing your old friends after you return home might leave you feeling anxious and frustrated in ways you were not expecting. Some of our patients have spoken about not being able to relax around their friends because of the risk of picking up an infection. They worried about appearing rude but at the same time felt like they had to protect themselves.

'Because it was winter, everyone had colds. I was going to see my friends but then I'd get there and someone would sneeze, and I felt like I had to leave.'

Kate, had a transplant in 2015

It is a great idea to take control of this situation and explain everything to your friends early on. They will understand and do their best to help you – but you might have to make it clear that it could take months for you to recover properly.

PARTNERS

It can be hard to work out why relationships succeed or fail at the best of times, and your stem cell transplant could make your relationship more complicated. For some couples, a situation like this brings them closer together; but for one reason or another, your relationship might become strained after your transplant or even break down.

It will be important for you both to talk to each other about how you are feeling so there are no misunderstandings. If your partner appears to be distant, help them to open up about their feelings; they could be hiding their concerns because they don't want to burden you with extra worries. Try to find the time to enjoy each other's company, talk about the things that make you both happy and try to forget about your situation for a while.

If you are concerned about your relationship and you feel like you can't resolve it without help, have a chat with your transplant team. They will be able to put you in contact with a counsellor who you can talk to, either with or without your partner.

The essentials

- To reduce the chance of arguments, try to stay calm, understand the other person's point of view and suggest some compromises.
- Plan to have difficult conversations with someone close to you while you are both engaged in an activity (such as travelling, for example). It will give you both something else to focus on if things get a little tough.
- Don't bottle things up. Talk to the people closest to you about your concerns and try not to worry about how they might take the news.

- If you're feeling down, remember what makes you happy. If you love a certain film or type of music, stick it on – you might be surprised at the difference it can make.
- Knowing when you need help, when you need some space and being able to make people understand will help you stay calm and in control.

DEALING WITH LOSS

Unfortunately stem cell transplants are not always successful. Over time you may have to come to terms with the passing of someone that you had become close friends with during your treatment. This is never easy to cope with and it could be a particularly emotional time for you. It might be hard to hear right now, but it will get easier with time.

There is no right or wrong way to deal with your feelings – but it is not a good idea to just ignore them in the hope that they will go away. Try to find a way to express your emotions because it will help you come to terms with how you are feeling. If you would like to talk to someone, your transplant team can organise a counsellor for you. Alternatively you may wish to contact one of the charities or bereavement services listed in 'Other useful information' on page 69.

WHO ELSE CAN I TALK TO?

Sometimes you might decide that you want to talk about a problem with somebody who isn't a close friend or family member. Luckily there are plenty of options available to you, so you can always try out a few until you find somebody who you are comfortable with. This includes a variety of youth support co-ordinators, clinical psychologists, counsellors and support groups that can all be accessed through your transplant team. You may also find comfort in talking to religious figures or charitable organisations, such as the Samaritans or our Anthony Nolan Patient Services team.

Don't forget, you can also find support from people who have been through similar experiences to yourself online, through social media and the Anthony Nolan Patients and Families Forum at [anthonynolan.org/forum](https://www.anthonynolan.org/forum)

'You are so isolated when you are going for treatment and you feel like you are so on your own - but you're not.'
Georgie, had a transplant in 2015

COPING MECHANISMS

In simple terms, a 'coping mechanism' is anything you do to make you feel less stressed. Different things work for different people and it could be that you have to find your own coping mechanisms for a range of situations. We can't tell you what will work for you, but here are a few suggestions. Some are quick little 'pick me ups' while others might help you in the longer term:

LONGER TERM IDEAS

Find out more - some people worry about the unknown, and finding out more information about something like a stem cell transplant can make it easier to come to terms with. You can always talk to your transplant team about any questions you have, visit the Anthony Nolan website or contact our Patient Services team.

Get organised - there are many things to remember during your recovery, so try to settle into a routine. You will have days when sticking to your plan is more difficult but if you feel like you are doing something positive and that you're in control, it will help.

Talk to people - as the old saying goes, 'a problem shared is a problem halved.' Sometimes simply talking to people close to you can make a huge difference. Remember you can also talk about any problem you have with a professional, a counsellor or your transplant team.

Sleep well - being able to regularly get a good night's sleep will make you feel better and allow you to cope with your emotions more easily. See our sleep tips on page 43.

PICK ME UPS

Take a deep breath - it sounds simple but it can really help to calm your nerves.



Treat yourself - what you are going through is not easy, so enjoy the little things in life. Buy that slice of cake when it tempts you, play a video game with your friends or enjoy a makeover, whatever takes your fancy.

Play some music - make a playlist of your favourite songs that always lift your spirits.



