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 next.

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

We have one of the world's leading research institutes. We spend all day, every day, discovering what it is that makes the perfect match, and how we can

improve every step of the transplant journey.

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 and Families forum. Visit anthonynolan.org/forum

WHAT MAKES A MATCH?

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

The better the match, the better the chance your donor's 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.

There are many HLA genes but when it comes to matching, we are most interested in six of them. Each gene has two versions (called alleles) and you inherit one from

your mother and one from your father, making 12 in total. If 11 match up it's an 11/12 match. If all 12 match then you've got yourself a 12/12 match.

When it comes to finding a match, the higher the better, but you can still recover well from a match that isn't 12/12.

There are millions of different combinations of these genes. There could be many 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.

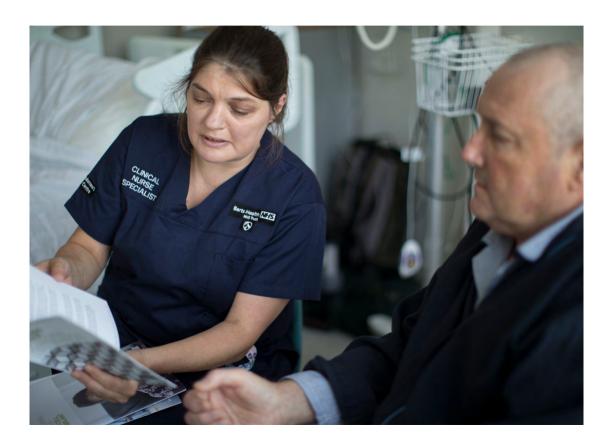
THE PERFECT MATCH

Are there any other factors?

A couple. When choosing a donor, their age is taken into consideration. Young people are most likely to be chosen to donate because our research shows it leads to better outcomes for our patients.

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 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.





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) coordinator 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 will talk to you about all your possible options. This may include looking for a **cord blood match** or a **haploidentical transplant.**

When someone gives birth, blood stem cells from the umbilical cord can be collected and frozen. These stem cells don't need to be as well matched because they are not as mature as adult blood stem cells. This means it can be easier to find a suitable cord match. Haploidentical transplants use a related donor whose tissue type is a half-match to your own. Parents are always a halfmatch for their children.

and vice versa. Siblings have a 50% chance of being a half-match for each other. Almost all people have at least one potential haploidentical match in their family.

Have a look at our website for more information about the different types of stem cell transplants: anthonynolan.org/transplants

Q. Will my donor give blood stem cells or bone marrow?

There are two different ways to donate which results in two different products: bone marrow and blood stem cells. They do the same job but your medical team will decide which one

is used, based on what's best for you, your 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

THE JOURNEY

saving the lives of people with blood cancer

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



If you have any 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 your 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 look at all the donors available internationally.



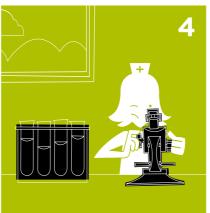
Shortlisting your donors

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 own 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 (mainly 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

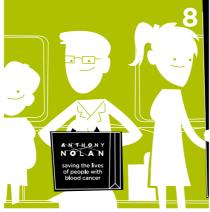
Meanwhile, somewhere in the world, your donor is preparing to give their stem cells through one of two methods.



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 operation where two needles are used to collect bone marrow from their pelvis. Whichever method is used, 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. The cells will kick-start your immune system and help you produce the new blood cells that you need to recover.



... and beyond

The first few weeks and months 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. It's a long road to recovery, but we'll be with you every step of the way. If you need support, have questions, or would just like a chat, we're here for you. Get in touch at patientinfo@ anthonynolan.org or call 0303 303 0303.

'STAY STRONG:

Harun, who had a stem cell transplant

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 (Oct 2021). We plan to review this publication within three years. For updates or the latest information, visit anthonynolan.org

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saving the lives of people with blood cancer