

DONATING TO **YOUR RELATIVE**

WHAT TO EXPECT WHEN YOU'RE
DONATING BLOOD STEM CELLS
TO A FAMILY MEMBER



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 Anthony Nolan on patientinfo@anthonymolan.org

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DONATING TO YOUR RELATIVE

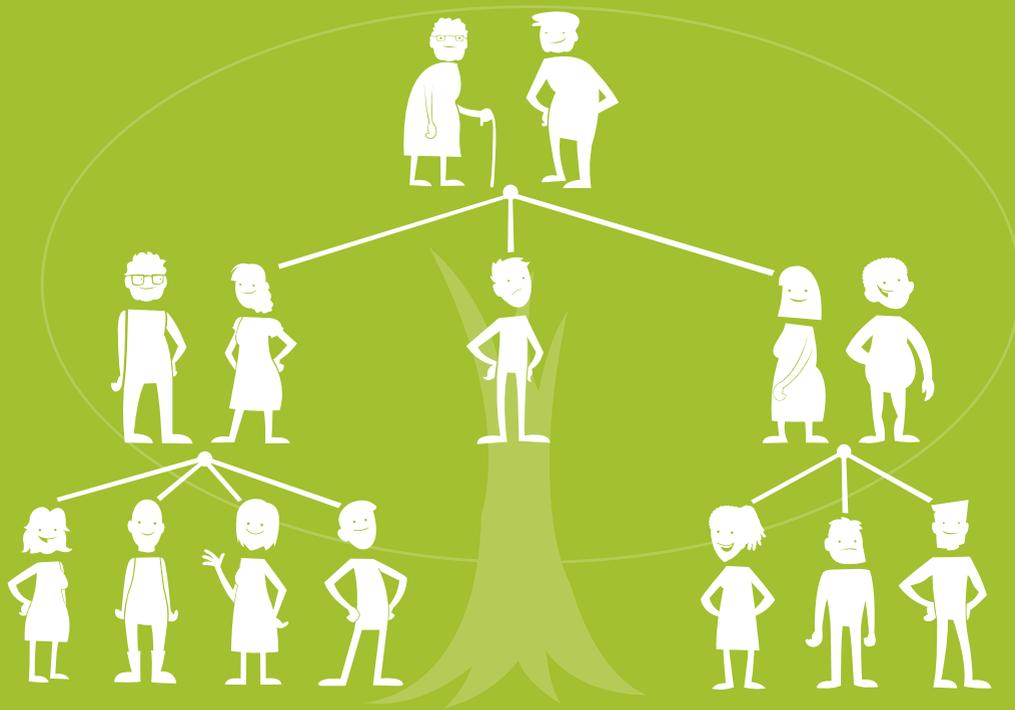
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TO A FAMILY MEMBER



saving the lives
of people with
blood cancer

ANTHONY NOLAN
PATIENT EXPERIENCE
TEAM

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WHAT'S IN THIS LEAFLET?

If you're reading this, it's most likely because one of your family members needs, or is considering, a stem cell transplant as part of their treatment for a blood cancer or blood disorder.

This also means there's a chance that you may be able to donate your own blood stem cells to your relative. Before you go ahead with having further tests to see if this is possible, it's a good idea to get some more information.

But before we get to that, you probably have some further questions. You might want to know:

- How likely it is that you'll be chosen as a match for your family member, and why
- What happens next if you are a match (and if you aren't)
- How the donation process works

We know this can be a difficult and anxious time for you and your family. We hope this leaflet goes some way towards answering your questions.

The hospital team will guide you safely through the donation process and give you specific details of what happens next. At Anthony Nolan, we can also provide you and your relative with further information and support whenever you need us.

If the treatment is taking place in another country, the process may be different. Use this leaflet as a rough guide, but it's important to get more information from your relative's medical team, especially if you have any questions about how you'll be donating, whether you'll need to travel to that country, and other medical issues.

'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 (front cover), who donated stem cells to her brother Jake

STEP 1: CHECKING IF YOU'RE A MATCH

Stem cells that are suitable for transplant can be donated through three different methods: an adult donor's blood, an adult donor's bone marrow, or an umbilical cord.

When the stem cells are coming from someone else (it could be a family member or a stranger) we call it an allogenic or allograft transplant.

The donor is usually chosen based on how well they 'match' up with the patient. This means their tissue type or human leukocyte antigen (HLA) needs to be as similar as possible to the person receiving the stem cells. We analyse this using a method known as 'tissue typing'.

Your HLA is what makes you 'you' – it's your very own genetic fingerprint, like your blood group, only much more unique to every individual. It's made up of genes, and within the genes are five key sites, or loci.

Each one of these sites has two alleles (types of genes), making 10 in total.

