

# Everything you need to know after your stem cell donation



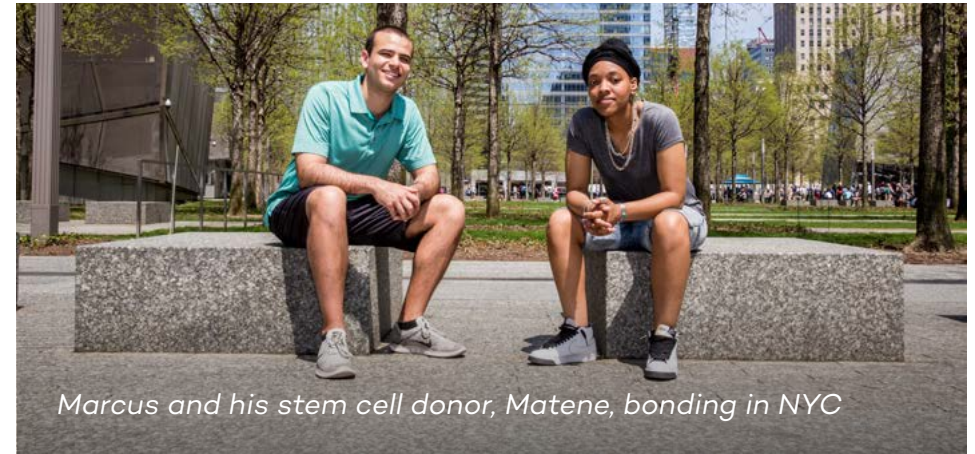
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## Congratulations!

You have accomplished something truly incredible – you have given someone a second chance at life through your generous stem cell donation.

On behalf of DKMS UK, the patient, and their medical team, we sincerely thank you for your donation. As a stem cell donor, you are now part of a remarkable community.



*Marcus and his stem cell donor, Matene, bonding in NYC*

You should feel immense pride, and we want to celebrate this amazing achievement! You may also be wondering what will happen next...

This handbook will guide you through the process following your stem cell donation, explain what the process is on the patient side, provide guidance on how to correspond with the patient if you would like to, and share additional ways you can support DKMS's mission.

Thank you again for your selfless act and commitment to giving someone a second chance at life.

# What to expect following your stem cell donation

## Looking after yourself

Every stem cell donor's experience after donating is unique. Some may feel tired or experience aches, while other donors may have no side effects at all.

Some common side effects of stem cell donation are:

- Bruising easily
- Feeling tired
- Mild flu-like symptoms (headaches, muscle aches, and bone pain.)

These should last no longer than two to three days. We will contact you shortly after your donation to ensure you have fully recovered.

Some donors may notice a change in their mental health following a stem cell donation. Some may feel a euphoric high, while others may feel anxious or concern for the patient. Whatever you are feeling is very normal.

If you have any urgent questions or concerns after your donation, please reach out to the Follow-up Team.



Fran, stem cell donor

## Your availability during the next two years

Following your donation, you will be temporarily reserved on the stem cell register for a period of two years while you remain committed to the patient you've donated to. This means you will not be matched with any other patients during this time.

In rare cases, the patient may require an additional donation. If this happens, we will reach out to you. Please note, an additional donation is entirely voluntary.

We encourage you to keep in touch and inform us of any significant changes to your availability or health during the next two years. This is important in case the patient requires your assistance again. For example, if you leave the country for an extended period, become pregnant, or have personal reasons that affect your availability.



Our Follow-up Team is always here for you

## What happens next?

We will now monitor your health after your stem cell donation through our follow-up programme. We will contact you at specific intervals as outlined below:



**Same week as your donation:** We will call you within a few days of your donation to confirm that you are doing well.



**After one month:** You will receive an email asking you to complete a short medical questionnaire and we will provide a letter for your GP to arrange a blood test. The blood test is optional but we recommend you have it to ensure your blood values have returned to normal. If you need any support with this, please let us know.



**After six months:** You will receive an email from us with a short medical questionnaire to complete.



**After one year and then every year for 10 years:** You will receive an email from us with a short medical questionnaire to complete.



DKMS UK Follow-up Team

## Common FAQs

Now that you have donated, our Follow-up Team are on hand to guide you through the next steps post-stem cell donation.

Here are some commonly asked questions:

### Can I donate blood after my stem cell donation?

If you are a regular blood donor, we recommend that you refrain from donating blood for six months if you donated via PBSC and 12 months after bone marrow donation. This waiting period allows the body to fully recover from the stem cell donation process.

