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THE IMPACT OF LANGUAGE ON DONATION: LIFE-CENTERED LANGUAGE

Well-established research shows that when Americans are surveyed, 85 percent of them say they want to donate. Using positive, life-centered and sensitive language about donation with families makes it easier for families to act on this inclination. A life-centered conversation has a few key elements:

- Every part of the conversation is proactive, moving the family forward.
- The requestor listens closely to the family and learns about their loved one.
- The requestor uses open-ended questions, obtaining small “yes’s” throughout the conversation.

Invariably, it will feel better to the family to hear about “life” rather than “process.” Below are a few key techniques, accompanied by examples of each, by which you can direct the conversation in a life-centered direction.

1. Introduction to the Family

If you do not already know the family, someone who does should introduce you as one who helps families make end-of-life decisions. As you express your sympathy, you can ascertain whether they understand death or its inevitability. Ask about their loved one as a person before beginning to talk about donation.

2. Transition to the Donation Discussion

It is important to have a transition from your discussion with the family of their loved one's death to conveying to them that they now have the ability to prevent further grief by saving or improving lives through donation.

- “Mr. and Mrs. Haynes, because of the type of injury Frank had, you and he have an opportunity now to save other peoples’ lives through organ donation.”
- “Unfortunately, none of us know why tragedies like Frank’s death happen. Despite our best efforts we were unable to save his life, and I am very sorry. Although I cannot explain what happened, I do know that today you have the opportunity to give hope to others by donating Frank’s eyes and tissues.”

3. Recipient-Centered Donation Discussion

The empathy evoked through mention of potential recipients serves two purposes: first, to increase consent rates, as people are more likely to donate if they can identify with the potential recipients, and second, to help ease the suffering of the family as they begin to focus on the hope they might bring to someone else's tragic situation — and the legacy that their loved one could leave behind.

“Mr. and Mrs. Haynes, I have checked with the donation agencies, and Frank is able to donate his eyes to help two people see. He may also be able to donate his heart valves to someone with a heart defect, his skin to help heal a burn victim and possibly other tissues as well.”

“By donating Frank’s organs today, he will become a hero for the parents, children and brothers and sisters of all the recipients by providing a second chance at life.”

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4. Help the Family Overcome Reservations and Misconceptions

As in any conversation with a family, it is important to be sensitive to their needs and concerns. You can address their concerns with a positive outlook and by bringing attention to what their loved one would have wanted.

- "I understand that you and your husband did not have the opportunity to discuss donation. This is just one of many decisions you will have to make in the next few days that you might not have gone over. Based on what I have heard you say about your husband, donation is a fitting legacy. Given the opportunity, he would have wanted to give these gifts to others."

5. The Asking

When the family feels favorably toward donation or has no more specific objections or questions regarding donation, it is appropriate to move to the actual donation request. If the family does not wish to move forward, let them stop you, then take a few steps back and attempt to overcome their objections.

- "Do you have any more questions to ask at this point? If not, I'll be happy to guide you through the rest of the process."

6. Acknowledge the Gift

Thank the family on behalf of the recipients in the way that seems appropriate.

Coordinators from Pacific Northwest Transplant Bank have been specially trained to use life-centered language when they talk with families about organ donation. Organ Procurement Coordinator Trudy Robinson said that this type of approach "emphasizes the connections we all have to each other and the continuum of life. In the midst of sadness, it's a way to celebrate life and honor those who give the gift of life."

Through mindful preparation for the discussion, you can request donation as both an advocate for the potential recipients and as an advocate, helping the family achieve an outcome that gives them a measure of happiness at a time of great loss.

Most people will donate because it is the right thing to do. Given the opportunity to save a life, most people will do so. By framing your conversation about donation positively, you can enable the family to feel good about making a difference in others' lives.

Source: University of Pennsylvania, Center for Bioethics, Program for Transplant Policy and Ethics. Study of the Presumptive Approach to Consent for Organ Donation, 2004.



