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Organ Donation: Choice, gift, and ministry

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More people considering organ donation while alive

By David Lichter
Executive Director

My driver's license has one of those little orange circles in the lower right corner with the word "donor" inside it. On the back is my signature, dated May 5, 2017, with a check mark next to "All organs, tissues, and eyes." I would not envy the person who would get my eyes, and, as I age, I am sure there is a natural elimination process that will make the harvesting shorter work. However, I just read in our local paper the obituary of a religious sister who donated her body to the Medical College of Wisconsin!

Donate for Life notes that while 95 percent of US adults support organ donations (see www.donatelife.net/news/organ-donation-permissible-american-muslims), only 54 percent are actual registered donors (www.sciencedaily.com/releases/2017/04/170410110849.htm). Statistics show that 38 percent of people with a driver's license choose to be a donor, but less than 1 percent of all deaths occur in a way that allow organ donations to be possible. Most of us are well aware of the statistics of how many people are on the waiting list for organs.

I am grateful that we have several very fine articles on chaplaincy and organ donations in this issue of Vision. They provide pastoral approaches, but also explain well the Catholic ethical tradition regarding organ donations and how to be with families at the time of an organ donation.

I suspect we all also know family members and friends who have thought about or have made donations. My wife, Jackie, went through the process a few years ago when her dear friend, Laurie, needed a kidney, and Jackie wanted to donate hers. But after all the testing and preparation, when the time came, Laurie could no longer physically go through the transplant procedure. She died not long ago.

Jackie continues to think about donating that kidney, and another cousin recently offered another good example, as she gave hers in a multiple organ transplant event. Our cousin documented the donation via Facebook and other social media — not for self-aggrandizement, but to share the value and ease of doing so, even though it was initially painful and kept her out of work for a few days. She feels a part of a larger giving community of donors now also.

These examples have me thinking about a growing culture of donors who have made giving organs while alive much a more acceptable and possible—even attractive—choice for people, even though it's not yet on par with giving blood. Organdonor.gov notes that nearly 6,000 living donations happen each year, which is about four out of every ten donations. That's a hefty percentage.

I hope this issue's articles help all of us to speak about and encourage a culture of donations, abate the fear, and assist families in discussing the most common fears and misgivings.

Pastorally sensitive process helps families understand neurological death

By D.W. Donovan

Ministering to the family of a neurologically devastated patient can be complex. A person can be declared dead by either cardio-pulmonary criteria or by neurological criteria. But while the latter has wide acceptance within the medical community, it is not as intuitively self-evident to the average lay person. Collectively, we have been trained by repeated exposure to television shows and movies that death occurs when the heart stops. The term “brain death” can suggest that they are not quite dead — and this provides an unfair sense of hope to the family.

Death by neurological criteria occurs when a person has suffered a neurological injury beyond the capacity to sustain life. Physicians can measure this with an extraordinarily high level of certainty through a variety of diagnostic tools.

This is important for two reasons. It allows for the possibility of organ donation, and it allows medical staff to cease curative-focused treatments for a patient who only appears to be alive because the heart will keep beating as long as the ventilator forces air into the system.

Nearly 25 years ago, as a part of my CPE residency, my colleagues and I participated in a multi-site study that helped identify best practices for ministry to the families of neurologically devastated patients. I found the results invaluable as a chaplain and mission leader in the years to come, and several articles outlining the results of the study were written by our department director, Dr. Lex Tartaglia (www.researchgate.net/profile/Alexander_Tartaglia), and his associates. I commend those articles to you:

<https://journals.sagepub.com/doi/abs/10.1177/090591999900900308>

<https://journals.sagepub.com/doi/abs/10.1177/154230500505900404>

Later in life, I studied this issue in depth as a part of my doctorate in medical ethics with the Jesuits. While news stories can confuse the issue, the Catholic Church has been consistent in both its support of organ donation and its assertion that death should be defined by and determined by medical professionals. For an excellent summary of Church teaching, visit <https://sites.sju.edu/icb/position-catholic-church-organ-donation>.