### Can I get my expenses reimbursed?

We ask that donors submit their expenses and loss of earnings within three months of their stem cell donation. If you are experiencing any issues or have any questions, please email [donor.reimbursements@dkms.org.uk](mailto:donor.reimbursements@dkms.org.uk) who can support you.

### What is the 'targeted stem cell count'?

During your collection, there may have been some discussion of targeted cell count. The transplant team request a number of cells based on different factors, such as the patient's condition, how the cells are transplanted and the patient's and donor's weights. If you have any questions about your collection, please reach out to the Follow-up Team.

If you would like to discuss anything you read in this booklet, please contact our Follow-up Team on **020 8747 5660** or by email on [followup@dkms.org.uk](mailto:followup@dkms.org.uk).

## News and updates from the patient

### What information can be shared about the patient?

When we first call you after your donation, we will share some basic information about the patient who received your stem cells if you would like to know it, including their age range, gender, and the country where the transplant took place. At this point, this is all the information we can share with you.

### Cryopreserved stem cells

You may have consented for your stem cells to be cryopreserved and we'll discuss the next steps and details with you when we call you after your donation. We will be reaching out to the patient's medical team for confirmation that your stem cells have been transplanted and we will keep you updated. Please note, this will not be relevant to you if you did not consent to the cryopreservation of your stem cells.

### Future updates on patient:

If you have expressed a desire to receive updates on the patient, we will be contacting the patient's medical team for you to find out how they are doing. There are different rules about when and how often we can request this information, depending on the guidelines of the patient's country.

Please note that it can take some time to receive a response. Once we obtain information about the patient's health, we will reach out to you via email or post.

Keep in mind that regulations concerning contact between donors and patients vary by country.

**“As a stem cell donor, you have given real hope to the patient. Thank you for your selfless act.”**

*Dr Khaled El-Ghariani, Consultant haematologist and medical advisor to DKMS*



## Common FAQs

### Why does the patient need a stem cell transplant?

A stem cell donation by an unrelated donor (allogeneic stem cell transplantation) can be a potentially lifesaving treatment option for patients who don't respond fully to conventional treatments such as radiotherapy or chemotherapy, or who relapse after prior treatment.

### How are the cells transplanted?

Before the patient can receive the donated stem cells, they will receive high dosages of chemotherapy and possibly radiation therapy in order to completely remove all the diseased cells in their blood system. This high dose of treatment removes their blood-forming cells in the bone marrow to make room for the new stem cells and also weakens the patient's immune system so it cannot attack the donated stem cells. The donated stem cells move through the bloodstream to where they belong in the bone marrow and replace the patient's unhealthy blood stem cells.