One of the Oregon Donor Program's Threads of Life Quilts displayed at PNTB's recent Idaho Donor Family Picnic

NATIONAL HISPANIC CAMPAIGN COMMITTEE

In an effort to increase donation among Oregon and SW Washington's Hispanic community, Lions Eye Bank of Oregon (LEBO) and Community Tissue Services (CTS) have joined the Coalition on Donation Hispanic Campaign Committee. The purpose of the Hispanic Campaign Committee is to help each member organization reach and educate their Spanish-speaking audiences.

In addition to outreach activities during National Hispanic Heritage Month, September 15th through October 15th, we will also be reaching out to the Hispanic community in early November in honor of National Donor Sabbath.

If you have a Spanish-speaking family who has questions about donation, please refer them to the Spanish-language 24-hour toll-free telephone service available from the Coalition on Donation. Trained, Spanish-speaking operators will be able to answer your callers' questions about donation.

1-800-485-VIDA (8432)

FDA LIMITS USE OF VOLUNTEER EYE RECOVERY TECHNICIANS

Since the opening of the eye bank in 1975, we have relied on the kindness of many of Oregon's licensed and apprentice embalmers to help with procurement of eye tissue, and we have been incredibly grateful for their selflessness and generosity. Today the eye bank is operating in a tremendously changed environment. In May of 2005, the Food & Drug Administration (FDA) finalized regulation for eye and tissue banks entitled "Current Good Tissue Practices (CGTPs)." The CGTPs touch on every aspect of tissue procurement, processing and distribution, including strict limits on the use of non-technical recovery personnel. Regulators are demanding assurance that procurements are being done by trained professionals who can and will be held accountable for their actions.

To meet the demands that the FDA has placed upon the eye bank, our preference would be to have one or two people in each region who are willing to comply with annual trainings, as well as adhere to the regulatory changes that are being imposed upon eye banking. With contemporary funeral directors coming under their own increasing burdens, it is unfair to ask them to take on these additional demands.

We greatly wish to service all communities and are currently working on finding, hiring and training new technicians. This is a slow and arduous process. The initial technician training requires a time investment and travel to Portland where we have the greatest amount of donor activity to ensure a hands-on training opportunity. Because of increased regulations we must minimize the number of trainees per training session, further, because of these changes, we are prioritizing areas with the greatest donor activity for hiring and training as our first areas of need, and then moving out into our more remote areas that have less donor activity.

We recognize the frustration that many nurses must go through when they call in a referral and we are unable to provide a technician for procurement. We greatly value your patience and continued support while we work to comply with new FDA regulations and cover our service area adequately. Rest assured: serving our communities to the best of our ability is of the utmost importance, and we will continue to increase regional staff to aid in this endeavor.

REQUESTOR SPOTLIGHT

Barry Heath, Manager of Pastoral Care at Salem Hospital, has displayed exemplary insight into the eye and tissue requesting process, as is evidenced by his remarkable consent rate of 63 percent.

Barry believes that, "I am there as a fellow traveler in their journey. I am not there to make things better...it is about putting yourself with them in the vulnerability." Applying this philosophy to donation requesting, Barry reports, "the starting place for any request is to find out what the patient would have wanted. Put the request in the context of their life." Asking, "is there anything about their life that would give understanding of what they would have wanted?" is a question Barry often asks families.



Salem designated requestor Pastor Barry Heath

When asked for words of advice for fellow requesters, Barry states that compassion and a focus on the family are essential. Also, he advises calling the Donor Referral Line before the request to know what donation opportunities are available to the family. He often uses this information in his conversations to illustrate for the family exactly what good their gift of donation will do.

Barry Heath's extraordinary work is an example of the thoughtful care we all seek to provide to every family we talk with about donation opportunities.

FREQUENTLY ASKED QUESTIONS

Q: What diseases or conditions rule a patient out for organ donation?

A: Transplant programs take great precautions to protect recipients from transmissible diseases. Often this can include turning down organs from patients with evidence or suspicion of a disease or condition that could be transmitted to the recipient. Some organs may also be turned down because their function is not sufficient for a recipient.

