How to go about receiving donor details and writing to the donor family

Receiving anonymous details about your donor

Following your liver transplant, you may be thinking about the person who kindly donated such a precious gift, as well as their family. This is natural after a transplant operation.

In the early days after the transplant, you will need to recover physically. You may also feel quite emotional during the first few weeks following your operation as you start adjusting to life with a new liver and new medication.

You will know when the time is right for you to receive details about your donor. Some patients choose not to receive this information. It is a very individual process and the Liver Recipient Transplant Co-ordinators will help you with any queries.

We can provide you with some anonymous details about the donor, which includes the age range and gender of the donor. Some patients also enquire about the reason the donor died, and we can provide this information if you wish to know. We will only give you the information you ask for.

What do you do next?

Some patients want to know details about the donor and then choose to keep this information to themselves and their family. Other patients decide they want to write a letter to the donor's family.

This is an individual process

If you do want to receive details about the donor, contact the transplant Coordinators and they can agree a time for you to receive these details, for example at your next clinic visit.

Writing to the donor family

If writing to the family is something you feel you want to do, you do not have to write straight away. You will know when it is the best time for you. For some patients, this might be in the first couple of weeks, but others may not feel comfortable writing for months. We would usually advise to wait until 3 months after the transplant to allow yourself time to recover. Do not be put off if the best time for you to write is not until a year after the operation, this is fine.

The letter

Some patients choose to buy a thank you card or a blank card to write in. Other patients write a letter or a poem. Some will include a photo. You can write as much or as little as you feel comfortable with.

Do not write your full name, address, telephone number or name of the transplant hospital, as we need to protect your confidentiality. You can include the first names of yourself and your family.

You might start the letter by saying 'hello' or 'dear friends' or 'dear family'. Never make assumptions about the religion, race or culture of the donor family. You should write the feelings from your heart and not what you think the family want to hear.

Author: Julie Hart Issue date: July 2024 Review date: July 2027

Information for Patients

When you have written your letter or card, do not seal the envelope or write anything on it. Send it to us with a covering letter including details of your name and date of birth to the address below:

Liver Recipient Transplant Co-ordinators

2nd Floor Nuffield House Queen Elizabeth Hospital Edgbaston Birmingham, B15 2TH

We will then read through the letter and forward it on to the Donor Records Department, who will write to the donor family to check they are ready to receive the letter. Remember, the letter will only be passed on to the donor family when they are ready to receive it, so do not worry that you may cause distress or upset. If the donor family is not ready, the letter will be kept on file for a time when they are ready to accept the letter. For this reason, please note the process of forwarding on your letter can take several weeks to months.

Our experience is that the donor families very much appreciate receiving such letters and find it a comfort to know their relative has been able to help others. Please be aware that commonly families might feel unable to reply to you – do not consider this a reflection of how they feel about receiving your letter. Often, it is simply enough for them to hear you are progressing well. Their loved one might have donated multiple organs involving multiple recipients, thus maintaining contact with all recipients can be potentially overwhelming.

However, the donor family might want to reply. You may want to take some time to think about how you would feel if this happens. If the donor family send a letter, we shall contact you when we receive it to gain your consent, prior to forwarding the letter on to you in the post if you agree.

If you have any questions regarding this process, you can contact the Liver Recipient Transplant Co-ordinators on office telephone: **0121 371 4528.**

Liver Recipient Transplant Co-ordinators

2nd Floor Nuffield House Queen Elizabeth Hospital Edgbaston Birmingham B15 2TH

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email interpreting.service@uhb.nhs.uk

PI24/0257/06 Leaflet title: How to go about receiving donor details and writing to the donor family