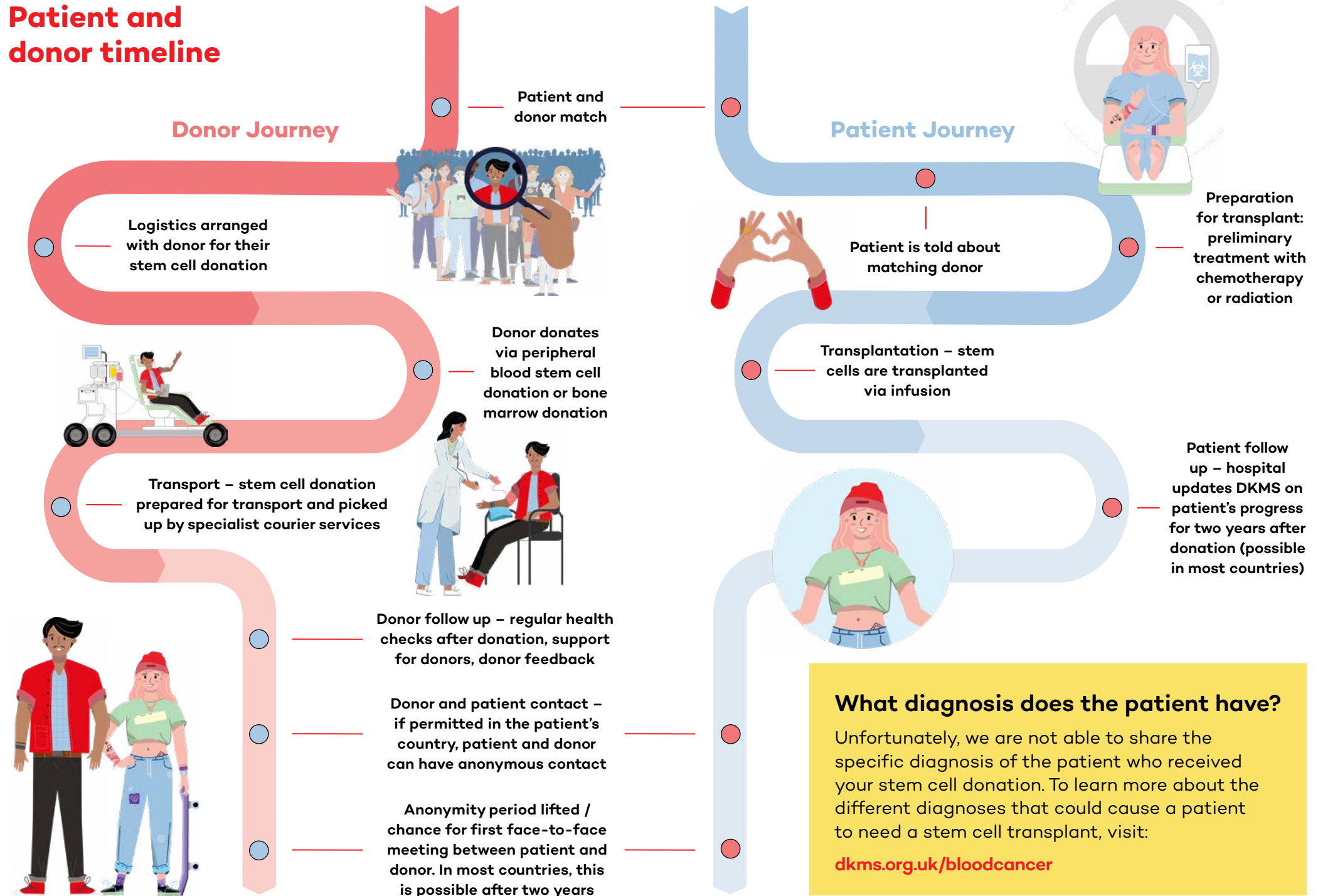
### What happens to the stem cells in the patient's body?

The donated stem cells settle into the bone marrow, where they begin to grow and produce red blood cells, white blood cells and platelets (this is called engraftment). Because the immune system and the blood system are closely linked and can't be separated from each other, a transplant from a donor means that not only the donor's blood system but also their immune system is transferred from you to the patient.

### What is the recovery like for the patient?

As a result of the patient having this new immune system, there could potentially be some adverse effects for the patient, such as immune rejection of the donated stem cells by the patient or immune reaction by the donor cells against the patient's tissues (graft-versus-host disease). The individual survival rate after a transplant depends on the age and health of the patient, the illness and the occurrence of complications. Between 40 to 80% of the transplants are successful.

# Patient and donor timeline



**What diagnosis does the patient have?**

Unfortunately, we are not able to share the specific diagnosis of the patient who received your stem cell donation. To learn more about the different diagnoses that could cause a patient to need a stem cell transplant, visit:

[dkms.org.uk/bloodcancer](https://dkms.org.uk/bloodcancer)

## Finn's story: from transplant to thriving!

At just 7 years old, Finn was diagnosed with a rare and life-threatening blood disorder where white blood cells attack other blood cells in the body.

Finn and his family suffered years of worry, uncertainty, medical tests and long hospital stays before he had his two transplants. His first donor was from Brazil. Sadly, Finn's stem cell levels dropped dangerously and he risked relapsing, but thankfully another 100% compatible match was found for him in Portugal.

Aged 10, Finn received his second stem cell transplant. Happily, he is now back at school and enjoying life to the full. Finn shares: "I'd like to say to my donors that you are my heroes, you gave me a second chance in life, thank you!"

Motivated by their experience, Finn and his family have been dedicated to adding more lifesavers to the stem cell register, to give hope to other people facing blood cancer and blood disorders.

Finn's mum, Jo, says: "When we found out that only a small number of people are registered as stem cell donors, we felt really scared, not knowing if Finn's match was going to be out there."

"But after his second transplant, he's been so well that he's been back at school and doing everything that any child should be doing. He's laughing and enjoying life to the max!"

If you'd like to help us add more potential lifesavers to the stem cell register, see the section about Donor Champions on **page 16**.



