

DONATING STEM CELLS TO YOUR RELATIVE



ANTHONY
NOLAN

saving the lives
of people with
blood cancer

At Anthony Nolan we take great care to provide up to date and accurate facts about stem cell transplant. 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.

Ordering more copies

If you'd like to order more copies of this guide please get in touch with us on **patientinfo@anthohnolan.org**

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

The information contained in this booklet is correct at the time of going to print (October 2019). We plan to review this publication within three years. For updates or the latest information, visit **anthohnolan.org**

Cover image: Linet, who was a stem cell donor match for her sister Diana (left) in 2016.

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ANTHONY NOLAN
PATIENT SERVICES

WHAT'S IN THIS BOOKLET?

We've produced this booklet for anyone thinking about donating their stem cells to a relative who needs a transplant to treat a blood cancer or blood disorder. It will explain why a donation is needed and what happens at each step of the process.

To help you decide if donating is the right choice for you, this booklet has been written with guidance and advice from specialist healthcare professionals and remarkable past donors who have been where you are now.

If you need to ask us any questions, or you would like some more advice, please get in touch with the Anthony Nolan Patient Services team at:

patientinfo@anthohnolan.org or on **0303 303 0303**.

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KEY FACTS

- The reason your relative needs a stem cell transplant is to treat either a blood cancer or a blood disorder. These conditions often stop blood cells from doing their jobs properly, making your relative unwell.
- Matching is based on your human leukocyte antigen (HLA) tissue type. We look at five HLA genes that we inherit from our parents. The better the match, the better the chance of a successful transplant.
- If you're a sibling, you will be tested first because you have the best chance of being a full match.
- Haploidentical (haplo) transplants use stem cells from a family member whose tissue type is a half-match. Parents are always a half-match for their children, and vice versa.
- Most people donate via Peripheral Blood Stem Cell (PBSC) collection, which involves a series of injections that increases the number of stem cells in your blood. They are then collected in a similar process to giving blood, which takes a few hours.

- Around 10% of people donate through their bone marrow. It's collected from your pelvis while you're under general anaesthetic.
- Depending on how you donate, you may experience some mild side effects afterwards. With plenty of rest, these should clear up in a few days.
- If a matching, related donor cannot be found, we'll search the Anthony Nolan register and other registers from around the world to find an unrelated matched donor.

WHY DOES MY RELATIVE NEED A STEM CELL TRANSPLANT?



You're probably reading this booklet because a family member of yours needs a stem cell transplant to treat either a blood cancer or a blood disorder. As their relative, you have a good chance of being able to donate your stem cells to them – you may have already been asked by the medical team if you want to donate.

This can be a very difficult and emotional time for everyone involved. Deciding whether to be your relative's donor can put a lot of pressure on your shoulders alongside the continuing worry of whether they're going to get better.

It's important that you have all the facts at hand to understand both why your relative needs a transplant and how the donation process works. The following information should answer any questions you have and help inform your decision on whether or not to become a donor.

WHY ARE STEM CELLS IMPORTANT?

Stem cells are our body's building blocks. All other cells, tissue, organs and bones develop from stem cells.

Blood stem cells live in our bone marrow - the soft tissue found in the middle of our bones. They're responsible for creating lots of different types of blood cells. They all have a unique job that keeps our blood healthy including red blood cells (for carrying oxygen), platelets (to help blood clot) and white blood cells (for fighting infections).

Our blood stem cells need to produce exactly the right amount of each type of blood cell. If your relative has a blood cancer or blood disorder, there's likely to be a problem with this carefully-controlled process. This means that some of their blood cells can't do their job properly, making them unwell.

HOW DO TRANSPLANTS WORK?

When a matching donor is found, your relative will start treatment to prepare their body for the transplant.

First, they will have a course of chemotherapy and possibly radiotherapy. You may hear this referred to as ‘conditioning therapy’. This removes the abnormal cells which are causing their condition.

The donor’s stem cells will also be collected during this time. The day after conditioning therapy finishes, the donated cells are infused into your relative’s bloodstream in a similar way to a regular blood transfusion.

The transplanted stem cells then travel to the bone marrow and start producing new blood cells. Over time, this forms the basis of a new immune system that can recognise and remove any remaining abnormal cells. It will also protect against harmful bacteria and viruses that cause infections.

For more information on stem cell transplants, please visit our website: **anthohnolan.org/understanding**

‘I can’t put into words how lucky I feel to have been able to donate to my brother. Seeing him get better, and knowing I was able to play a part in his recovery, is the best thing I could have asked for.’

Harriet, who donated stem cells to her brother Jake

HOW DO YOU TEST FOR A MATCH?



