



LIFESHARING™

Donor Family and Recipient Communication

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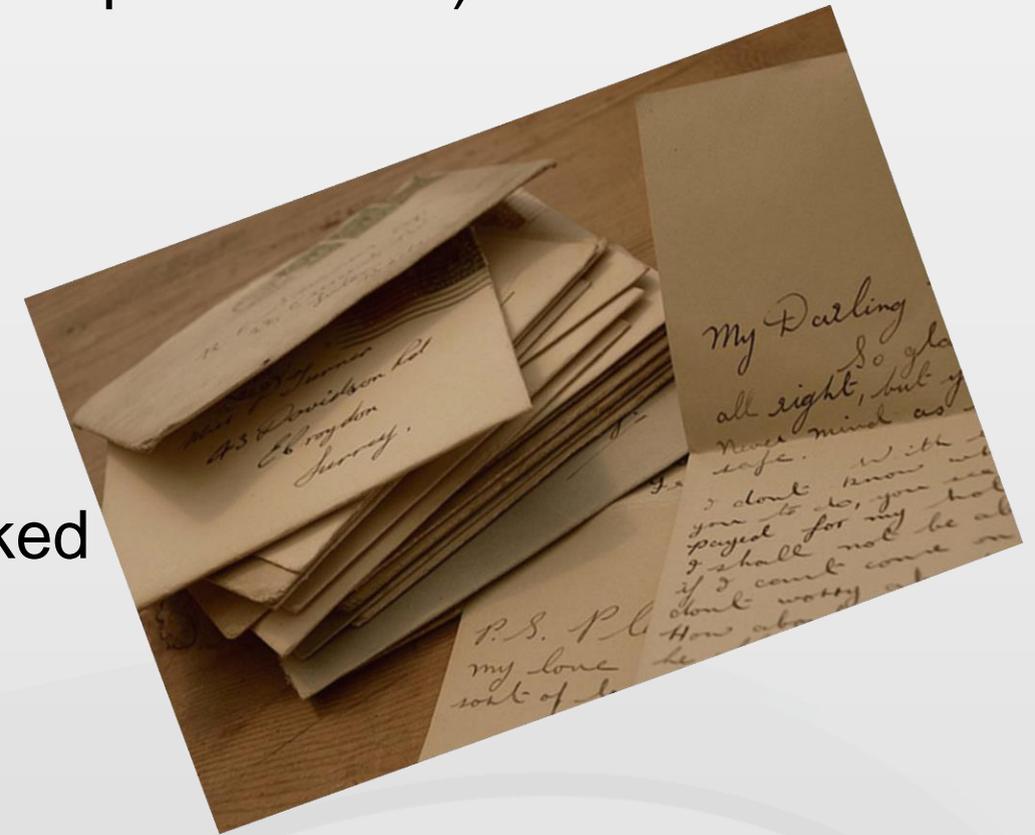
Lifesharing Correspondence Data

- 4 Family Service Specialists
- 1 FS Manager
- 126 donors on average
- 4 transplant centers in DSA (1 Peds, 3 Adult)
- 141 letters in 2016 increased to 227 in 2020



Correspondence Process

- OPO Receives letter (from donor family *OR* recipient via transplant center)
- OPO FS department screens letter
 - All donor/recipient/UNOS data match
 - Does recipient or donor family want correspondence
 - Is letter “appropriate” to forward
- If screened to proceed
 - Cover letter created and correspondence double checked
 - Copies are made and attached to EMR
 - Donor Family is contacted
 - Data entered into spreadsheet
 - Letter is sent out
- If not... process looped back to fix problem, *or* escalated to manager



Improving Communication

- Created user friendly pamphlets on writing to donor families/recipients
- Offered to speak at transplant support groups
 - Trialed with Sharp (CASH) Heart Transplant
 - Present on donation process
 - Clarify recipient misconceptions
 - Educate on letter writing and meetings
- FSS assigned to different transplant centers to improve communication
- Created an option for families for direct correspondence





Writing to Transplant Recipients

The decision to write to recipients is a very personal one. You might not be ready to write to the recipients at this time. There is no time limit for sending a letter. However, the sooner correspondence is sent, the more likely the recipient can be located and will receive the letter.

All correspondence is anonymous and identities are kept confidential to protect the privacy of both families. If your loved one was an organ donor, you do not need to wait to write to recipient(s). You may send a greeting card, letter, or photos. If your loved one was a tissue donor, it may take up to five years before the tissue is transplanted.