*Stem cell recipient, Finn, with his mum, Jo*

## Communicating with the patient

In most countries, you can anonymously write to the patient from the day your stem cells have been transplanted. Due to a two-year anonymity period, contact can only occur anonymously through letters or email, so you cannot meet each other in this time.



### Anonymous correspondence

To make sure the anonymity period regulations are followed, DKMS will act as a go-between for your correspondence. If you would like to send a message to the patient, we will be able to pass this on to the patient via the responsible transplant clinic (TC).

If you are sending a letter by post to us for us to pass on, make sure to include your donor ID separately (e.g., on a cover sheet or envelope) so we can properly allocate your correspondence. Please do not include your donor ID in the body of your correspondence.

A DKMS staff member will read your letter to make sure it doesn't contain any information that could give away who you are. We are required to remove any information that could compromise your anonymity, including:

- your name
- initials
- place of residence
- any other details that could reveal your identity.

If the patient is being treated abroad, please write your letter in English. If you have any questions, feel free to contact us. Please email any correspondence to **followup@dkms.org.uk**, and send letters to:

Follow-up Team  
Ashburnham House  
Castle Row  
Horticultural Place  
London W4 4JQ

## Some hints and tips

Here are a few suggestions for what you might include in your letter:

- Wishing the patient well on their recovery journey
- Sharing your feelings about your stem cell donation
- Expressing your hopes for the patient's future.

A great time to send a letter is after DKMS provides an update on the patient's health, the festive season, or around the anniversary of your donation.

## Waiting for a reply

Donors may sometimes wait a long time for a response from the patient, or they may not receive one at all.

The patient may need more time to respond as they might still be ill or may not wish to be contacted at this time. Just as reaching out to the patient is a personal decision for you, it is also a personal choice for the patient who received your stem cells. From our experience, many patients often respond to the donor's letter after some time, especially when their health has stabilised and they can share positive updates about their progress.

Mark donated his stem cells to Ivor and the pair formed a unique bond. Here is an example of one of the anonymous letters Mark sent to Ivor.



*Dear recipient,*

*It's been about 7 years now since I donated my stem cells and you had your transplant...*

*I often think about you and how you are doing. I hope well and still living a good life with your family and friends.*

*Anyway I hope that this might open up the communication between us again, if you wish to of course. But, for now, I hope it finds you well.*

*From your donor.*

## Donor Club

You've already done something incredible, for which the patient, their family, and everyone at DKMS are truly grateful. Donating stem cells is a unique experience, and we would love you to join the DKMS Donor Club with others just like you!

As a member, you'll:

- Connect with other donors and share your stories and experiences
- Join our private Facebook group
- Receive an exclusive stem cell donor t-shirt
- Get invited to exclusive Donor Club events.

You'll also have the opportunity to help shape the future of the donor experience by:

- Taking part in surveys
- Attending workshops to improve the donor journey
- Sharing your ideas to help make the process even better for future donors.

## Donor Champions

If you're motivated to do more, you can become a Donor Champion, a crucial volunteer role at DKMS! You can share your donation experience at local events – whether that's giving a short talk, helping out at awareness stands, or encouraging others to register by showing how simple donation really is.

What you can expect:

- Flexible opportunities – you'll only be contacted when there's a local event and you can choose when to help
- Travel and lunch expenses reimbursed (in line with our volunteer expenses policy)
- Full training provided.

To learn more about the Donor Club or becoming a Donor Champion, please email [donorclub@dkms.org.uk](mailto:donorclub@dkms.org.uk).

## More ways to support DKMS

Following your donation, there are lots of ways to get involved with DKMS, helping us give more people with blood cancer or disorders a second chance at life. You could:

- Share your personal donor experience with us and the world – we'd love to hear your story! Contact our media team by email at [digital@dkms.org.uk](mailto:digital@dkms.org.uk) to learn more.
- Register potential lifesavers: organise a donor recruitment event in your community or workplace. Contact our Donor Recruitment team by email at [donor@dkms.org.uk](mailto:donor@dkms.org.uk) and we will support you all the way.
- Join or start a DKMS volunteering hub. Contact our Volunteering team at [volunteer@dkms.org.uk](mailto:volunteer@dkms.org.uk) to connect with like-minded people in your area and help us save lives.
- Fundraise for DKMS – Your stem cell donation began with a simple registration, and each one costs DKMS £40. By taking on a challenge, hosting a bake sale, organising a workplace event, or fundraising in your own way. For tips and support, contact [fundraising@dkms.org.uk](mailto:fundraising@dkms.org.uk).
- Like and share our social media posts to help spread awareness.



