

Donating stem cells to your relative

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



**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 (January 2023). 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.

Anthony Nolan is a registered charity
No 803716/SC038827

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ANTHONY NOLAN
PATIENT SERVICES

What's in this booklet?

We've produced this booklet for anyone who has the opportunity to donate 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@anthonynolan.org** or **0303 303 0303**

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Key facts

- Your relative needs a stem cell transplant 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.
- Stem cell matching is based on your human leukocyte antigen (HLA) tissue type. Our HLA is made up of six genes 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. 25% of people who need a transplant will have a matching donor in their families.
- 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. You receive injections to increase 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. Stem cells are collected from your pelvis while you're under general anaesthetic.
- Depending on how you donate, you may experience some mild side effects afterwards. These should clear up in a few days with plenty of rest.
- 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 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 with your decision on whether or not to be a donor.

Why are stem cells important?

Stem cells are immature cells in your body. All other cells, tissue, organs and bones develop from stem cells.

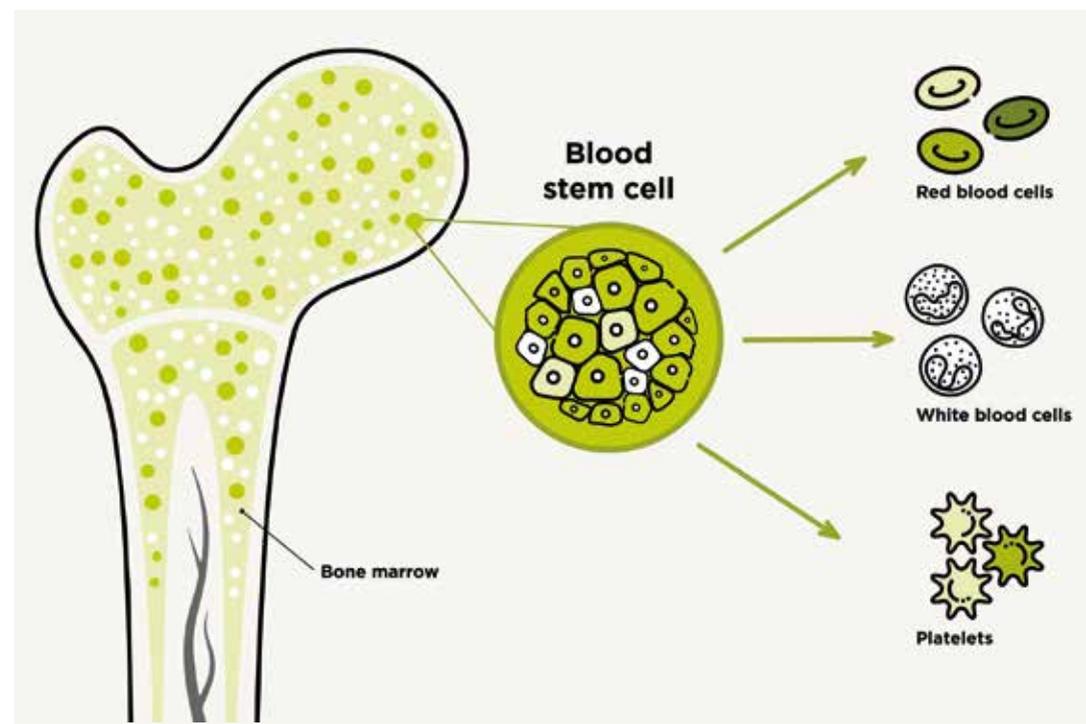
Blood stem cells are cells which are found in the bone marrow. Your bone marrow is spongy tissue found in the middle of some bones, like your hip, thigh and breastbone.

Blood stem cells can become three main types of blood cell:

- **Red blood cells**, which carry oxygen around the body.
- **White blood cells**, which help to fight infections.
- **Platelets**, which help to form blood clots and stop bleeding.

Blood stem cells are like templates with instructions for creating new blood cells. They create the millions of blood cells needed in your body every day by copying themselves over and over again.

If one copies (also known as divides) itself incorrectly, this can lead to millions of 'wrong' templates and instructions. If this happens, your new blood cells may not work properly, and you could develop a blood cancer or a blood disorder.



How do transplants work?