Have a laugh - everybody has something that always makes them laugh, so create a playlist of clips on YouTube that make you smile or ask your friends for their best comedy recommendations.



GLOSSARY OF TERMS

TRANSPLANT TERMS

Acute lymphoblastic leukaemia (ALL)

To work properly, your body's immune system needs to make fully-formed white blood cells called lymphocytes. Before they mature they are known as lymphoblasts. In ALL patients, they grow too quickly and never begin working properly. ALL develops quickly and it is the most common blood cancer in children.

Acute myeloid leukaemia (AML)

Myeloid cells can develop into red blood cells, platelets and white blood cells. Before they mature they are known as myeloblasts. In AML patients, they grow too quickly and never begin working properly. AML develops quickly and is more common among elderly people.

Autologous stem cell transplant

This is when your own stem cells are collected and then put back into your body after you have had chemotherapy.

Blood Cancer

A blanket term for all cancers that originate from cells in your blood or bone marrow.

Blood cord transplant

When you receive your new stem cells from blood that was donated from a baby's umbilical cord at birth.

Blood disorders

A range of other diseases that can be cured using a stem cell transplant. They are normally caused by inherited mistakes in our DNA – examples include aplastic anaemia and sickle cell disease.

Bone marrow

The spongy tissue found in the middle of bones. It contains stem cells that can develop into all types of blood cells.

Chemotherapy

One or more drugs that kill fast-growing cancer and abnormal cells.

Chronic lymphocytic leukaemia (CLL)

To work properly, your body's immune system needs to make fully-formed white blood cells called lymphocytes. Before they mature, they are known as lymphoblasts. In CLL patients, they grow too quickly and never begin working properly. CLL develops slowly over many years and is very rare in people under 40.

Chronic myeloid leukaemia (CML)

Patients with CML produce too many of a particular white blood cell called a granulocyte. This stops other blood cells working properly. CML develops slowly over many years and is very rare.

Conditioning treatment

This prepares your immune system for your new transplant cells. It often consists of chemotherapy and/or radiotherapy that removes any abnormal cells in your blood.

Donor

The person who will donate their stem cells to you.

Engraftment

This is the process after your transplant, when your new stem cells travel to your bone marrow, begin to grow and make new blood cells.

Graft vs host disease (GvHD)

Sometimes after a transplant, your new immune system attacks your body's other cells because it sees them as different. This can cause a variety of long and short term side effects.

Graft versus leukaemia (GvL)

When immune cells from your stem cell transplant recognise and eliminate any remaining cancer or abnormal cells present in your blood.

Haploidentical stem cell transplant

This is when you receive your new stem cells from a relative whose tissue type is a half match to your own. It is often a good alternative if a matched donor can't be found.

Hodgkin Lymphoma

A type of lymphoma that is most common in young adults.

Human leukocyte antigen (HLA)

Five genes that are used to determine someone's tissue type. Each gene has two different versions that you inherit from your mum and dad.

Leukaemia

A group of cancers that stop white blood cells from developing properly. This can 'clog up' your bone marrow and stop it making other blood cells needed for a balanced immune system and healthy blood.

Lymphoma

A blood cancer that affects your lymphatic system. Lymphoma patients produce too many of a certain type of white blood cell called lymphocytes. This can compromise the immune system.

Match

When a donor has a similar tissue type to a person who requires a transplant.

Matched unrelated donor (MUD) transplant

When you receive your new stem cells from somebody who is not related to you but who has been tested to make sure they are the best match for your transplant.

Myelodysplastic syndromes (MDS)

A group of blood disorders which prevent a person's bone marrow from producing the correct number and quality of blood cells. It is very rare but can lead to acute leukaemia.

Myeloma

A type of blood cancer that is caused by producing too many plasma cells. These cells are part of your immune system and are responsible for making antibodies. This can 'clog up' your bone marrow and stop it making other blood cells needed for a balanced immune system and healthy blood.

Non-Hodgkin lymphoma (NHL)

NHL is one of the most common cancers in the UK. Most lymphomas are Non-Hodgkin and around half the cases are diagnosed in people over 70.

Radiotherapy

High energy beams (often X-rays) that kill fast-growing cancer and abnormal cells in the area of the body that is treated.

Sibling stem cell transplant

When you receive your new stem cells from either your brother or sister.

Stem cells

Found in the bone marrow. They can develop into red blood cells that carry oxygen, white blood cells that fight infections and platelets that help to clot your blood.

Stem cell transplant

You will receive healthy stem cells from a chosen donor. When they enter your bloodstream, they will begin to grow and make healthy new blood cells.

Total body radiation

A type of radiation treatment that removes abnormal cells from your blood before your new stem cells are transplanted.