You and your relative will be matched based upon your human leukocyte antigen (HLA) tissue type. Your HLA is what makes you 'you' – it's a key part of your individual genetic make-up. It's similar to blood groups, but much more diverse. To be a suitable donor, you need to have a tissue type that matches your relative – but matching your blood groups isn't necessary.

We look at five HLA genes*. Each one of these genes has two versions (called alleles) that you inherit from your mother and father, making 10 in total. If 9 match, it's a 9/10 match. If all 10 match, you're a 10/10 match. When it comes to finding a match, the higher the better, but the transplant can still be successful if the match isn't 10/10.

All this can be worked out from a blood sample. Someone in the medical team will take some blood from your arm using a needle. The blood will then be sent to the lab for testing.

The better the match, the better the chance of your stem cells being accepted by your relative's body – this is known as engraftment. The better the engraftment, the less likely that problems will develop after transplant.

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

As a related stem cell donor, there are two types of transplant you could potentially be selected for.

Sibling

If your brother or sister needs a transplant, you will likely be tested first because you have the best chance of being a full match. This is because you have the same parents and our tissue type is a combination of our parent's tissue type. There's a 25% chance of fully matching your sibling. If you have other brothers and sisters, they will be tested at this point too.

'Speaking to other people, I recognise how lucky I am. If it wasn't for George, I would have desperately needed a stranger's help. It could have been a completely different story.'

Will received stem cells from his brother to treat acute lymphoblastic leukaemia

Haploidentical

When a matching sibling or unrelated donor can't be found, a haploidentical transplant can sometimes be used instead. These transplants use stem cells from a family member whose tissue type is a half-match. Parents are always a half-match for their children, and vice versa. Siblings have a 50% chance of being a half-match for each other. This means there's a greater choice of potential donors – most people have at least one haploidentical match in their family.

In the past, these half-matched transplants wouldn't have been possible because of low success rates and post-transplant complications like Graft vs Host Disease (GvHD). However, improvements in the transplant process and new treatments have helped to make haploidentical transplants a viable alternative.

Unfortunately, haploidentical transplants are not a suitable treatment for all blood cancers and blood disorders. Your relative's medical team will be able to give you more information about the best possible option for them.

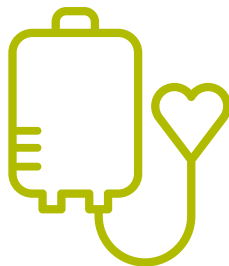
'I'm really close to my mum, as a result of everything I have been through. My mum stayed by me, always.'

Megan received stem cells from her mum to treat her aplastic anaemia

Other options

Usually your wider family and friends will not be tested as it's very unlikely they will be a match. If they want to help other people in need of a stem cell transplant, they may be interested in joining the Anthony Nolan register.

If a matching related donor isn't available, your relative's medical team will contact Anthony Nolan. We will search all the possible donors in the UK, and registries across the world, to find the best match. We can also search for cord blood stem cell matches in the UK and around the world.



WHAT HAPPENS NEXT?



Before you decide to go ahead with testing, the medical team at your relative's hospital or transplant centre will talk to you about donating, from what it involves to its potential impact on you. This includes the pressure you might feel to donate and feelings of guilt if your relative develops complications during their recovery. They'll make sure you have all the information you need.

If the blood test shows you're a suitable match and you're happy to proceed, the medical team will arrange a 'donor assessment' and medical screen for you. This is to make sure you're fit and healthy enough to donate. Your medical confidentiality will always be carefully protected.

During this appointment, feel free to ask as many questions as you want. This meeting is for you and it's really important that you fully understand what's involved so you can make an informed decision about donating. It's also vital that you feel as confident and comfortable about your decision as possible.

'When I was sitting with my sister who had cancer, in the hospital, it felt hard to ask questions. I wanted to know whether I'd need time off work or if there'd be any long-term after-effects. The staff were very friendly and supportive and I got the information I needed.'

Julia, who donated stem cells to her sister Deborah

WHAT WOULD STOP ME BEING ABLE TO DONATE?

It might not be medically safe for you to donate your stem cells, which can be upsetting when you want to help. However, the doctors will make their decision based on what's best for you and your relative.

You may not be able to donate if you:

- weigh less than 50kg or have a body mass index (BMI) of over 40
- have severe lung disease, such as asthma, emphysema or lung fibrosis
- have uncontrolled high blood pressure or other heart complications
- have an autoimmune condition
- have epilepsy or other neurological conditions (if you have epilepsy, you can donate if you've not had a seizure or taken epilepsy medication for 12 months)
- are at risk of contracting hepatitis C, HIV, malaria or other infections
- have sickle cell disease or thalassaemia major
- have recently given birth.

In addition, there are some conditions and medical complications that would prevent you from ever being able to donate. These include a medical history of cancer, stroke, heart attack and major heart surgery.