However, our acceptance criteria can vary from day to day; on one day we may have a wait list candidate who can accept a less-than-perfect organ, and on the next day that person may not be a candidate. For this reason, hospitals need to refer all deaths or patients who meet the clinical trigger to the donor referral line, so we can evaluate each potential donor against the needs at that moment. There are currently no conditions or diseases that result in an automatic ruleout by the referral line, and all ventilated patients are referred to the Pacific Northwest Transplant Bank.

Our acceptance criteria vary so widely because transplant programs take into consideration the risk of the less-than-perfect organ versus the risk of dying on the wait list. On some occasions, the risk of contracting a serious illness may be less risky than death without a transplant. For example, a recipient who receives a hepatitis B core antibody positive liver has a 50 percent chance of seroconverting; however, with medications, this probability drops below 30 percent. This disease may take 15 years to become symptomatic. For a patient who faces an imminent death without a liver, the 70 percent chance that he will not contract hepatitis may be a good gamble.

With 89,000 people nationwide waiting for life-saving organs, the need to carefully evaluate every organ that can possibly be transplanted is crucial. Thanks to your timely referrals, Pacific Northwest Transplant Bank is able to ensure that no viable organ is left unused.

BONE GRAFTS RESTORE MOBILITY, QUALITY OF LIFE

Nearly 36 million Americans have musculoskeletal conditions that limit mobility and quality of life. Thanks to the generosity of those who give the gifts and the dedication of the medical staff who approach families about donation, many of these people can be helped by donated tissues. One of the areas of tissue donation that has benefited from ongoing technological advances is in the varied applications of donated bone.

Surgeons prefer donated bone grafts, called allografts, in many cases for several reasons:

- With an allograft, the recipient does not incur the risk of pain and infection from a second surgical site, as is the case in an autograft procedure (in which tissue is recovered from the patient's own body and grafted where it is needed).
- The use of allografts often reduces hospital stays and patient discomfort, when compared to autografts.
- Some bone grafts are osteoinductive, meaning that they signal the body to begin regrowing bone in that area.
- Large bone grafts would not be possible without allografts.

Bones, such as the femur, humerus, ilium and tibia are used in shaft replacement for bone cancer, spinal surgery and trauma patients. These bones can be used whole, as shafts or plates, with or without heads or attached joints, and with or without ligaments, depending on the patient's needs and the surgeon's preference. These bone grafts can be machine-tooled into nearly any shape the surgeon requires, including wedges, rings, blocks, or even screw shapes.



Cortical bone powder

Crushed or powdered bone can be used both in dental surgeries and for the repair of bone fractures or spinal injuries. The powdered bone is also available in a putty or injectable gel form; surgeons can inject the putty or gel into the area needing repair, and the patient's own bone will usually regrow into the area. Some surgeons have reported that bone regrowth into the gel is so successful that seven or eight years after the allograft, they were unable to identify the site of the graft on X-ray.

These advances in the care of trauma, cancer or otherwise disabled patients are only possible with the generosity of donor families and the skill of those who request donation. On behalf of the fortunate recipients who regain their quality of life, we thank you all for your efforts.

OREGON DONOR PROGRAM CALENDAR OF EVENTS

National Donor Sabbath

November 11-13

Congregations across America join forces to raise awareness about the critical shortage of organ and tissue donation.

Call Oregon Donor Program to request a Donor Sabbath packet: 503.494.7888 or 1.800.452.1369

Lifesavers Breakfast

A benefit for Oregon Donor Program

November 17, 7:30 - 8:30 a.m.

Lloyd Center Doubletree Hotel, Portland

For reservations, call Oregon Donor Program at 503.494.7888 or 1.800.452.1369

Michael Allen Harrison Holiday Concert

A benefit for Oregon Donor Program

December 15, 6:00 p.m.

The Old Church, 11th & Clay, Downtown Portland

For tickets, call Oregon Donor Program at 503.494.7888 or 1.800.452.1369

Contact 503.494.7888 or 1.800.452.1369 for details on all events



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