

“Why didn’t they write?” – patient insights...

by Jim Gleason, heart recipient (19 years out)

In my favorite transplant love story movie, *Return to Me*, there is a touching scene dealing with the difficulty many transplant recipients experience in writing that thank you note to their donor family. In this scene, Grace, the heart recipient (played so perfectly by Minnie Driver), is still torturing herself about actually mailing the letter she has written and been carrying around with her since receiving her new heart a year ago. Her sister (with five small kids in tow) offers her the encouragement she finally needs to so tentatively drop that letter into the nearby mailbox there at the zoo (where, coincidentally, her donor’s spouse, played by David Duchovny, is working and they come into contact for the first time). While this may be just a movie fictional story, it does accurately capture the difficulty many recipients find in expressing themselves after a life saving organ transplant.

Reaching out to a large random sample of recipients, I asked for insights as to why patients hadn’t written to their donors, at least to express a simple thank you. The response was not overwhelming, indicating I hope that most actually do write, but enough replies came back to provide a realistic insight into that lack of communication. But let’s be reminded up front that both sides of this gifting process understand that neither is under any obligation to communicate, accepting and respecting each other’s rights in that it is an anonymous giving and accepting process. That said, human nature being what it is, there is often an expectation by donors of some acknowledgement and a corresponding interest by some recipients in knowing something about the donor. But given the process, neither side knows enough about the other to be able to understand what to expect or what is acceptable, and thus lies some of the basis for the insights shared in this too brief article, reasons which are as varied as the parties involved in the issue overall.

Reason #1: Perfection/inadequacy - Most write, but either rip it up as not being good enough, wanting it to be perfect, not being able to find the “right words.” Tony shares: “I haven’t written to my donor family cause I just don’t know what to say. Words cannot describe how thankful I am to them for giving me a second chance at life! That was a miracle itself! It is overwhelming to me at times cause I wouldn’t have my daughter either! There are no words that could express my feelings for saving my life and giving me the child I have always wanted! I am forever grateful” I can hear you thinking as you read this, “But she just did say it!” Or as Ken, a liver recipient one year out, put it simply when he finally did write: “You never received any of the other letters I previously wrote, because I was left feeling none of them were good enough to express my feelings reasonably well. This attempt may not be as good as I would wish, but I feel ashamed that so much time has gone by without a word of acknowledgment or thanks from me. If I continue to keep striving for perfection it will delay the message to you even longer.” So while an often cited professional or friendly advice “to just write it from your heart” empowers some to overcome this “never perfect enough” concern, saying that isn’t the same as actually doing it, which leads to the second most common response.

Reason #2: Fear – Even once written, actually mailing it (as in the movie) is still a big challenge for many, mostly out of fear of causing pain to someone they feel so grateful to for this ultimate life saving gift offered at a time of extreme tragedy for the donors, and it is recognized that that donor is often the living person who said yes to the donation request, the one who will be reading the letter. Here is where that fear of the unknown comes to play, not knowing the family situation of the donor family, are they ready to hear about where their loved one’s gifts went? Will such a note bring back all the pain and grief felt at the time of donation? And then we have the choice of words, not just the “perfect” words, but the expression of that gratitude, reason #3.

Reason #3: Grief vs. celebration of life – As Pat wrote: “...there wasn’t any way to say how grateful I felt to have gotten this chance at a normal life with my big, ever-so delighted family without feeling that hearing all our good news would cause sadness and hurt to the donor’s family.” This was repeated in many variations as this from Sandy affirms: “As the years rolled on, I found it much harder to write, because now I didn’t know what to say. I was still equally excited, but felt as if I was saying look at me, I am doing great, while your loved one is no longer here.”

Reason #4: **Privacy** – John is one who did write shortly after his transplant, and received a loving response, would like to write again but hasn't since out of respect for the donor family's privacy, not wanting to intrude further on their lives. As many shared, Richard too wrote, but tore it up many times, even though wanting desperately to hear from the donor. Instead he keeps the thanks in his daily thoughts and prayers for the donor and their family, never actually finishing that note out of respect for their privacy.

Reason #5: **Ignorance** – Not as common with today's education and support for writing, but cited by some long term transplant survivors such as Eddie, who got kidney transplants in '71 and '80, such communications were not encouraged and he got little if any knowledge of a process by which such a note could even be given. Eventually such patients acknowledge feeling it is too late and reason #2 comes back into play, not wanting, as Joan, a long term liver recipient said, to "reopen wounds" for the donor's loved ones, not knowing if that is a widowed spouse, child's mother, loving sibling or whomever.

Reason #6 – **Protective oversight** – From a "new heart family" we see another roadblock when "...in 1985, I wrote a heart-felt note to my donor family. Many years later I discovered that the letters are screened by the hospital staff and they can decide not to send it without letting the letter writer know." This can also be well intentioned OPO staff making protective judgments based on their direct contact with the donor or patient family. I have also known donor families who have hidden recipient letters from a loving mother out of protective concern, only to find that "discovering" one such letter years later, she was open and thankful for that message, eventually asking for a meeting with the recipient.

Maybe the best advice for patients in overcoming such reasons can be found in the following insightful sharings from Steven and Robert (among others), heart recipients, who wrote similar words (merged together here...): My Coordinators told me to just be myself and write from the Heart (pun intended). I wasn't sure how to do that, but after more false starts, I finally sat down one afternoon to write the note and I told myself that no matter how it came out I would send it. I decided to write it with pen instead of typing as I thought this more personal. I did mail the letter and have never heard back from them. After many, many false starts we hear another's variation on this: ...but the thought that came to me was "Just write it from your donor's heart". The letter that I eventually sent took me twenty minutes to write from start to finish. You would think that deciding to write a letter would be an easy task compared to the decision facing the donor family and at the worst time of their lives. Sometimes we need to look at the big picture. Fortunately, we as transplant recipients get a second chance to do just that.

But then, maybe things haven't really changed much in 2000 years when we recall how in the bible story about Jesus healing the ten, only one comes back to say thanks. But my experience tells me that our numbers today are at least better than that 10% and are getting better with each passing year. From this grateful fourteen year out heart transplant correspondent, let me say on behalf of recipients everywhere who still wrestle with the issues above, our love and thanks go out to donors everywhere, if not in letters still locked in our hearts, at least in daily thought and prayers for you and your loved one.

And one last thought, as eight year out heart patient Gene acknowledges, "...I know the above feelings are just excuses and I hope to someday to be able to write a letter"

For an expanded discussion on this topic, you can read the on-line chapter #31 of my on-line book, "Gift from the Heart" (67 pages of letters, shared e-mails from donors and recipients, and related resources) on patients communicating with donor families at <http://www.rjwitte.com/changeofheart/GiftFromTheHeart/Section2/CHP-31-DONOR-COMMUNICATIONS.pdf>