More information is available on the medical exclusion criteria page of the Anthony Nolan website (anthonymolan.org/medicalcriteria). These guidelines are intended for unrelated volunteer donors but may also be relevant to your situation.

If you have any concerns about being able to donate, please talk to your relative's medical team. They will be happy to answer any questions you have.

'I wanted to be a match so badly, as I wanted to fix things for my brother. I feel for those siblings who aren't a match, because for me it was something I wanted so much.'

Liz, who donated stem cells to her brother Matt



HOW DO I DONATE MY STEM CELLS?



If you're fit and able to donate your stem cells, the next step will be to set dates for the donation and transplant. As time goes on, it's possible that the dates will need to change. For example, your relative's condition may change close to the transplant and the doctors could decide to delay it. This will all be handled by the medical team, but you may need to keep your plans flexible.

There are two methods of donation:

- Most people donate their stem cells in a process called **Peripheral Blood Stem Cell (PBSC) collection**.
- Around 10% of people donate their **bone marrow**, which requires a general anaesthetic to minimise discomfort.

Both methods are described briefly on the following pages, but the medical team will discuss them with you in more detail during your donor assessment.

DONATING VIA PBSC



1. Have some tests

At a specialised hospital, you will have some tests done such as blood tests and a chest x-ray. The hospital will let you know the results and confirm details for your donation.



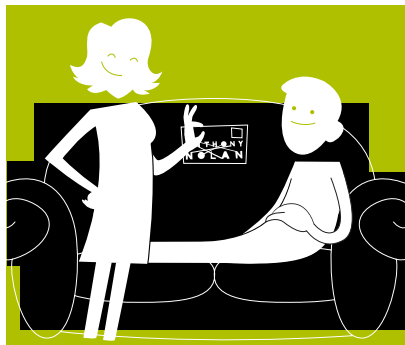
2. Daily injections

Once a day for four or five days, you'll have injections. They contain granulocyte colony stimulating factor (G-CSF). This is a naturally-occurring hormone which stimulates the growth of stem cells in your blood.



3. Donation day

On the fifth day you'll go to the hospital for your donation. You'll be connected to a machine which takes blood from one arm, collects your stem cells, and returns your blood to the other arm. The process takes four to five hours. Most of the time, enough stem cells are collected in one day. But sometimes you might need to have another session the next day.



4. Get some rest

After your donation you'll probably feel tired, you may have trouble sleeping and might experience flu-like symptoms. These pass after a few days. Get plenty of rest and you'll soon feel back to normal. Less than 1% of donors experience more serious side effects.



5. The difference it makes

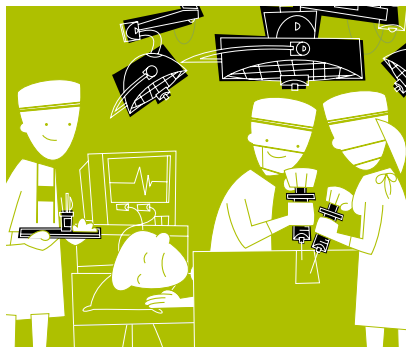
Your stem cells will start to make new blood cells for your relative. They will form a new immune system that will remove any remaining abnormal cells.

DONATING VIA BONE MARROW



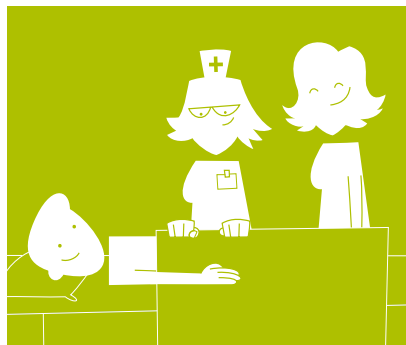
1. Have some tests

At a specialised hospital, you will have some tests done such as blood tests and a chest x-ray. The hospital will let you know the results and confirm details for your donation.



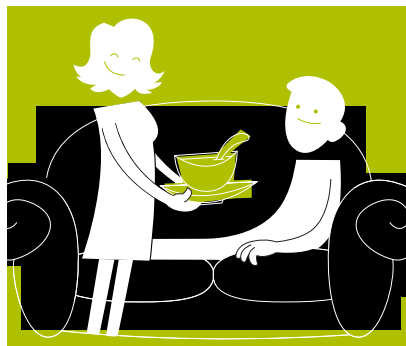
2. Donation day

You'll have the procedure under general anaesthetic. Lying on your front, two needles are inserted into the back of your hip bone to extract bone marrow. This might sound a bit scary, but don't worry. People think donating bone marrow is really painful, but donors have said it's no worse than how you'd feel after a heavy workout in the gym.



3. When you wake up

You'll have two plasters over the marks where the needles were inserted. You may need to stay overnight in hospital to recover, before going home the next day.