Having a clear understanding of neurological death, and being able to describe it to the patient’s loved ones, is the first critical step in providing the best possible care in the worst of situations.

And these truly are traumatic situations. Although injuries to the brain can come in many forms, a typical case might involve a blunt-force impact to the head. Mr. X arrives at St. Somewhere after a fall from his fourth-story apartment. He has significant injuries to his entire body, and early indications are that his brain was damaged as well. His family is in shock, hoping and praying for the best, and still trying to comprehend what might have happened.

Except in the most extreme situations, there is no need to discuss death by neurological criteria at this point. In most cases, the family is not able to think through the complexity of that concept, and it is important that they do not believe we have given up on this new patient. The message at this point is simple: “Mr. X has sustained severe, life-threatening injuries. We will do everything possible to support him and we will watch him carefully through the night. We’ll meet again sometime tomorrow and let’s see where we are.”

Unfortunately, Mr. X does not improve overnight. His Glasgow Coma Scale, which summarizes the results of a series of bedside examinations, remains very low (3 on a scale of 3 to 15). We arrange a family conference for that afternoon. From the study mentioned above, we have developed a process that is helpful and pastorally sensitive. Mr. X’s neurosurgeon, his nurse, and the trained chaplain are all present for this meeting.

We begin with a short summary of his clinical condition. The neurosurgeon takes his time, allowing time for questions. The family mentions how strong Mr. X is, and they believe he will pull through. Oftentimes, the potential for a miracle is brought up. This is not the time to try and convince the family of anything. While it would be disingenuous to openly agree with such statements, there are ways of expressing support: “I hope you are right. And nothing would make me happier than to have him walk out of this hospital. We will do everything that we can to support that process.”

It’s a good place to transition into what I call the three possibilities. While the neurosurgeon may be the first to explain this, the chaplain should be well-versed in this language and concept, because the family will most often turn to the chaplain as they process their oftentimes overwhelming grief.

“There are three possibilities. The first is that he gets better. It could be a little bit better or it could be a lot better, as I know that you are all hoping for. The second possibility is that he stays the same. The third possibility is that he gets worse. He could get a little bit worse, or it could be so bad and his brain is so badly injured that he dies from these injuries. That is called death by neurological criteria, and we will get you more information on that later if we need to. With this kind of injury, we usually have a pretty clear picture of how things will go in the first 72 hours. We will keep supporting him. We will keep monitoring him closely and doing everything that we can.”

Note that we have not brought up organ donation and that our message is still one of ongoing support. The local organ procurement organization is likely involved at this point, but they also understand that it is premature to speak to the family now. You may feel some ethical angst keeping that information from the family, but it helps to stay focused on caring for them: you want the OPO to be ready to speak to them with the right information at the right time.

Unfortunately, Mr. X’s condition continues to deteriorate. Bedside exams suggest that he has herniated, meaning that the injury has irrevocably destroyed the ability of the brain stem to function. It is time to test to see if death by neurological criteria has occurred. We meet again

with the family and share with them that despite our best efforts, his condition has worsened. We carefully explain the concept of death by neurological criteria and how the brain stem controls the most basic of functions. We explain how we can test for this through a series of arterial blood gas labs. I have often used the example that a person who is drowning will gasp for breath even though they know they are underwater, because that reflex is the most primal. Finally, we note that when testing is complete, we will come back to them and share that either he is not dead or that death by neurological criteria has occurred and been confirmed. If that does occur, we will give them a chance to say goodbye, but we will remove the ventilator at that point. We are very clear: we do not treat dead people.

If Mr. X is found to be dead by neurological criteria, we will invite the family back to say goodbye. If the OPO has determined that the patient is a viable candidate for organ donation, we will introduce them at a moment that seems appropriate. For reasons that are beyond the scope of this article, it is important that they take the lead in making the request for organ donation (or informing the family that organ donation will take place if the patient made that prior decision).