There are millions of different combinations of these HLA types – and some are more common than others. For some patients, there could be thousands of people out there who match their HLA. For others, it could be a struggle to find even one.

It's so important that we find the best possible match because the donor's stem cells need to be accepted by the patient's body. This is called engraftment.

SIBLING TRANSPLANTS

So how likely is it that you'll be a match for your relative? If you're a sibling, you're normally tested first, as a fully matched sibling donor is normally the preferred option for patients; you have a 25 – 30 per cent chance of being a match for your brother or sister. This is because our individual tissue types are a combination of both our parents' tissue types. So not every combination will be the same and not every sibling will be a close enough match to donate.

HAPLOIDENTICAL TRANSPLANTS

The transplant team usually begins by testing brothers and sisters, since these are much more likely to be a match. Other relatives, like cousins, are much less likely to be a match. But in certain cases, the team may consider using stem cells from a family

member whose HLA is half matched.

We call this a 'haploidentical' match. Parents are always a half-match for their children, and vice versa. Siblings have a one-in-two chance of being a half-match for each other. Almost all people have at least one potential haploidentical match in their family.

Haploidentical transplants are becoming more common, but they won't be an option for everyone. The transplant team will let your relative know whether it's possible and provide you with the relevant guidance.

OTHER OPTIONS

Family members aren't the only option for someone who needs a transplant. If there isn't a suitable related donor available, the transplant team will ask us to look for an unrelated donor. Find out more on page 8.

STEP 2: TALKING THINGS THROUGH

Before you decide whether to have further blood tests to check your HLA type and see whether you are a match for your relative, the doctors and nurses at the transplant centre will talk to you about the process. They'll make sure you have the information you need so you can decide if you're happy to go ahead with the tests.

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'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

STEP 3: MAKING SURE YOU'RE FIT TO DONATE

If you're a suitable match for your sibling, and you're happy to donate your stem cells to them, the transplant centre also needs to make sure that you're fit and well enough to donate.

In some cases, it might not be medically safe for you to donate stem cells. The transplant centre will talk to you about this in more depth.

It can be upsetting to learn that you're unable to donate when you want to help. It may help to consider that the doctors need to make their decision based on what's best for you and what's best for your relative. It's also important to remember that there will be other treatment options available for them.

You may not be able to donate if:

- You are above or below a certain weight
- You have severe lung disease, such as asthma, emphysema or lung fibrosis
- You have uncontrolled high blood pressure, abnormal heart rhythm, or other heart problems
- You have an autoimmune condition
- You have epilepsy or certain other neurological conditions
- You are at risk of contracting hepatitis C, HIV, malaria and other

- infections – for example, through high-risk sexual behaviour, intravenous drug use, travelling in areas of high risk for infectious diseases or tattooing
- You have anaemia, sickle cell disease or thalassaemia
- You've recently been pregnant – discuss this with the transplant team if you think it might be an issue

You won't be able to donate if:

- You have ever been diagnosed with HIV, hepatitis C or HTLV, or you currently have hepatitis B
- You have ever had cancer
- You have ever had a stroke, heart attack, heart failure, angina, heart bypass operation or heart valve replacement
- You have ever had a clot on the lung (pulmonary embolus)
- You have haemophilia
- You are currently pregnant



Julia (right), who donated stem cells to her sister Deborah

STEP 4: ONCE YOU'RE CLEARED TO DONATE

If it turns out that you can donate stem cells to your family member, then the next step will be to book a date for the donation and transplant process.

Sometimes these dates may need to change - if, for example, your family member's condition changes close to the transplant and the doctors decide the process needs to be delayed.

There are two methods of donation; most relatives donate their stem cells in a process called peripheral blood stem cell collection (PBSC). Some donate their bone marrow, which requires a general anaesthetic to minimise discomfort during the procedure. We briefly describe the two different methods on the next pages, but the transplant team will discuss both of them with you in more detail during

your donor assessment. Talk to them about any concerns you have, and find out who to contact in case you've got any questions once you've donated.

WHAT HAPPENS IF YOU'RE UNABLE TO DONATE TO YOUR RELATIVE?

This can be disappointing and worrying news, but even if you can't donate, it's likely that there are other options available for your relative.

If no related match is available, then the transplant centre will usually get in touch with us and we'll search for an unrelated match to donate to your relative. We'll look through our register, searching all of the potential donors here in the UK. And then we'll search the international registries, to see if there's a match in another country.