4. Get plenty of rest

For the next few days you'll probably experience tenderness and bruising where the needles were inserted, as well as general tiredness. Take some paracetamol and get some rest. You might need to take a week off work and avoid vigorous activities.



5. The difference it makes

The stem cells in your bone marrow will start to make new blood cells for your relative. They will form a new immune system that will remove any remaining abnormal cells.

WILL I NEED TO DONATE AGAIN?

You may need to donate more blood cells to your relative, if they need something known as a Donor Lymphocyte Infusion (DLI). This is when more white blood cells are given to your relative to cause an immune reaction that helps 'boost' the original stem cell transplant.

Although DLIs can treat patients that have relapsed, it doesn't mean the transplant has failed if your family member needs a DLI. DLI's are sometimes planned prior to transplant to try to prevent relapse happening. Your relative's medical team will be able to talk to you about why they need their DLI.

When you gave your first donation, the medical team may have been able to freeze and store some of your blood cells that were not needed. If this happened, you may not need to donate again for the DLI. If you do donate again, it will be a simpler procedure than before, and you shouldn't need to have more injections. The process is very similar to giving blood.

As before, you don't have to donate if you don't want to – the choice is yours. The medical team will address any queries or concerns you might have and give you a medical check before you donate.

For more information on DLIs and when they might be needed, please visit **anthonymolan.org/DLI**

'I never questioned for a minute that I would want to be a donor for my brother. It was something life changing for him and a mere inconvenience for me.'

Catherine, who donated stem cells to her brother Dave

WHAT IF I CAN'T DONATE?

Support yourself

Trying to find a donor for your relative and worrying about if they will make a successful recovery can make this a very difficult time for you, and your family.

Everybody reacts to stressful events in their own way and we all find different ways to cope with them. Some people prefer to talk things through with friends and family, while others benefit from talking to a therapist about their concerns.

As the relative of someone who has blood cancer or a blood disorder, it's easy to neglect your own needs. However you choose to manage the situation, it's crucial to take the time to consider how your mental health is being impacted and seek help, if you need it.

More information on possible coping mechanisms and talking therapies is available on our website:

anthonymorgan.org/mind

Charities and organisations that can support you and your mental health are listed on p31.

Support your relative

After their transplant, it will take time before your relative starts to feel anything like 'normal' again. Although they may look much better than they did before, they could still have a long period of recovery ahead of them. During this time, they may experience a range of side effects which affect their physical and mental wellbeing, such as fatigue.

Try to offer them support when it's possible for you to do so. They may need help with general day-to-day chores or simply want someone to talk to about what they're going through. For more information, please visit our website: **anthonymnolan.org/body**

'Although it was a very upsetting few years for my brother and his family he has made a full recovery, he appreciates every day and cherishes life.'

Catherine, who donated stem cells to her brother Dave.

Support Anthony Nolan

When the time is right, you may decide to join our register of potential stem cell donors. As you can imagine, it could make a vital difference to families who are unable to donate stem cells to their relative who is in need of a transplant. If you've been tissue-typed for your sibling and would like to join the Anthony Nolan register, please contact **donor.support@anthonymnolan.org**

If you're not eligible to join the register but you'd still like to help, you can support Anthony Nolan in many other ways. You can volunteer on our behalf, take part in a fundraising event (from a bake sale to a marathon), support our campaigns, or simply make a much-needed financial donation to ensure our lifesaving work can continue in the future.

Find out more at **anthonymnolan.org/8-ways**

ANTHONY NOLAN CONTACT DETAILS

WHERE CAN I GET MORE INFORMATION AND SUPPORT?

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

NEED TO TALK?

The Patient Services team at Anthony Nolan are here for you. Call us on **0303 303 0303** or email: **patientinfo@anthonymolan.org**

GET CONNECTED

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

FIND INFORMATION

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

OTHER USEFUL CONTACTS

BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY

**bacp.co.uk
01455 88 33 00**

Information about counselling and therapists in your area.

CLIC SARGENT

**clicsargent.org.uk
0300 3300 0803**

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

IMPROVING ACCESS TO PSYCHOLOGICAL THERAPIES (IAPT)

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

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

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.

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.

NHS CHOICES

nhs.uk

helpline: 111

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

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.

TEENAGE CANCER TRUST

teenagecancertrust.org

020 7612 0370

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

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'IT HASN'T BEEN A STRAIGHTFORWARD
FOUR YEARS FOR MY BROTHER, AND
FOR A LONG TIME I WORRIED MY
STEM CELLS WEREN'T GOOD ENOUGH.
HE'S HAD A ROUGH TIME WITH GvHD.
HOWEVER, HE'S STILL HERE AND I AM
VERY GRATEFUL FOR THAT!'

Liz, who donated stem cells to her brother Matt



saving the lives
of people with
blood cancer

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