There are two main types of stem cell transplant:

- **Allogeneic** (or allograft) transplants use stem cells collected from someone else – either a relative, like you, or an unrelated donor from the stem cell register.
- **Autologous** (or autograft) transplants use the patient's own stem cells. They are collected and then put back in the body after chemotherapy.



If your relative needs an **allogeneic** transplant, their medical team will search for a donor. This may have already happened, and they may have identified you as a potential donor.



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

First, they will have 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. This is like 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 tested for a match 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.

HLA types are 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.

Your HLA is made up of six genes. Each one of these genes has two versions (called alleles) that you inherit from your mother and father, making 12 in total. If 11 match, it's a 11/12 match. If all 12 match, you're a 12/12 match. When it comes to finding a match, the higher the better, but the transplant can still be successful if the match isn't 12/12.

HLA types can be worked out from a blood or swab sample. Someone in the medical team will take some blood from your arm using a needle or swab the inside of your mouth. The blood or swab sample 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.

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 parents' tissue types. 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, who 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 may be an option.

Haploidentical 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 good 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, who 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 at [anthonynolan.org/join](https://www.anthonynolan.org/join)

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.

If necessary, we will also check for cord stem cell matches in our cord bank. Find out more about cord blood transplants at [anthonynolan.org/cordtransplant](https://www.anthonynolan.org/cordtransplant)

What happens next?



You'll have a chat with your relative's medical team before you decide to go ahead with testing. They'll discuss with you:

- how they will test to see if you are a match
- what donating will involve
- the potential impact donating will have on you.

Remember: The potential impact of donating includes your mental wellbeing as well as your physical health. You may feel pressured to donate, either from yourself or others. You might also feel guilty if your relative develops complications during recovery. You should receive all the support you need to cope with these feelings.

If the blood or swab 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.

Please ask as many questions as you want during this appointment. 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 with my sister in 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
- are at risk of contracting hepatitis C, HIV, malaria or other infections
- have anaemia, sickle cell disease or thalassaemia
- have recently given birth.

There are also 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. Your relative's medical team will discuss all these with you and they'll be happy to answer any questions you may 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 your donation and your relative's transplant.

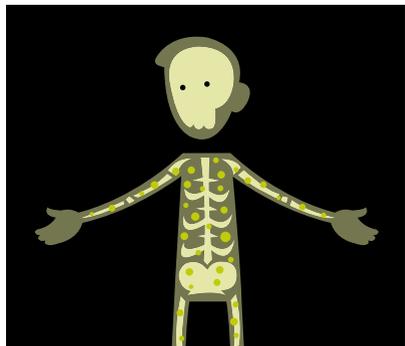
As time goes on, it's possible that the dates will need to change. For example, your relative's condition may change close to the transplant and the doctors could decide to delay it. This will all be handled by the medical team, but you may need to keep your plans flexible.

There are two ways you can donate your stem cells:

- **90% of people donate via their bloodstream** in a process called peripheral blood stem cell (PBSC) collection. You'll receive a course of injections for a few days before, and then go into hospital for the day where stem cells are collected from your bloodstream over 4-5 hours and filtered out using a special machine.
- **10% of people donate through their bone marrow.** The cells are collected from your hip bone while you're under a general anaesthetic so you won't feel a thing. You'll stay in hospital for two nights.

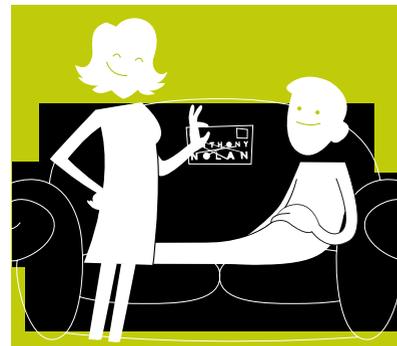
Your relative's medical team will decide which type of donation will be best. This will depend on your relative's condition. They will talk you through each type of donation in more detail at your donor assessment appointment.

Donating via PBSC



1. Have some tests

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



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.



2. Daily injections

You'll have injections once a day for four or five days leading up to your donation day. They contain granulocyte colony stimulating factor (G-CSF). This is a naturally-occurring hormone which makes your blood create more and more stem cells so you have lots ready to donate.



5. The difference it makes

Your stem cells will be transplanted into your relative and start to make new healthy blood cells. They will form a new immune system that will remove any remaining abnormal cells.