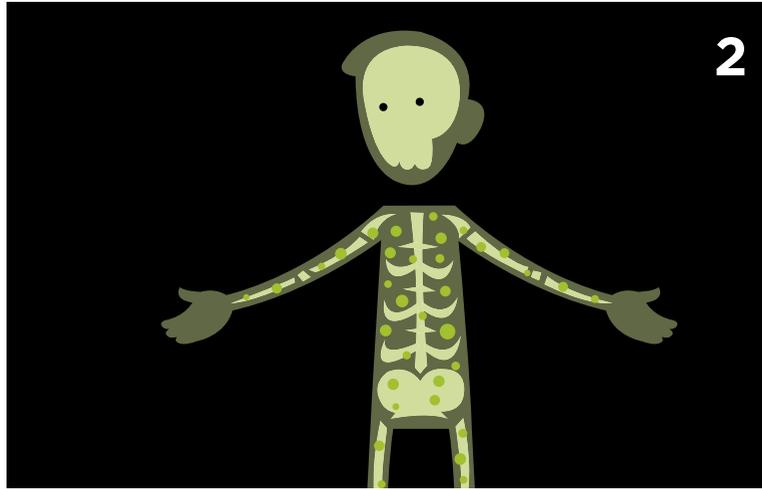
If the hospital thinks it's a good idea, we can also check if there's a match in our cord bank. Cord blood comes from the umbilical cord and placenta after a baby is born. It's rich in stem cells, which doctors can use for a transplant. Doctors can collect the blood quickly and easily just after a birth, freeze it and store it at a cord blood bank to use when it's needed.

DONATING VIA PBSC



Have some tests

You go to a specialised hospital and have some tests done – blood tests, a chest x-ray, that sort of thing. The hospital will let you know the results of the tests, and confirm details for your donation.



Daily injections

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



The big 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, removes the stem cells, and returns your blood to the other arm. The process takes four to five hours. Most of the time enough stem cells can be collected in one day. But sometimes you might need to have another session the next day.

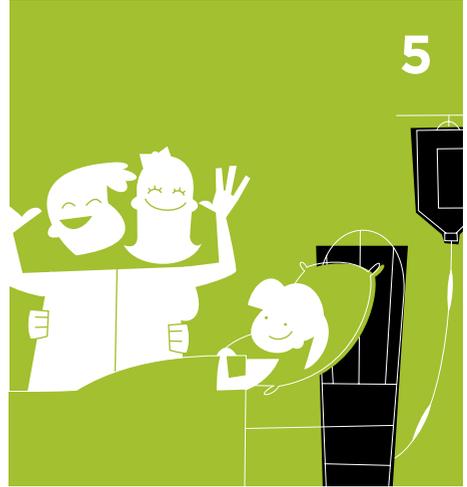
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Get some rest

After your big day you'll probably feel tired and might experience some flu-like symptoms. These always pass after a few days. Get plenty of well-deserved rest and you'll soon be feeling right as rain.

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The difference it makes

Your stem cells will give your relative a new blood and bone marrow forming system. If they have blood cancer then this new immune system will help them fight the disease.

DONATING VIA BONE MARROW



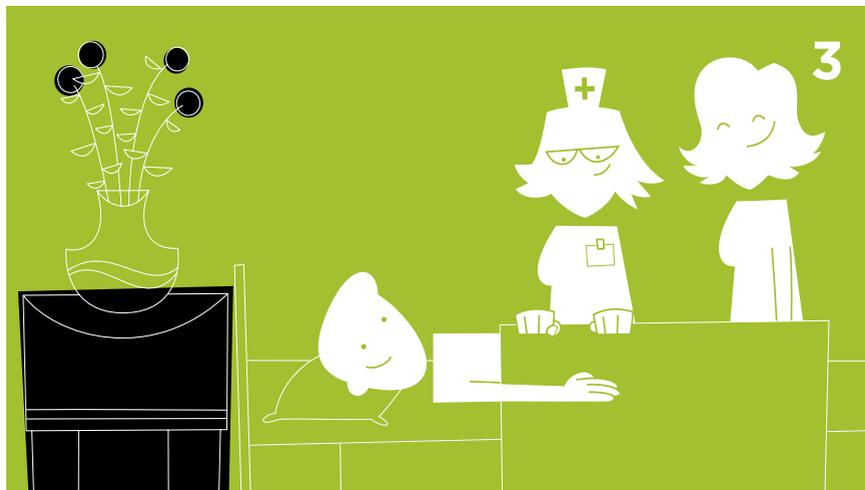
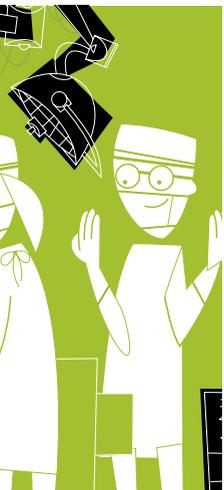
Have some tests

As with donating by blood, you go to a specialised hospital for some simple tests. The hospital will let you know the results of the tests, and confirm details for your donation.