Find out more at [dkms.org.uk/get-involved](https://dkms.org.uk/get-involved) or scan the QR code.



## Going the extra mile: Elizabeth's story

Elizabeth from London joined the stem cell register at work:

"I remember there was a table in the canteen where they were registering donors. Although I was apprehensive, I signed up mainly because I knew there was low participation from Black donors."

Five years later, Elizabeth was identified as the best match for a patient in need of a donor, and she went on to donate her stem cells.

She explains: "You can't say you're part of a community, no matter how broad, if you don't actually give back. Matches are based on genetics so if you're Black, you're more likely to donate to someone of a similar heritage."

Inspired by her own donation experience, Elizabeth was motivated to help raise awareness about DKMS and the stem cell register. A keen footballer at Clapton Community Football Club, Elizabeth rallied her community and organised a donor registration event at a match day, with the support of DKMS.

Elizabeth explains: "It was great to work with DKMS to raise awareness about the stem cell register. I was proud to donate my stem cells, and through the event I was able to share that! Plus, we were able to add 52 new lifesavers to the stem cell register."

Get involved in a DKMS event.  
Find out more at [dkms.org.uk/events](https://dkms.org.uk/events)  
or scan the QR code.



*Stem cell donor Elizabeth, volunteering at donor registration event*

## Direct contact with the patient

In many countries there is at least a two-year period of anonymity where it is possible to contact each other anonymously through DKMS UK. Unfortunately, some countries prohibit contact completely. Whether direct contact between donor and patient is possible depends on the rules of the country of the transplant centre (TC).

You may be wondering if you want to contact the patient. Whether you would like to make contact is and remains your own personal decision. There is no general answer to this question and every donor or patient is free to decide whether or not they wish to do so.

DKMS will support you in your individual decision-making process and will gladly provide you with all the information you need.

If you are interested in direct contact with the patient, please contact the Follow-up Team to obtain the necessary consent forms for this process. The patient will also receive these forms from the TC, and together you can decide what personal information you're comfortable sharing. Once DKMS receives the signed consent from both parties, the agreed-upon information can be exchanged.

### Meeting in person

Once the anonymity period has come to an end, both you and the patient have the opportunity to meet in person. If the patient is under 18 years old, parental consent will be required for the exchange of addresses, ensuring that everyone feels comfortable and secure.

Meeting each other can be an incredibly moving experience. After all, you are connected in such a profound way – your donation may be the reason the patient is here today. If you're considering reaching out to the patient or if you have any questions, please don't hesitate to contact us.

Taking the step to meet in person is a big decision, and it's important that you and the patient feel ready and comfortable. Whatever decision you make, we will support you every step of the way.

## A bond for life: Poonam and Viren's story

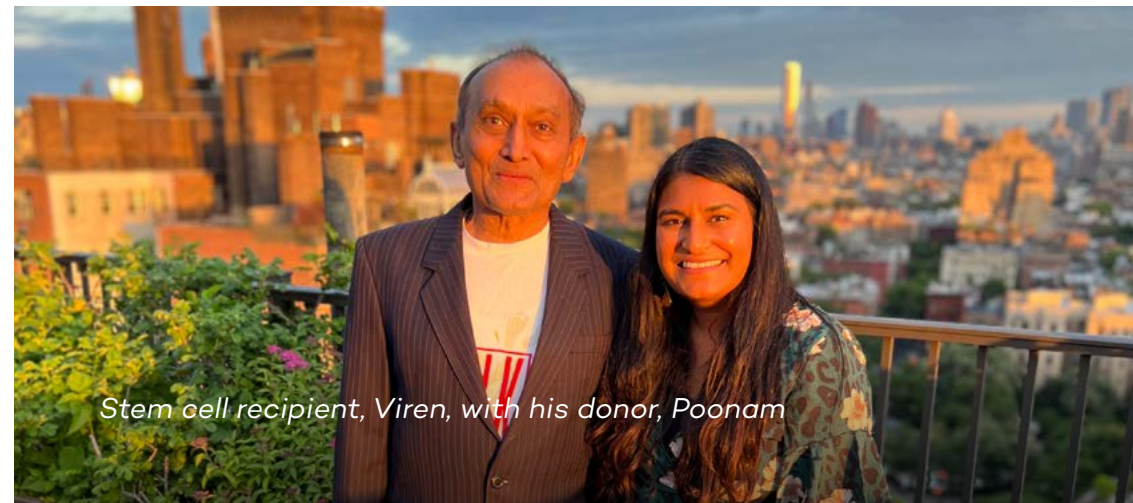
In 2020, Poonam donated her stem cells at the London Clinic. The patient was a man she knew nothing about and they were initially only able to communicate anonymously through DKMS.

