ESSENTIAL FACTS FOR **TRANSPLANT PATIENTS**

HELLO

If you're reading this, it's because you've been told you need a stem cell or bone marrow transplant. We'd like to help you understand what's going to happen.

We are Anthony Nolan and we save the lives of people with blood cancer and blood disorders who need a stem cell transplant. Every day, we use our register to match remarkable individuals willing to donate their stem cells to people who desperately need lifesaving transplants. This is called an allograft transplant.

We have one of the world's leading research institutes where we work hard to discover more and more about what makes the perfect match, and how we can improve life after transplant.

We know that finding a donor is just the start of what will be a long road to recovery for you and your family, and we're here for the whole journey. Visit our website **anthonynolan.org/patientinfo** for information and support. And connect with others online in our Patients & Families Forum: **anthonynolan.org/forum**

WHAT MAKES A MATCH?

Matching is done based on your human leukocyte antigen (or HLA) tissue type. Your HLA is what makes you 'you' – it's part of your individual genetic make-up. It's similar to your blood group, but much more diverse.

The better the match, the better the chance the new cells will be accepted by your body – this is known as engraftment. The better the engraftment, the less likely it is you'll develop problems after your transplant.

Your HLA is made up of 5 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 up it's a 9/10 match. If all 10 match then you've got yourself a 10/10 match.

When it comes to finding a match, the higher the better, but you can still recover well from a match that isn't 10/10.

There are millions of different combinations of these genes. There could be thousands of potential donors for you, or it could be a challenge for us to find one. It all depends on how common your tissue type is.

Questions? Just need a chat? Get in touch with our Patient Services team at **patientinfo@anthonynolan.org** or call **0303 303 0303.**

THE PERFECT
MATCH

Are there any other factors?
A couple. When a donor is chosen, their age is often taken into consideration. Young people are most likely to be chosen to donate as they are less likely to have health problems which might delay or prevent donation.

Another factor we consider is whether you test positive for cytomegalovirus (or CMV for short) – a very common virus that often has no side effects. Ideally we would want to find a donor who tests the same for this virus as you do.

We will also do tests to make sure that the donor hasn't developed any medical problems since joining our register.

FAQS

Q. Along with my siblings, will you test my other relatives?
Not usually. However, if your siblings don't match and we can't find a matching donor, your doctors may then consider testing other relatives.

Q. How will the search for my donor begin?
Your hospital or transplant centre will contact Anthony Nolan to start the search for your donor. A BMT (bone marrow transplant) co-ordinator will make sure that everything is done as quickly as possible and you can talk to them about any concerns you have. You do not need to do anything yourself.

Q. I've been told there isn't a match for me. What's next?
Your consultant may talk to you about looking for a cord blood match or a haploidentical transplant.

Cord blood is from the placenta and umbilical cord after a baby is born. After the birth, we collect the stem cells and cryogenically freeze them for transplants. Because they come from a baby, they are less developed so they don't have to match quite as closely. Our factsheet *Having a Cord Blood Transplant* on **anthonynolan.org** has more details.

A haploidentical transplant involves a donor whose tissue type is a half-match to your own. Parents are always a half-match for their children, and vice versa. Almost all people have at least one potential haploidentical match in their family. Our factsheet *Having a Haploidentical Stem Cell Transplant* on **anthonynolan.org** has more details.

Q. Will my donor give blood stem cells or bone marrow?
The two donation methods result in two different products: bone marrow and blood stem cells. They do the same job. This decision, made by your medical team, is based on what's best for you, the donor and the treatment of your condition.

Q. When can I contact my donor?
Most registers allow patients and donors to communicate anonymously after a transplant. After two years you may be able to make direct contact with your donor, depending on where your donor is from and the rules of their country's registry. Find out more at **anthonynolan.org/contactmydonor**

'After a long struggle post transplant, I am now well enough to enjoy a wonderful life with my family.'
Julie, had a transplant in 2009

THE JOURNEY

ANTHONY
NOLAN

saving the lives
of people with
blood cancer

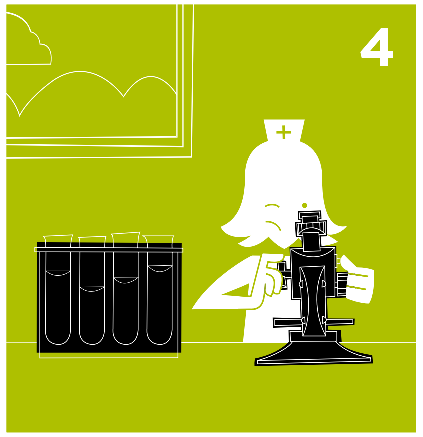
If you've been told that you need an allograft transplant, you probably have a lot of questions. So let's go through what happens next.

If you have siblings
Your hospital may take a blood sample from you and your siblings, if you have any. If your sibling is a match and is healthy and happy to donate, the transplant centre will almost always choose them as a donor.

