Acknowledging the Gift of Life: Sharing Information with Donor Families

“With donation we did not leave the hospital with nothing, but with the positive feeling that we made a difference”

– Donor family member

“After reading the letter, the reality of Lindsay’s death took on a different meaning to me. Through my grief, I was able to trust that my daughter made her decision to donate her organs so selflessly…I feel such peace knowing that my Lindsay gave three strangers life and through this gift she lives on forever.”

– Donor Mom

Helping someone in need

Transplantation is made possible only through the generosity of organ donors and their families. Each year, thousands of people are given a second chance at life through the generosity of America’s organ donors and their families, who are asked to think of others during a time of profound grief for themselves.

Why do they do it? Donor families frequently report that their reason for donating is to help someone. They frequently say that the act of donation created a single positive experience during an otherwise devastating event.

Is it possible to help the donor families?

Yes. Members of donor families generally want to learn the outcome of their gift, and to know that their generosity has made a difference in someone’s life. Such knowledge can have a powerful, positive and healing effect on the donor family and provide some closure for their loss.

Hearing general information about the recipient, such as age or gender, makes the donation real for family members. Many times, family members share this positive experience with others, resulting in increased public awareness and acceptance of organ donation.

What information is shared with donor families?

Typically, when a transplant recipient receives his or her organ(s), the donor team from the local organ procurement organization sends follow-up letters to the donor family. This letter includes very basic, “non-identifying” information that can help the donor family personalize their loved one’s gift. For example, knowing that their loved one’s heart saved the life of a 43-year-old female can be important to a grieving family.

What type of optional information may be shared initially with donor families?

Sharing information that this same 43-year-old woman works as a public school teacher, is raising two children and loves to travel may be even more meaningful to a donor family.
Would you consider allowing this type of information to be shared with the donor family at the time of your transplant? Your name and all identifying personal information will remain confidential.

What type of information might you share?

Below are some suggested details that you might consider sharing with your donor family. The choice of whether or not to share this information is entirely yours. It will not in any way affect your placement on the waiting list or candidacy for transplant.

If you would like to provide some basic information about yourself to your donor family, please check any of the details below that you would be willing to share. And remember: your name, location or any other identifying information will not be released to the donor family.

☐ Age       ☐ Male/Female       ☐ Marital Status
☐ Occupation       ☐ Number of Children       ☐ Number of Grandchildren
☐ Geographic Area (such as: Southeast, Northeast, Midwest)       ☐ Pets
☐ Hobbies       ☐ Other

☐ I agree to have the information that I have checked above shared with my donor family.

☐ I do not wish to have any information shared with my donor family.

I understand my consent or non-consent has no impact on my ability to receive an organ for transplant.

Signed ________________________________  Print Name ________________________________

Corresponding with donor families

In addition to initially sharing some very basic information, after an appropriate period of time following the transplant, you may wish to write a letter or “thank you card” to your donor family. Some people do this months, a year, or even several years, after their transplant experience. The decision to write to your donor family is entirely your own. In this situation, too, your identity may be kept totally confidential, if that is your preference.

Your transplant coordinator or your local organ procurement organization will facilitate the communication exchange between you and the donor family members. These same professionals can offer you guidance, if needed, on when to write to the donor family, what to say and how to say it.

To learn more about communicating with your donor family, visit:

- www.transplantliving.org
- www.nationalkidneyfoundation.org
- www.dnaz.org/forms/donor_families_recipients/letter_for_recipients.asp
- www.lifelineofohio.org/8637.cfm
- www.nebraskamed.com/transplant/donor_recipient_correspondence.cfm

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