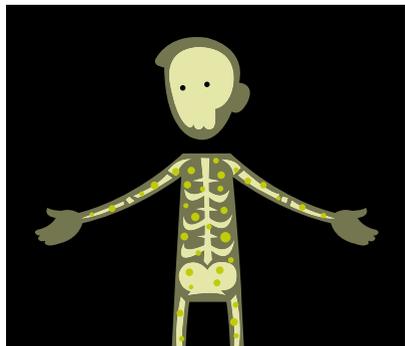


3. Donation day

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.

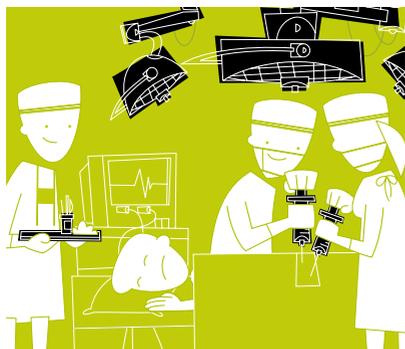
Find out more about donating via PBSC at anthonymolan.org/donation-journey/donating-pbsc

Donating via bone marrow



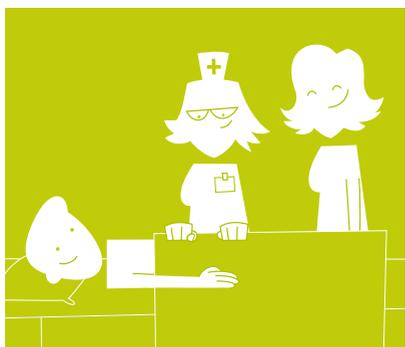
1. Have some tests

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



2. Donation day

You'll have the operation under general anaesthetic. Lying on your front, two needles are put into the back of your hip bone to take the 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

You'll probably feel tender and bruised where the needles were inserted, as well as general tiredness, for a few days. Take some paracetamol and get some rest. You might need to take a week off work and avoid tiring activities.



5. The difference it makes

Your stem cells will be transplanted into your relative and start to make new healthy blood cells. They will form a new immune system that will remove any remaining abnormal cells.

Find out more about donating via bone marrow at anthonymolan.org/donation-journey/donating-bone-marrow

Will I need to donate again?

You may need to donate more blood cells to your relative if they need something called 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 who have relapsed, it doesn't mean the transplant has failed if your family member needs a DLI. DLIs are sometimes planned before 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.

You don't have to donate again 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 another medical check before you donate for a DLI.

You can read more about DLIs and when they might be needed at anthodynolan.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?

Be kind to yourself

It can be tough to find out that you're unable to donate for your relative, especially if finding a matching donor is tricky. It can also be a tough and brave decision to not donate if it's not right for you, or to find out that your relative's transplant has failed after you have donated.

In all cases, please try to not feel guilty. The transplant process is not easy and lots of factors can affect the journey and outcome. So it's important to take a step back and look after yourself.



I wasn't prepared for my sister's transplant not working the first time. When you donate to a stranger, you can feel good but walk away. When it's your family member, it's much more personal and harder emotionally. There's more worry. My advice is to prepare yourself mentally and physically.

Mark, who donated to his sister in 2019 and 2022



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

It's understandable that you'll be focused on your relative's health but you need to look after yourself, too. We support those we love much better when we're also supporting ourselves.

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:

[anthonynolan.org/mind](https://www.anthonynolan.org/mind)

Charities and organisations that can support you and your mental health are listed on p35.

Be there for your relative

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

Try to offer them support when you can. You may be able to help with general day-to-day chores or can simply be someone to talk to about what they're going through. For more information, please visit our website: anthohnolan.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

Be a champion for 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@anthohnolan.org**

If you're unable 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 anthohnolan.org/help-save-a-life

Getting support

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.

Improving Access to Psychological Therapies (IAPT)

nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/

Find an NHS psychological therapies service, such as cognitive behavioural therapy (CBT), counselling, other therapies, and guided self-help.

Macmillan Cancer Support

macmillan.org.uk

Macmillan Support Line **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

Infoline **0300 123 3393**

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

NHS

nhs.uk

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.

Young Lives vs Cancer

younglivesvscancer.org.uk

Helpline **0300 303 5220**

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



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



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saving the lives
of people with
blood cancer