Your card or letter must be mailed to Lifesharing, and then forwarded to the recipient(s)

Tips for the Letter-Writing Process:

- Share General Information
 - Your loved one's **FIRST NAME** only
 - Your loved one's interests, hobbies, etc.
 - A favorite memory
 - Photos
- Only write information you are comfortable sharing.
- Details about medical information or cause of death should be avoided.
- To ensure confidentiality, please only use **FIRST NAMES**.
- Do not reveal any other details regarding home or contact information.

transplant center, please allow extra time for it to arrive. Be patient, it may take a few weeks for the recipient to receive your letter.

You should also know that you may not hear from the recipient. But we do know that recipients appreciate hearing from donor families and are grateful for the Gift of Life.

Questions:

If you have any questions or concerns, please contact a Lifesharing Family Services Specialist at familyservices@lifesharing.org or 619-543-7225

Mailing your letter:

Please send your correspondence and contact information to the Family Services Department.

LIFESHARING
c/o Family Services
7436 Mission Valley Road



7436 Mission Valley Road, San Diego, CA 92106 | Tel: (619) 543-7225 | Fax: (619) 543-0317 | www.lifesharing.org



Writing to Donor Families

Most of our donor families take great comfort knowing that their loved one helped others and they look forward to hearing from recipients. Still, some transplant recipients have told us that they struggle to find the "right words" to express their gratitude. The best advice is to speak from the heart, and tell the family how much you appreciate the gift that their loved one has given.

Identities are kept confidential to protect the privacy of both recipient and donor family. Your card or letter must be mailed to your transplant coordinator. It may take several weeks before the donor family receives your letter.

Tips for the letter writing process:

- Begin the letter when you are feeling positive
- Offer sincere condolences on the loss of their loved one
- Describe how the transplant changed your life and how much you appreciate their loved one's gift.
- Use simple language. Avoid detailed medical information or complex terms.
- Use first names only to ensure confidentiality.
- To further ensure confidentiality, do not share the name of your surgeon or transplant center.
- It's OK to offer general information about yourself and your family (hobbies, interests).

The decision to write to the family of your donor is a very personal one. You might not be ready to write to them at this time. It may take time before you're ready to write such a letter — please know that there is no time limit for sending correspondence. Just keep in mind, it may be difficult to locate family members if several years have passed.

It's possible that you may not hear back from the donor family. If the letter is unable to be delivered to the donor family for any reason, Lifesharing will communicate this with your transplant coordinator.

Questions:

If you have any questions or concerns, please contact your transplant coordinator.

Mailing your letter:

Please send your correspondence and contact information to your transplant center.



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Direct Correspondence or Meeting Request

- Case by case basis
- Donor family and recipient evaluated
- Mutual agreement by recipient and family
- Appropriately informed
- Information exchange or meeting is arranged
- Meetings in person OR online
- Family follow up as needed



Guidance for Direct Contact: Donor Families and Recipients

What is direct contact?
Direct contact is when donor families and recipients have direct communication with one another without the facilitation by the donor organization (Lifesharing) or recipient Transplant Center. This may occur only after both parties have expressed interest in sharing identifying information. Examples of direct contact include writing letters or emails directly to each other without going through Lifesharing, phone calls, and video calls such as FaceTime.

What if a donor family and recipient want to meet in person?
Although it isn't required, we recommend having the first meeting at the Lifesharing office. Lifesharing arranges for Family Services Specialists to facilitate the meeting. Meeting for the first time at the Lifesharing office provides a safe, neutral meeting site for both parties.

Considerations for Direct Contact

It is our experience that the majority of time, direct contact between donor families and recipients is positive; however, we want to ensure both parties have considered the possible benefits and concerns. A few points to consider include:

- Sharing information can simplify the process of communication between donor families and recipients and not require Lifesharing or the transplant center to be involved.
- There is opportunity to learn more about each other in a more direct, simplified way.
- Often donor families and recipients have an image of each other prior to direct correspondence. Sometimes it turns out the way they imagined and sometimes their image is not the reality.
- Donor families and recipients may find that the difference in background and beliefs can present a challenge.
- One side may want to communicate more than the other. If this becomes burdensome, please let Lifesharing or your transplant center know so we can assist you with how to respectfully move forward.
- At any time the other party may change their mind and feel they cannot continue direct communication. Both parties would be notified that any communication going forward would need to go through the transplant center and/or Lifesharing.

If you have questions, please contact your transplant coordinator or Lifesharing

7436 Mission Valley Rd. San Diego, CA 92108 | 



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