

FRAMING THE DONATION QUESTION

In all of the consent/decline databases we've seen in the past few years, donations are most often lost for the same two reasons, "He said he didn't want to be a donor," and, "She never mentioned it, so we better not." We feel these objections are such a threat to raising donor numbers, we want to publicly share some of what we teach in our new workshops, **The Language, Principles and Variations of Good Donation Conversations** and **Phone Requests for Eye and Tissue Donation: What to Say and What to Avoid**. If you are a donation professional, we hope you will find these ideas helpful. If you a member of the general public, we hope you will find them reassuring.

First Person Authorization

For over a decade now, the donation strategy in the U.S. has rested on the idea that people should decide for themselves to become donors and their families, at the time of a loved one's death, should fulfill their wishes. This is commonly called First Person Authorization. We've outlined elsewhere some of the reasons for the adoption of this strategy.¹ We'll just say here that it seemed like a good idea at the time and the basic assumption was that it would raise donation rates. But donor numbers in the U.S. have stagnated since 2007. Short of changing the system to one of presumed consent or opting-in, which would take political effort and still probably rely on family willingness, we think it's time to take another look at how families are asked about donation when the potential donor was not registered. The assumption in the conversation now is that the deceased's wishes should be the most important element of the family's decision-making. We'll propose an alternative way of framing this question which we believe will increase donor numbers and be more therapeutic for families.

¹Verble M, Worth J. Addressing the unintended adverse consequences of first-person consent and donor registries. *Progress in Transplantation*. 2012; 22(1):25-40.

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The two most frequently heard objections cited above appear to result from several things, but certainly one of them is how the subject of donation is introduced. The assumption that the deceased's wishes are paramount is reflected in introductions like, "Did John ever mention wanting to be a donor," "Did you discuss what he wanted to do about donation," "Was John the kind of person who liked to help people," and, "John has the opportunity to save several lives." The survivors are being asked to decide to donate not on their own values, feelings and judgments, but on the basis of someone else's who can no longer speak for himself. This generates multiple problems for both donation specialists and for survivors.

What's the Problem with this Framing?

1. Families are being asked to recall conversations that may (or may not) have taken place in the past under circumstances different from the one they find themselves in at the time of an actual death. They may think back to a conversation that was jocular or one based on inaccurate or sensational information.
2. Family members may not be able to remember any conversation at all, no matter how hard they rack their brains, and, as donation is such a common news topic, they may take that as a sure sign John didn't want to donate.
3. Families are not psychics. John is dead. What he really thought, or what he would've thought had he had a serious, in-depth conversation is forever lost and inaccessible.
4. Research into donation decisions has long established that the primary motivation for donating is altruism. The chance to be altruistic when facing great loss is one of the most healing

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of all opportunities. We are reminded of this every time we see newscasts of people who, in response to losing everything in a hurricane, tornado or flood, throw themselves into helping their neighbors and total strangers. At the time of loss when the donation decision is framed, if the framing is not as something a family can do for itself, but as someone else's (the deceased's) action, that motivation and its healing benefits are minimized.

5. The deceased potential organ donor is often idealized in the minds of donation specialists and the general public as a wonderful person who has suffered an untimely death that is the worst possible thing that could happen to his family. This is often true. But, frankly, it is also often not true. Many potential organ donors die in ways that exhaust their families. Some die after difficult lives. Some die in ways that infuriate their immediate next of kin. Families sometimes feel more relief than grief, feel anger, feel the need to protect themselves and their own interest. The narrow focus on the deceased's theoretical wishes pinches many surviving family members into molds that don't really fit their particular situations and can seem insensitive.

6. A lot of families are so weary by the time a death occurs they just want out of the situation as fast as possible. This is true even when they are pro-donation. Having the decision framed as the deceased person's, not theirs, provides families easy ways out that many will take, and some will later regret. But at the time, the donation specialist, having already established that the deceased's wishes are paramount, has very little leverage to get a family to stay long enough to think through their decision.

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7. Some family members have reservations about donating but are too polite to say so. It is a common strategy to use someone else as an excuse to get out of anything a person feels unsure about. (“I’d love to, but my sister is expecting me.”) The donation decision is no different, except that the sister can no longer be phoned.

A Better Way to Frame the Question:

In the absence of a donor registration, the decision to donate should be framed as the family’s opportunity to make something good come out of a difficult situation through their own actions. This might sound like, “Mrs. Matthews, you have the opportunity to donate organs and tissue for transplant and make a difference in several people’s lives. I’ll give you information you’ll need to make that decision. Please ask me any questions you have. After I’ve given you the information and answered your questions, tell me what you want to do and I’ll help you do whatever that is. The first thing you need to know is that you could possibly help two people who are....”

What Are the Advantages?

1. It puts the question to the only person who can answer it, and makes it clear it is her decision, not one that can, or should be, be passed off to someone else. When **responsibility** is placed squarely on most people’s shoulders, they step up to it, at least long enough to hear information out.

2. Family members get considerable **therapeutic benefit** by acting generously under stress and donation specialists get to tell unsure family members that they will be supported in their decision-making.

3. This framing lays down a **pathway** for how the decision is to be made – on the basis of information and with questions answered. It

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makes clear family members are to make the decision on the basis of accurate information and their own situation.

4. It shows an **authentic concern** for the surviving family members. Very few of us really appreciate the implication that our needs are secondary. This is no less true for family members who have been at the hospital around the clock for days holding all their other needs in abeyance.

5. **Nothing is lost.** If the family knew the deceased wanted to be a donor, they will recall that without prompting and say so. And if they frame the decision as honoring John's wishes, then it's perfectly all right to follow their lead.

Would it be better to keep the First Person framing until the registry numbers reach a tipping point?

High registry numbers and high donor numbers don't correlate. Approximately 25% of the OPOs in the U.S. had their best numbers ever in 2012. However, those OPOs are not necessarily located in states that have high registry enrollment numbers. Conversely, many OPOs whose numbers peaked years ago cover catchment areas with high sign-up rates. You can compare the Donor Designation Shares per state on the Donate Life America website to the Deceased Donor Recovered numbers for 2012 on the OPTN website and see this evidence for yourself.

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This white paper covers only one point we believe pertinent to raising donation rates. If enough people let us know they found it helpful, we'll post other points.