

# Writing to your donor family to say thank you





## Why writing to your donor family matters

Your life changing organ transplant was only possible thanks to the generosity of your donor and their family's courage and support for donation. The gift of organ donation is the start of a physical and emotional journey for you as a recipient and for your family and friends as you recover and look forward to a better life. Your donor's family are coming to terms with life without their loved one and many take great comfort from the knowledge that their last act was to save lives through the gift of organ donation.

Donor families tell us that receiving a letter from their loved one's recipient is a great comfort and makes them feel that their gift has been truly appreciated. 90% of donor families state that they would like to hear from the person who received their loved one's donation, so you can be confident your donor family are hoping to hear from you.

"There are now four people alive because of Beth and we are so proud of that. It was just fantastic to get the letter from the recipient. To think that something good had come from this was tremendous."

#### **Beth's parents**

Ella's Mum was a donor, she received a Christmas card from the daughter of one of her recipients. It said 'thank you for letting your mum help my mum'.

"It meant the world to me. Nothing will take away the pain of losing someone you love, but to know that another family still have a mum because of my mum's gift, it is just so incredible."

Ella

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Jane received a lung transplant and she and her daughter have written to her donor family.

"After my transplant, I was poorly for a long time. But as soon as I began to recover, I knew I wanted to write. It was difficult at first, what should I say? But as soon as I did it I knew it was the right thing to do. I wanted to let them know that my children had their mum because of the decision they bravely made."

#### Jane

## Finding the words: Facing anxieties that can stop you writing to your donor family

We know that writing can feel daunting and finding the right words can be difficult. Remember, your letter is about thanking and acknowledging your donor family, it is not an English exam! Simply say what you feel: it does not matter if your communication is long or short, the fact you have written will mean so much. If you feel nervous writing your Recipient Coordinator will be happy to help you or perhaps you could involve a family member and include their thoughts about how your transplant has affected the whole family.

"There is no need for guilt when a gift is freely given."

Susan, donor mum

"from our point of view our child did not have to die to give someone their life back, instead tragically our child had died and we then had a choice, whether to give someone else life or not"

#### Susan, donor mum

Many recipients worry that writing will add to their donor family's grief or that talking of their hopes for a new and better life would be inappropriate when their donor family are grieving. Please know that this is not the case. Every family has the choice of when to open your letter so it will never be read at the wrong time. Donor families make the brave decision to support donation because they want their loved one to save others. Your news will show they have achieved this and most take great comfort from that knowledge.

Trevor received a letter from one of the recipients of his wife's donation explaining that *"she had given them their life back."* Trevor said: *"It was such a tremendous source of comfort. It was not such a complete loss."* 

Trevor, donor family member

"Not hearing from any of the 12 recipients of Will's organs for the first 16 months after his death was so upsetting. Everybody tells me it is because the organ recipients don't know what to write or are worried they may upset us. But they **all** need to know that when you lose a loved one being ignored is the very **worst** thing. It is so important for us as bereaved parents to understand that Will's generosity has been recognised and that he is thought about by the recipients and their families."

Liz, donor mum

# Sitting down to write: What you should and should not say

When you write to your donor family maintaining your confidentiality is of great importance. Therefore it is important that the information contained in your letter helps maintain this. The tick box below is an easy way to ensure you achieve this and also gives you some ideas about information you may wish to share in your letter, simply tick off as you write your letter.

•	Just use your first name when introducing yourself and signing your letter.	
•	Ensure you don't include any confidential information about your address, where you work or the hospital where you received your transplant.	
•	You may wish to include a photograph. That's ok but please check there is no identifiable information included i.e. school jumpers with logos, signs in the background.	
•	What was life like before your transplant, how is life after your transplant and what are your hopes for the future and your family?	
•	How long were you on the transplant waiting list for?	
•	Leave the envelope of your letter unsealed. Our team caring for the donor family may wish to talk to the family about the content of your letter before they forward the letter itself.	$\Box$

# The practical bit: How to send your letter

We want writing to your family to be as easy as possible. We appreciate that not everyone has a writing set with paper and envelopes at home and it is important that you can communicate in the way which is easiest for you.

## Sending a physical letter or card

If you want to send a conventional letter or card, these are the steps to send it once completed. On a separate piece of paper from your letter or card please write the following:

- Your name
- Date of birth
- Date and type of your transplant
- The hospital where you received your transplant

This information will not be passed to your donor's family; it will be used to make sure we can identify your donor family correctly. **If you fail to include this information, it may not be possible to send your letter on as we may not be able to match your records with the donor's family.** 

Then put your letter or card in an envelope, along with the above information on a separate sheet of paper and send it to us directly at Donor Family Care Department, NHS Blood and Transplant, 14 Estuary Banks, Speke, Liverpool L24 8RB.

Alternatively, you can give it to your Transplant Coordinator who will read your letter or card to ensure you remain anonymous, before sending on to the above address.

## Sending an Electronic Letter

Write your letter either as an email or as a word attachment to an email and send to: transplant.recipientcare@nhsbt.nhs.uk

Ensure you include on the email the information listed above to help us identify your donor family. We will then either print your letter onto high quality stationery and send it to your donor family on your behalf or if they prefer we will send it as an email from our NHSBT account to them.

# FAQs

#### Is it ever too early or too late to write to my donor family?

No. Your donor family will be told your letter is coming to them so they can open it at a time that is right for them. This way it will never be the wrong time to hear from you.

#### Will my donor family write back?

Every donor family is different. All will appreciate your contact and some will write back quickly while others may not feel able to at that time. Either way your letter will make a real difference to how they feel about their loved one's donation.

#### Can others write?

Certainly! Your family and friends have been impacted by your illness and transplant and their stories also show the difference organ donation makes. If they want to write they are welcome but please consider writing with them rather than leaving it to them.

## What can I and can I not say on social media?

We live in an increasingly digital age and you may want to share news of your transplant across social media. Please remember that your good news is your donor families' bereavement and we don't want the privacy of either of you to be compromised. Therefore please do not share the date and hospital of your transplant and treat any information you have about your donor family in strictest confidence. If you want to make contact with your donor family please do this via NHSBT so we can ensure it is done in a way that works for you and your donor family. Ways to make contact are listed on page 6 of this leaflet.

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