Mr. X's family had the benefit of a well-trained chaplain, working hand-in-hand in a well-coordinated process with a compassionate neurosurgeon. While his death was a tragedy, clear and compassionate communication helped the family through one of the worst days of their lives. Each situation is different, but the basic principles outlined here have proven to be most helpful as you accompany such a family through an extremely complex pastoral situation.

Dr. D.W. Donovan, BCC, is chief mission integration officer at Providence Holy Cross Medical Center. He earned his doctorate in medical ethics from the Loyola University Chicago and is published in the area of organ donation and ethics.

When the gift can't be received: The double loss of organ rejection

By Anne M. Windholz

He was thirteen. His black hair was tousled, his eyes brown with long lashes. He had shot himself. But only after it was hours too late did his dad ask about organ donation, reaching for something that might redeem unspeakable loss.

I was a rookie chaplain when I served this family. For many reasons, the case haunted me: The untold misery of a child who thought killing himself was the only solution. The agonized horror of his mother as she spoke of discovering him. The stiff faces and sad eyes of the medical team. The helpless father and that lost window of opportunity for some other child. And, of course, my worry that it was my fault the opportunity was lost.

In fact, the opportunity never existed — as I later learned, the boy had been down at home for some time before the parents found him. But nonetheless, when his father learned it was “too late,” his grief was doubled. For many people, donation salvages good out of catastrophe, at least a little bit. It offers the possibility of turning a tragedy toward a happier ending and promotes emotional catharsis. When that hope is dashed, the chaplain must be prepared to help survivors find meaning — personal, spiritual, theological — in a double loss.

Theological meaning-making has informed human transplant medicine for a long time. In 2008, the *Journal of Healthcare Chaplaincy* republished a 1993 issue devoted to organ donation and heart transplants (www.tandfonline.com/toc/whcc20/5/1-2?nav=toCList&). Among its many excellent articles, certain theological themes recur and continue to resonate almost thirty years later. Now an interreligious commitment adds to our understanding of how the relationship with God and neighbor is central to the decision to donate. Some key ideas include:

- Organ donation is excellent stewardship, even an act of co-creation with God¹;
- Saving another's life through donation is an act of supreme generosity, exemplifying the Jewish ideal of *Mitzvah*;
- Giving one's life for a friend is an exemplary form of love (John 15:13), and for Christians donation may be understood as a form of Eucharist²;
- Such altruism and relief of suffering exemplifies enlightenment in the Buddhist understanding of the term;
- Depending on circumstances, the ethical imperative to save a life calls for organ donation — a perspective inspiring to Muslims.

¹ O. Ray Fitzgerald, “Organ Transplantation and Tissue Donation: A Theological Look” *Journal of Healthcare Chaplaincy*, 5:1-2: 145-60. In the same issue also see M. Susan Nance and William H. Davis, “Theological Reflections on Organ Donation and Transplantation” and Jeremiah McCarthy’s “Organ Donation”. A more recent discussion is Erica Graham’s “A Biblical Approach to Cadaveric Organ Transplants” from the Center for Bioethics at Cedarville University 14 (11.1.2014).

² Fitzgerald, 153-154.

However, these religious themes also translate into a more secularized rhetoric where organ donation websites celebrate donors as “superheroes,” and emotional meetings between recipients and their donors or donor families go viral on social media. These are all vehicles for inspiration, catalysts for hope, and venues for creating “converts.” In the wasteland of disease and sudden death, they provide oases of meaning.

Such meaning-making is profoundly important. Certainly many families, medical staff, and chaplains find it comforting to know that another person’s life may be preserved, not just in spite of, but indeed because of, an otherwise senseless loss. I know this from personal experience. My brother-in-law died young, at age 47, of a massive heart attack. For years after his death, his wife attended celebrations honoring donors. His eyes became sight for someone blind; his skin became touch for someone injured. His (and his wife’s) individual choice became redeeming gift.