MEDICAL TERMS

Absolute Neutrophil Count (ANC)

Measures the number of white blood cells (which fight infections) in your blood.

Anaemia

When your blood does not have enough oxygen in it because you are not making enough healthy red blood cells.

Analgesic

A pain killer.

Antibiotics

Drugs that kill bacteria and fungi that can cause infections.

Anti-emetic

Drugs that stop you from feeling and being sick.

Blood Culture

A test to see whether you have an infection in your blood.

Blood tests

Your blood will be tested for many different things both before and after your transplant, to check that everything is working properly. You will not necessarily have all of the tests every time you give blood.

Central Venous Catheter (CVC)

A thin tube that goes through the skin near your collarbone and into the big vein that leads into your heart. It is used to deliver blood, treatments and the stem cells themselves.

Cytotoxic drugs

Drugs that kill fast growing cancer and abnormal cells.

Full blood count

Measures the number of red blood cells, white blood cells and platelets in your blood.

Haematocrit

The volume of your blood that is made up of red blood cells. It is normally between 45-50%.

Haemoglobin

The protein that carries oxygen in your red blood cells.

Haemorrhage

Another name for bleeding. This term is normally used to refer to internal bleeding.

Hickman line

A common brand name for a type of central line.

Immune compromised/Immunocompromised

When your immune system is not as effective at fighting off infections as it should be.

Immune suppression/Immunosuppression

When the strength of your immune system is controlled, using drugs, to reduce the effects of GvHD.

Intravenous

Delivery of treatments directly into the bloodstream.

PICC line

A peripherally inserted central catheter (PICC) line is a thin tube that goes through the skin in your arm into the big vein that leads into your heart. It's used to deliver blood, treatments and the stem cells themselves.

Platelets

Cells that clot blood and repair wounds. They can be affected by chemotherapy.

Red blood cells

Carry oxygen to the organs in your body. They make up 35-50% of the total cells in your blood.

Relapse

When your original illness returns after a transplant.

Remission

When there is no sign of your illness following your transplant.

Septicaemia

When your immune system overreacts to an infection, which leads to tissue and organ damage.

White blood cells

Cells that make up your immune system and fight infections.

White blood cells differential

Measures the number of different types of white blood cells present in your blood.

PEOPLE**Clinical Nurse Specialist (CNS)**

A nurse with specialised training in a particular treatment, such as stem cell transplants.

Community Nurse

A nurse that will care for you in your own home.

Consultant

The 'main' doctor responsible for your treatment. They are an expert within their field.

Counsellor

Someone who is professionally trained to help you talk about your worries and feelings.

Dietician

Will give you advice on food and nutrition.

General Practitioner (GP)

Your 'normal' doctor, who probably referred you for your initial diagnosis. They will also be involved in managing any symptoms that arise after your transplant.

Haematologist

A doctor who specialises in blood illnesses.

Multidisciplinary Team (MDT)

A group of healthcare professionals who are responsible for all aspects of your healthcare, before and after your transplant.

Occupational therapist

Will provide support to help you carry out everyday tasks.

Palliative care team

Responsible for managing and relieving your symptoms of pain following transplant.

Pathologist

Analyses your blood for signs of any disease and what is causing it. This often involves looking at your blood cells with a microscope.

Pharmacist

A person trained to give out medicines prescribed by doctors.

Phlebotomist

A person trained in taking blood samples.

Physiotherapist

A trained professional who treats physical ailments, usually with exercise.

Psychologist

Someone who can help you manage your feelings.

Radiographer

The person who will administer your radiation treatment.

Social worker

Will help you to 'return back to normal life'. They provide support and direction for numerous issues such as education, work and financial support.

Youth worker

Someone who will help you to stay active and social following your transplant.

OTHER USEFUL INFORMATION**Anthony Nolan**

Where can I get more information and support?
If you or a loved one is affected by a stem cell or bone marrow transplant, there are many ways Anthony Nolan can support you.

Need to talk?

Our Patient Services team is here for you. Call us on **0303 303 0303** or email: **patientinfo@anthornolan.org**

Get connected

Find support from other patients and their families by joining our patient and families forum: **anthornolan.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: **anthornolan.org/patientinfo**

OTHER ORGANISATIONS THAT CAN HELP

Bloodwise

bloodwise.org.uk, 020 7504 2200

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

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.

CLIC Sargent

clicsargent.org.uk, 0300 3300 0803

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

Teenage Cancer Trust

teenagecancertrust.org, 020 7612 0370

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

The Daisy Network

daisynetwork.org.uk

A large support group for women suffering with Premature Ovarian Insufficiency (POI) also known as the early menopause.

British Association for Counselling and Psychotherapy

itsgoodtotalk.org.uk, 01455 88 33 00

Information about counselling and therapists in your area.