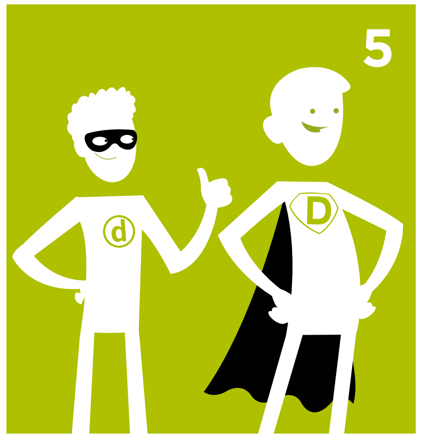
Searching our register
If your siblings aren't a match, your transplant centre will get in touch with us. We'll look at our register to search all the registered donors in the UK. We'll also have a look at all the donors available internationally.

Shortlisting your donors
We'll make a list of potentially matching donors and send it to your transplant centre within 24 hours. Our specialist donor selection team will take a closer look at each of these donors and shortlist the best ones.

Making contact
We'll contact each shortlisted donor to ensure they're still available and able to donate. They will then go to their GP to give a blood sample. This will be sent to your transplant centre's labs, where your blood sample has already been tested.



Choosing your donor
The lab will test the samples to find the best match. We know it's hard to wait but this process can take a few weeks. After all relevant factors have been considered (primarily your HLA tissue type) your doctor will choose your donor.



Making plans
Our team will contact the donor to tell them the great news and arrange a full medical check. Once they've passed this check, our team will make arrangements for the donation.

Preparing your body
Your team will set your transplant date, taking into consideration your treatment and the donor's availability. Before your transplant you'll have a course of treatment to prepare your body to adopt your donor's immune system.

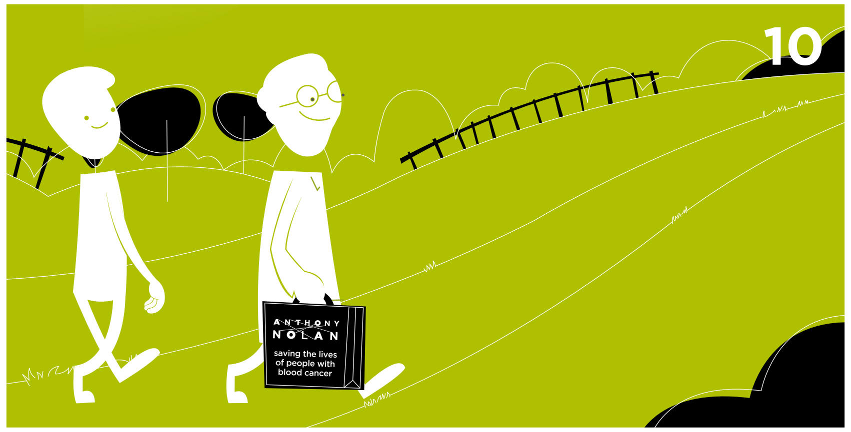
Your donor's experience
Meanwhile, somewhere in the world, your donor is preparing to give their stem cells through one of two methods.

Peripheral blood stem cell donation is most common. Your donor will have injections over four days to produce more stem cells. On the fifth day, a machine takes blood from one arm, filters out the stem cells into a bag, and returns the blood to the other arm.

If they donate via bone marrow they'll have a general anaesthetic and a short procedure where two needles are inserted into their pelvis to extract bone marrow. Whichever route they go down, they'll be in hospital for at least a day.

The precious cargo
One of our volunteer couriers will collect the stem cells. This could be from New York, New Delhi, or even New Zealand. Or perhaps from just around the corner. The cells are viable 72 hours after donation.

Day Zero...
When they arrive you'll receive the stem cells through an IV. That's when the magic begins. These new cells should kick-start your immune system and help you produce the new blood cells that you need to recover.



... to Day 100
The first few weeks after your transplant can be tough for both you and your family. But don't worry, your medical team will keep a close eye on you. And of course, we'll be here too.

So that's how it all works: from finding a match to having your transplant. We know it's a long road to recovery, but we'll be with you every step of the way. Get in touch on **patientinfo@anthonynolan.org**.

‘STAY STRONG: IF YOU CAN’T DO IT HOUR BY HOUR, DO IT MINUTE BY MINUTE.’

Harun, stem cell recipient

If you have any questions or comments about this resource, or would like information on the evidence used to produce it, please email: **patientinfo@anthonynolan.org**
The information contained in this booklet is correct at the time of going to print (Jan 2018). We plan to review this publication within three years. For updates or the latest information, visit **anthonynolan.org**

anthonynolan.org
facebook.com/anthonynolanpatients
twitter.com/anthonynolan

Health & care information you can trust
The Information Standard
Certified Member

ANTHONY NOLAN

saving the lives of people with blood cancer

Illustrations: Baby Cow
Reg charity no 803716/ SC038827

DOC4096 Version 001 (0118)
1346OP/0118