But how do we work with potential donor families who are told no donation is possible, or whose gift was rejected by the body of the recipient? Confidentiality laws mean that a donor may never know. In that respect, every donation is a leap of faith. But what do we do for the grieving when their hopes of resurrection do not lead to renewed life but rather end in a second death — or no resuscitation at all?

Chaplains called to help families know that listening and presence are our primary interventions. Even at hospitals where I have been responsible for notifying Gift of Hope about a death, I have not been asked to broach donation with the family. That has been the job of donor organization professionals.³ But when family members themselves ask chaplains about the possibility of donation (as with the 13-year-old suicide), our response must be nuanced and attentive to individual family dynamics. Unequivocal enthusiasm, replete with glowing theologies of participation in God’s life-saving work, may not be in the best interest of the survivors if donation might ultimately be denied.

In such situations, a gentle life review of the deceased patient’s broader legacy makes it possible to explore varied ways of giving, honoring, and paying it forward, while protecting loved ones from loading all their hopes in one basket. The body itself, while sacred because of the life it held and the love it gave, is by no means the only medium for making meaning. But in the immediacy of that beloved physical body being lost, we easily forget. The chaplain is perhaps the one member of the medical team who, in a time of crisis, can recall survivors to that broader picture: that people’s lives include their creations and causes, their relationships, their ideas and philosophies and passions.

³ Though chaplains and other staff may feel reluctant to talk about organ donation after a brutal accident, a drug overdose, or a suicide, studies have shown that, in fact, loved ones are largely receptive to such discussions. See Wellesley, Glucksman, and Crouch, “Organ Donation in the Accident and Emergency Department: A Study of Relatives’ Views” in the *Journal of Accident and Emergency Medicine* 14 (1997): 24-25; also Thomas E. Robey and Evadne G. Marcolini’s “Organ Donation after Acute Brain Death: Addressing Limitations of Time and Resources in the Emergency Department,” *Yale Journal of Biology and Medicine* 86 (2013): 333-342.

Furthermore, the very stories that the bereaved tell about their loved one contain a vitality that can be life-giving. These stories, no less than a bone, a cornea, or a new liver, are gifts that can ease suffering, offer hope, reinvigorate or even save a life. Reframing organ, eye, or tissue donation as part of the legacy without forcing upon it the freight of ultimate meaning, protects against crushing disappointment while preserving the altruism and grace undergirding such an offering of love.

After all, is acceptance of a gift the only measure of its generosity? Is “success” the only measure of a gift’s meaning? Which is to say, is an organ donation that fails after three months any less of a gift than a transplant that adds fifteen years to a sick neighbor’s life? And is an Incarnation that ends in crucifixion powered by any less love than one that ends with a peaceful death on a soft pillow?

We are resurrection people. Life from death is who we are as chaplains — life that comes not from the physical body but from witnessing over and over again an immeasurable, unexpected, unreasonable love that gives when giving seems impossible. Love is the real donation, whatever the outcome. Love that does not mitigate grief, undo tragedy, or bring a 13-year-old boy back to life. Love that risks double the loss and more. But it endures. Because its story keeps being told, over and over and over again: A father offering his child to bring life to the world.

Listen for the story.

Anne M. Windholz, MDiv, PhD, BCC, is spiritual care leader/staff chaplain at Northwest Community Healthcare in Arlington Heights, Illinois. She is also a pianist who for the past 15 years has been able to play only because someone made a bone donation upon their death that repaired her cervical injury. Every day at the keyboard is a gift.

Organ procurement groups can collaborate with chaplains

By Kelly Edwards

Gift of Life Donor Program

What is the ideal relationship between chaplains and organ procurement organizations like ours?

“We need to trust each other,” said Carolanne Hauck, director of chaplaincy care and education at Penn Medicine Lancaster General Health. “That trust is built over time.”