Mind

mind.org.uk, 020 8519 2122

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

Childline

childline.org.uk, 0800 1111

Helps anyone under 19 with free counselling. You can talk about any problem you might be experiencing, no matter how big or small.

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.

Expert Patients Programme

expertpatients.co.uk, 0800 988 5550 or 01925 320 000

Free self-management courses to help you take control and manage your condition.

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.

Look Good Feel Better

lookgoodfeelbetter.co.uk, 01372 747 500

Providing practical and effective free services for patients struggling with the visible side effects of cancer treatment.

NHS Choices

nhs.uk

helpline: 111

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

Managed Service Network (MSN) for Children and Young People with Cancer in Scotland

youngcancer.scot.nhs.uk

In Scotland, all cancer centres that care for children, teenagers and young adults are controlled under one service, known as a Managed Service Network (MSN).

Youth Cancer Trust

youthcancertrust.org, 01202 763 591

Provides support and free activity-based holidays for young people aged 14-30 living with cancer in the UK.

Turn2us

turn2us.org.uk, 0808 802 2000

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

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

GOV.UK

gov.uk

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

MyPlus Students' Club

myplusstudentsclub.com

Tips for getting a new job and information about companies committed to employing people with disabilities.

Think U Know

thinkuknow.co.uk/14_plus

Information and advice about staying safe online. This is run by the agency for Child Exploitation and Online Protection (CEOP).

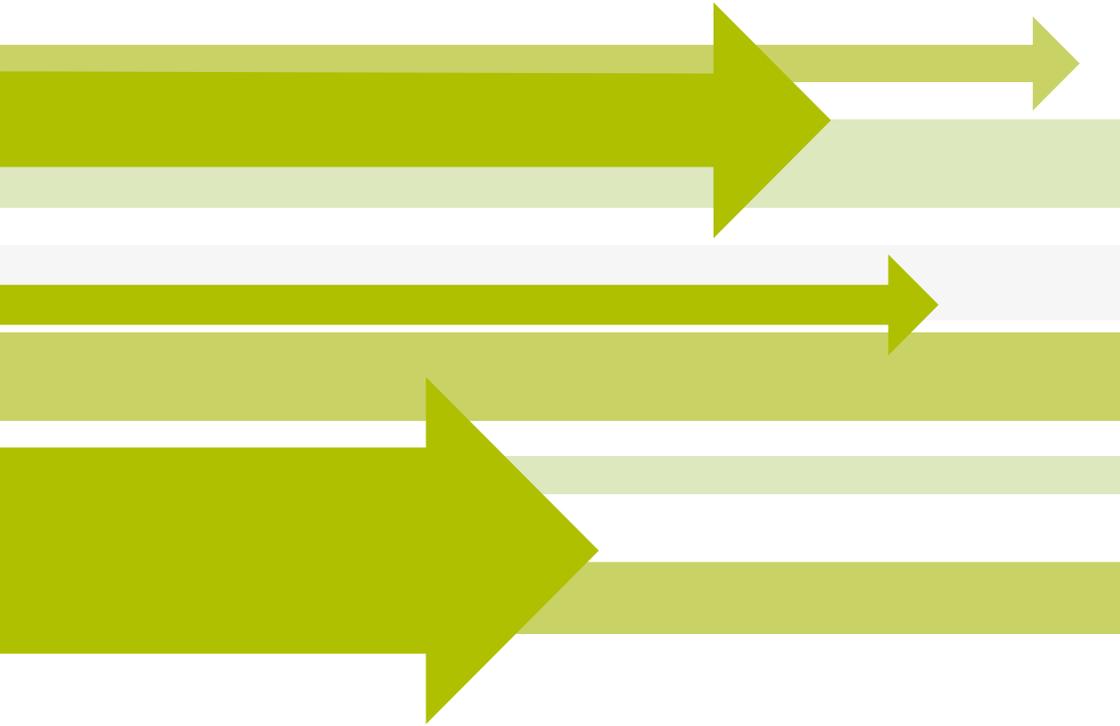
Child Exploitation and Online Protection (CEOP)

ceop.police.uk/safety-centre

If something has happened to you online that has made you feel worried or unsafe, you can report it here.



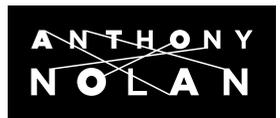
Produced with support from the Jack Petchey Foundation, in memory of John Petchey.



anthonymolan.org/patientinfo
facebook.com/anthonymolanpatients

patientinfo@anthonymolan.org
0303 303 0303

Reg Charity no 803716/SC038827
1230PA/0717 DOC4084 Version 001 (0617)



**saving the lives
of people with
blood cancer**