Poonam recalls, "All I knew about the patient was that it was a man. They explained we couldn't directly contact each other for two years, and only if both sides agreed. But we could write anonymously via DKMS if we'd like to. So, I wrote a letter quite soon afterwards.

In 2023, after two years of writing, Poonam and her family flew to New York to meet Viren and his family. Viren, originally from India, had moved to America and built a successful career. He faced a severe health challenge in 2019 when he developed myelofibrosis, and a stem cell transplant was his only hope.

During their visit, the families explored New York together, creating cherished memories. One evening, Poonam had a heartfelt conversation with Viren and his daughter. "He said to me, 'You do realise now you're like family to me, you're like a daughter to me'. I think of him as an older, caring friend," she shares.

Viren also expressed his deep gratitude and connection. "A bond was naturally in place. I don't think either one of us was surprised at how easily we related to each other. We are a part of life together. Few are as fortunate as I am."



*Stem cell recipient, Viren, with his donor, Poonam*

## Patient outcomes

Your stem cell donation has given a person with blood cancer or a blood disorder a second chance at life. This is a wonderful, selfless achievement and we can't thank you enough.

It is an incredible feeling when the patient you donated to recovers with the help of your stem cells and we will be there to celebrate with you.

We will also be there to support you if the patient sadly passes away. Everyone will react differently to this news – some donors are surprised by how much they are affected by the death of a person they do not know.

It is important to remember that, with your donation, you have given a patient who is very unwell precious, valuable time. They created memories and experienced moments with their loved ones that would not have been possible without your kind act.

Some questions that often come up after hearing the patient has passed away are:

- What is the exact date and cause of the patient's death?
- Why wasn't another donation organised?
- Could my letter still be forwarded to their family?
- Am I now available for another patient?
- Can I know the patient's name or more about them?

If you would like to discuss any of these questions or feel you need support during this difficult time, please contact the Follow-up Team on **020 8747 5660** or by email on **followup@dkms.org.uk**.

Alternatively, the following organisations can offer support:

- Cruse Bereavement is a charity that offers bereavement support. You can call their helpline on **0808 808 1677** to speak to one of their trained volunteers.
- Mind is a mental health charity with useful bereavement resources: **mind.org.uk/bereavement**

## Precious extra time: Polly and Chelsea's story

Polly from Derbyshire registered as a stem cell donor after her uncle was diagnosed with cancer in 2020. She was matched with a seriously ill patient just two weeks later and agreed to donate right away.

Unbeknownst to Polly, the patient waiting for her stem cells was Syd from Worthing, a self-employed plumber described by his family as a beloved character and 'larger than life'.

Syd's daughter, Chelsea, shares, "The years we had after dad's transplant were so special. We made so many memories, travelled together, plus he was there for the birth of my daughter, Molly, and even celebrated her first birthday."

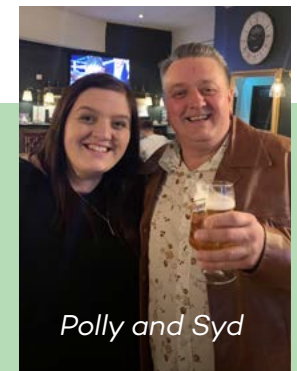
Sadly, despite receiving two stem cell donations from Polly, Syd's cancer returned, and he passed away in September 2024.

"One of the last things Dad said was, 'Please make sure you meet her and tell her what she meant to us all,'" Chelsea recalls. The two women have since kept in touch and are forever bonded through Polly's connection to Syd.

"Regardless of the outcome, I want to emphasise that, even though Dad is no longer here, that donation still meant the world to us because we had all that extra time together," reflects Chelsea.

**"Regardless of the outcome, I want to emphasise that, even though Dad is no longer here, that donation still meant the world to us because we had all that extra time together,"**

*Chelsea - daughter of stem cell recipient.*



*Polly and Syd*

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**[followup@dkms.org.uk](mailto:followup@dkms.org.uk)**

**020 8747 5620**

**Connect with DKMS UK**



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Published November 2025