There is a special kinship between chaplains and the people who work for OPOs. We are all on the front lines, working with families during their most difficult and heartbreaking time.

Carolanne once met a family whose teen son was in a terrible car accident. After prayer and deliberation, they chose donation. “It was such a privilege to walk alongside that family and be there for that decision process. I heard what their son meant to them. They saw donation was a way that would honor their son and their son’s life by giving someone else an opportunity to live,” she said. “They had a son who was dying, and in the midst of their pain and grief, they were thinking about others.”

Chaplains and OPOs share a responsibility to console families who grieve for lost loved ones, and to honor the life-saving gift of donation. OPOs have the added responsibility of representing the men, women and children on the organ transplant waiting list. It is our duty not to be neutral, but to actively advocate for people to choose donation whenever possible.

In an ideal world, these goals would always be in perfect harmony. But in reality, sometimes they are not. The suddenness of loss impacts every individual and every family differently.

Our Gift of Life donor program works with hospitals in the eastern half of Pennsylvania, southern New Jersey, and Delaware. Carolanne and her team of dedicated chaplains are some of our most valued partners. Over the past few years, the model we built together at her hospital has become our gold standard of collaboration.

In my role as Gift of Life’s representative to LG Health, I see their great system for chaplain cooperation firsthand. The hospital prioritizes regular education and training with us to ensure the chaplain team knows the communication process with donor families. They keep us apprised of family communication, including where the family is emotionally and how they are understanding the situation.

A chaplain’s work with organ donation isn’t limited to families. It’s important to incorporate hospital staff who may need support into their work as well. By knowing about family communication and the donation process, chaplains at LG Health serve as resources to their fellow teammates on the critical care units.

“Nurses are very protective of their patients and their family members. When they see Gift of Life is involved, they know their families are in for a very difficult conversation,” said Dave Brubaker, a staff chaplain at LG Health. “I work hard to try to be a liaison between the Gift of Life staff and our staff. I try to listen to concerns from both sides and figure out how we can improve this relationship.”

LG Health chaplains created an entire program to unite staff and families in a celebration of organ donation. One touching example is the flag raising at the very front of the hospital during the time that someone is donating. After 24 hours, chaplains take that flag to every staff member who cared for the patient, giving them the chance to sign it and write a message to the family.

“We can help each other get through the process of this person dying,” said Carolanne.

Chaplains also offer to print a donor’s heartbeat rhythm strip on a small length of paper and put it in a little vial, so people can keep the heartbeat of their loved one. Sometimes the hospital dedicates a memorial quilt to honor donors. Other times, like Blue and Green Day, the hospital welcomes transplant recipients and donor families to join in tributes to lost loved ones. So far, 29 lives have been saved thanks to selfless organ donors at LG Health, and countless lives have been improved through tissue donation.

However, one important part of the donation process always falls to Gift of Life Donor Program: being the first to approach the family about the possibility of donation. The most important request we have for our chaplain partners is to ensure that the Gift of Life transplant coordinator is the first to raise the topic.

This process relies on trust. For trust to be possible, it is so important that families hear information about donation that is compassionate and absolutely accurate. The academic research is clear: families who are given more information about the donation process are more likely to donate.

If you don’t know the best point of contact at your local OPO, I encourage you to find out. “It’s got to be a two-way street. Both parties have to really want to make this work and be willing to give and take,” Dave said. “We both ask every day: how can we improve this relationship? Because that’s a win-win for our families and everyone involved.”

Kelly Edwards is hospital services coordinator at Gift of Life Donor Program in Philadelphia.

Advance directives make ideal time to plan organ donation

By James L. Robinson

Advance care planning is now recognized as the single most effective tool for improving care at the end of life, but it is only effective as a full and complete process. Simply completing a few documents and assuming that health systems will honor your wishes is not realistic. That complete process includes having meaningful conversations with your family, completing advance care planning documents, keeping those documents accessible, and sharing them with family and physicians.

