

Writing to your donor family

A patient's guide

Introduction

In our experience many of our patients have asked for details about their donor and many have wanted to say 'thank you' to the family of their donor.

This leaflet is intended to explain what information the donor family is given, what information you as the recipient can request about your donor and the process of writing a letter to your donor's family.

We will also explain what can and cannot be included in the letter and what happens to your letter once we have received it.

It has been shown that donor families react very positively on receiving such letters. We have had feedback from donor families that these letters give them comfort to know how the recipient is doing and how the gift of life has transformed not only their lives but that of their families and friends too.

What are families told?

Within two to three weeks of organ donation, the donor families receive a letter from the specialist nurse in organ donation thanking them for their donation.

In this letter they are given very basic information on who received a transplant, information such as a rough age and gender. They do not disclose any identifiable information, such as full name, date of birth, or whereabouts in the country you live.

What are the recipients told?

Not every recipient asks for their donor details, but if you would like to know, then please ask to speak to one of the transplant specialist nurses or a member of the donor letters team.

Please be mindful that to protect the confidentiality of the donor, we can only tell you very basic information, their gender, a rough age, and some general information about their cause of death. We cannot tell you their name or where in the country they lived.

Writing to the family

We would strongly advise you wait until after you are discharged from hospital before writing to the family. We recommend writing between 6-12 months after your transplant, but if you do not feel ready or want

to wait, you can write years after your transplant.

When we are reading through donor letters sometimes there is identifiable information in the letter, and we must sadly decline this and ask you to rewrite it.

Things that cannot be in your letter, include:

- Your full name - you can use your first name.
- Address - you can use a rough description, such as, 'I live by the coast'.
- Royal Papworth Hospital - you can say 'my transplant centre'.
- Your contact number or email address.
- Social media accounts.

Please be mindful when writing your first letter to not include too much information about your recovery as this can be a little too much for a first letter.

How do I start my letter?

Think about what you would like to say in the letter, for example things that you struggled to do before transplant, the difference the transplant made to you, a

little about your life, such as your job, personality, hobbies, etc.

Please see some examples on the next page

Example letter 1

Hello,

My name is Rosie, I am 20 years old and was born with cystic fibrosis (CF). I had been relatively well as a kid, managing to keep up with my schoolwork and friends but when I turned 18 things changed. I became very breathless when walking and talking, I was having to have a nap in the day as I was so exhausted, and I started picking up more infections.

As my condition progressed, I spent more time in hospital having treatment and ended up having to have a line fitted to be able to have frequent long courses of additional treatments, including intravenous antibiotics. During one of my admissions, I was struggling so much with my breathing and could barely manage to do the short walk outside of the ward, the discussion of transplant came up.

When I was called in for transplant, I felt lots of emotions, but my two most prominent were elation at the prospect a new uninhibited life but also an immense feeling of sadness that someone's loved one had sadly died.

I wanted to write this letter to let you know how much my life has changed because of your brave decision. My recovery is going well, I am starting to go back to my normal life. I have been going out for a daily walks, seeing friends, and have even started the process of going back to university to study fashion and design.

My family and I think of your loved one every day, I wonder if you could tell me a little bit more about them.

Thank you for the most generous gift I will ever receive.

Love Rosie xx

Example letter 2

Dear friend,

This has been one of the hardest letters I have ever written but also the most important. I am so very sorry for your terrible loss; I understand no letter can ever take that pain away, but I hope this letter gives you some comfort in knowing what a difference organ donation has made to mine and my family's life.

My name is Jim, I am a 42 year-old man with a lovely wife, two children and a dog called Spot. I was an active, fit, non-smoker until I was diagnosed with chronic heart failure.

Before I received my heart transplant, I was struggling to do the most basic of daily tasks such cooking, cleaning, or walking the dog. The doctors could see I was declining despite being on lots of medications and trialling different treatments, therefore they made the decision to put me on the transplant list.

After my transplant, I remember getting up out of bed, walking and not feeling dizzy or breathless, it was a very overwhelming feeling of joy.

I am now six months post-transplant, doing great, going on lots of walks with my family and enjoying my new lease of life. All this is only possible due to the very selfless decision you made.

Thank you.

Jim

Some patients like to send a draft of their letter via email for the donor letters team to read through, then once it has been checked they then handwrite it. Some patients like to handwrite their letter but others prefer to type it - either is fine.

What happens to my letter?

Once you have composed your letter, you can either:

- Hand it to one of the transplant nurses in clinic.

- Email it to:
papworth.donorletters@nhs.net

- Post it to:
Donor letters team
Transplant team

1st Floor
Box 12
Royal Papworth Hospital
Papworth Road
Cambridge Biomedical Campus
Cambridge
CB2 0AY

Once we receive your letter, one of the donor letters team (Katie, Leanne or Orlaith), will read through the letter to check the content is suitable.

If there is any content we believe is not suitable then we will contact you and advise of

changes that may need to be made.

However, if the letter is suitable then we will send this to the donor family care service (DFCS). Once the letter reaches the donor family care service they will read through the letter and contact the donor family to make them aware there is a letter and ask if they would like to receive it.

Sometimes families chose not to receive the letter, and this can be for a variety of reasons. The donor family care service will keep the letter on file and if the family choose in the future to read it, they can request this from the donor family care service and they will send this onto them.

Unfortunately, we are not told if a donor family wishes to continue receiving correspondence; we are only made aware of their wish to refuse any further correspondence from recipient families.

This means that if a family does not write back or let the Donor Family Care Service know that they do not want to be contacted again, we must assume:

- They have received the letter but have not felt able to reply

- They have received the letter and would like further correspondence
- They have been offered the letter but have declined to have it at present, but may want it in the future

If the family choose to write back, then the donor family care service have their own team of specialist nurses who will read the letter, check it is suitable, send it onto us, we will read the letter and contact you to check if you would like to receive the letter.

Just to note, the process of sending and receiving communication between recipients and donor families can take a few weeks.

How do I contact the donor letters team at Papworth?

The Papworth donor letters team is run by Katie, Leanne, Orlaith and Chrissy.

We can be contacted via the TCCU helpline on:
01223 638007
(please leave a message).

Via email: (dedicated Royal Papworth donor letters email)

papworth.donorletters@nhs.net
Or by post at the following address:

**Donor letters team
Transplant Team
1st Floor
Box 12
Royal Papworth Hospital
Papworth Road
Cambridge Biomedical Campus
Cambridge
CB2 0AY**

Royal Papworth Hospital NHS Foundation Trust

A member of Cambridge University Health Partners



Papworth Road
Cambridge Biomedical Campus
CB2 0AY



royalpapworth.nhs.uk



01223 638000

Large print copies and alternative language versions of this leaflet can be made available on request.

View a digital version of this leaflet by scanning the QR code.



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