The big day

You'll have the operation 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.



When you wake up

People think donating bone marrow is really painful, but donors tell us that it's no worse than how you'd feel after a heavy workout in the gym.

You wake up with two plasters over the marks where the needles were inserted.

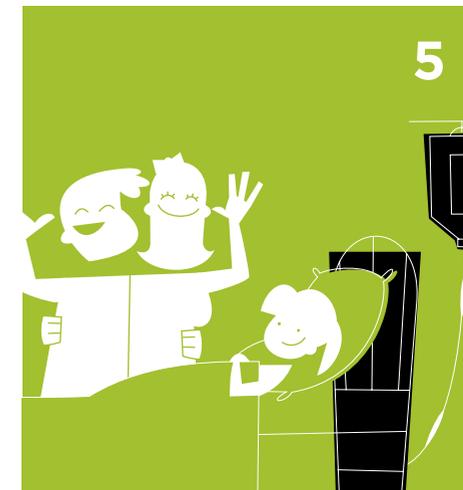
Sometimes you may need to stay overnight in hospital recovering from the anaesthetic before going home the next day.



Get plenty of rest

For the next few days you'll probably feel some pain where the needles were inserted, as well as general tiredness. Take some paracetamol and get some well-deserved rest.

You might need to take one week off from work or vigorous activities.



The difference it makes

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STEP 5: WHAT'S NEXT FOR YOUR RELATIVE

The next steps towards a transplant for your relative will be pre-transplant health checks and conditioning therapy (chemotherapy and radiotherapy).

On the transplant day itself, they will receive the stem cells in a transfusion, a bit like a blood transfusion. They'll also need to spend time in hospital afterwards as their immune system slowly recovers.

It can be useful to find out more about the transplant process, as well as searching and matching – so that you're fully informed and you know how best to support your family member. There's lots more information on our website at **anthonymolan.org/patientinfo**

Life after a transplant will come with its own set of challenges, as your relative builds up their strength and

gets back into the swing of day-to-day life with friends and family. Some people find that the journey to recovery is relatively straightforward; for others recovery can be very difficult and demanding, both physically and psychologically. It can also be difficult for loved ones who are caring for and supporting them.

But we're here for you and your relative to help you know what to expect, how to manage any after effects of transplant, and where you can both get more support. We have more information in our guide to long-term recovery after transplant: The Seven Steps: The Next Steps.

You can download or order this booklet at **anthonymolan.org/patientinfo**

WILL I NEED TO DONATE AGAIN?

You may have to donate more cells to your relative at some point, as they may need something called a donor lymphocyte infusion (DLI). This may be because they need a 'boost' of cells to make sure the transplant is working as well as possible. Or DLI could be an option if their original condition has come back.

If you do donate again you may only need a single procedure to collect cells from your blood, without needing to have any injections to increase the number of cells in your bloodstream. In some cases you may need to have a full repeat stem cell collection like your first donation. The transplant team will still give you a full explanation of the procedures, medical check and make sure you are happy to consent to the donation.

GETTING SUPPORT

If you have more questions, or you just want someone to talk to, then please get in touch. Our dedicated Patient Experience team is here for you and your relative before, during and after the transplant. Call us on **0303 303 0303** or email **patientinfo@anthonymolan.org**

You're also very welcome to introduce yourself on our online transplant community at **anthonymolan.org/transplantcommunity**

If your relative is having treatment in another country we can still provide you with information and support, but it's best if you speak to their hospital for details, as things may be done differently.

OTHER WAYS TO SUPPORT ANTHONY NOLAN

Even if you're not a match for your family member, you could still potentially save a life.

When someone finds out their relative has a blood disorder or blood cancer, they often ask us how they can help others in a similar situation.

If you have already been tissue-typed for your sibling and would like to join the Anthony Nolan register, please contact donorsupport@anthonymolan.org

When the time is right, and if you feel it is right for you, you could join our register of potential stem cell or bone marrow donors.

It could make a vital difference. Around 70% of people who need a

transplant won't be able to find a match from within their family. In the UK, the register is run by us, Anthony Nolan. If you are eligible then you can join online at anthonymolan.org/join

If you're not in the UK you can find out about your country's register by visiting bmdw.org.

AND FINALLY...

If you have any questions regarding the process of signing up, please don't hesitate to get in touch with us.

If you're not eligible to join the register but you'd still like to help, you can support us in any number of other ways. You can volunteer on our behalf, participate in a fundraising event (it could be anything from a fun run to a marathon), support our campaigns, or even just make a financial donation to enable us to continue our lifesaving work. Find out more at anthonymolan.org

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Julia, who donated stem cells to her sister Deborah

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