Organ donation is an often-neglected aspect of advance care planning, but it shouldn't be. Most discussions about advance care planning focus on completing three primary documents: the Medical Power of Attorney, the Directive to Physicians and Family or Surrogates (Living Will), and the Out-of-Hospital Do-Not-Resuscitate Order. Each state has legislation outlining the specific language and purpose of these documents, which can be found at www.nhpco.org/patients-and-caregivers/advance-care-planning/advance-directives. In my consultations with patients in the clinic about organ donation, I refer them to donatelifetexas.org, the Texas registry for Donate Life America, the official national organ donor registry.

A red heart on the Texas driver's license indicates that the person is an organ donor. In my discussions with patients, I also bring up the Medical ID app on smartphones. That app, which is included on all Apple iPhones, and can be downloaded for Android devices ("Medical ID (Free)/In Case of Emergency"), provides an opportunity to register with the Donate Life America registry, and that information is visible on the Medical ID app template when completed. CHRISTUS Physician Group recommends completion of the Medical ID app template, which allows medical first responders to view the owner's medical profile without logging into the phone.

Check the language and laws on Living Wills in your state to become familiar with the organ donation process. California, for example, recently amended the state's advance directive law, clarifying the rights of patients regarding organ donation.

The chaplain having "the conversation" in the hospital setting actually has the benefit of time. Unless the setting is critical, the ICU for example, there is usually time to explore the patient's priorities, what gives their lives meaning and purpose. This is the ideal moment to discuss organ donation. Even a conversation with a patient in hospital pre-admitting, focusing on advance care planning documents, can include a mention of organ donation. The chaplain can emphasize two points. First, completing advance care planning can ensure your end-of-life wishes, and second, taking one more stressful decision away from the family is a loving thing to do for them.

My discussions with patients in the physician's clinic include a specific mention of organ donation. Like all advance care planning, the purpose is to ensure that your wishes are honored at the end of life. Ellen Goodman of the Conversation Project shares that we have two fears at the end of life: that we receive the care that we want, and that we don't receive the care that we don't want. I would add a third: that we don't burden our families with decisions that they might not be prepared to make. By making the organ donor decision, and making those wishes known, a patient can spare family members additional stress in an otherwise naturally stressful moment. The prospect of organ donation decisions, particularly in a sudden, unexpected death, can seem an intrusion at a time of grief.

Henri Nouwen, in his book *Befriending Death*, wrote that our deaths can become an act of fulfillment and a fruitful gift to those we love. "I have a deep sense, hard to articulate, that if we could really befriend death we would be free people. So many of our doubts and hesitations, ambivalences and insecurities are bound up with our deep-seated fear of death that our lives would be significantly different if we could relate to death as a familiar guest instead of as a threatening stranger." Similarly, Archbishop Gustavo Garcia-Siller, MsPS, of San Antonio, in an advance care planning video on the CHRISTUS websites, states that advance care planning is "one of the most loving things you can do for yourself and your family."

James L. Robinson is advance care planning coordinator at CHRISTUS Physician Group in San Antonio, TX.

Priest's gift of kidney to parishioner gives everyone new outlook on life

By Rev. Martin J. Bancroft, Jr.

During my final year in seminary, the seminarians would go to a parish over the weekend to help and serve. One day I found the parish cook crying in the kitchen because her son was dying of liver disease and did not have long to live if he didn't receive a donor's liver (A live donor can give 60% of their liver).

He and I were the same blood type and very close in age. I had never thought about donating any part of my body, but her tears made me want to do something to help. I went to the hospital, and they put me through many tests over a matter of weeks. Preliminary tests were promising, but the last test revealed that my bile duct split in such a way that I could never donate my liver. The intended recipient never received a liver and died one month later. I felt terrible that I could not help him. But it wasn't meant to be.

Five years later, a parishioner told me her daughter was dying of kidney failure and didn't have long to live. She and I were the same blood type. Yet donating a kidney is different than donating 60% of one's liver. The liver is the only organ in our bodies that will regenerate. Giving away one kidney leaves the donor with one kidney for life. But that thought never entered my mind – I only wanted to help this mother and daughter. After months of testing, I was told that I would be her donor. This was never talked about in the seminary, but I asked myself one question: WWJD (what would Jesus do)? The answer was always there. The day they wheeled us into our separate operating rooms, I had a peace that was truly a gift from God. The operation was a success for both.

My life also began anew. Donating a part of my body to another human being was the gift of life to her and to me. It has been almost fifteen years since the donation, and both of us are doing well. Two years later, she gave birth to a healthy baby boy. Recently, I conducted the wake service for her father, who loved me like one of his own children, especially for saving his daughter's life.

Why did I donate? Maybe it was the power of the Holy Spirit that moved me to want to do something good for another person. I have no regrets. Life can be so short, and it's not about one's longevity but rather about what one does with the life one has been given. I pray that my donation made a difference in the life of someone else, and I am grateful for the opportunity.

I had not planned on becoming an organ donor. The timing was perfect, and by placing myself into God's hands, I somehow felt all would be well. And it was! As a Catholic priest, I am grateful for the call to this ministry, but I am even more grateful for answering the call to be an organ donor. One does not have to be a priest to donate the gift of life. One only needs to have compassion for the other, empathy in trying to feel their pain, and courage in trying to do good for another human being. Organ donation has changed my life for the better! It has helped me to focus on the other, to think outside the box, and to keep one hand on the plow while never looking back. God is good!

Rev. Martin "Mickey" Bancroft is a chaplain at Mather Hospital in Port Jefferson, NY.

Ethics of organ donation range across many realms

By Steven J. Squires

It is impossible to cover all the ethical dimensions of a complex issue such as organ donation in a short space, but we will look at some key considerations using the structure Jack Glaser's three realms of ethics (www.amazon.com/Three-Realms-Ethics-John-Glaser/dp/1556127227)

Societal (including the Universal Church)

Global ethics issues include consent or lack thereof by donors, transplantation from one species to another, and scarcity and commodification (buying, selling) of organs. In the U.S., commodification is illegal. Donation follows one of two paths – living or deceased.

Ethics discussions around deceased donation cover a wide range of concerns. Family objections cannot trump first-person consent in some states, despite dubious, prior “informed” first-person processes such as driver's license branches. Hospital protocols all maintain the difficult perceptual balance between providers and others not harming in life while performing acts of charity after death. The “dead donor rule,” definitions of death by neurological criteria vs. circulatory criteria, and organ procurement organizations all play a role in the ethical balance.

Death is a process, not an event. Ethics discussions can also include the attending physicians preparing a dying patient for transplant with interventions of little to no benefit to the patient, as well as issues surrounding the proper amount of time needed to harvest vital organs after circulation *irreversibly* ceases.

However, the breadth of ideology within the Catholic Church about organ donation has perceptually narrowed over time. Pope John Paul II framed all donations as “acts of self-giving love” and “praiseworthy” in *Evangelium Vitae* in 1995 and his address to the International Congress of the Transplantation Society in 2000. Around 40 years earlier, Pope Pius XII said in a 1956 address that a person can use his or her body (after death) for morally useful purposes, including the aid of others. Parish church bulletins often reinforce the selfless love of organ donation as modeling Jesus' agapeic love and healing. Chaplains can assuage patients and families with Gospel interpretation, or Church teaching. These are exemplars of selfless, morally praiseworthy acts.

Organizational (including the U.S. bishops)

The scope of control in organ donation is almost entirely regional, not national. States differ in how they define death, with subtle differences in what they adopt from the Uniform Determination of Death Act — which, despite the title, is a non-binding text that serves as a guide for state legislators.

Organizational participation rates in organ retrieval and distribution are uneven. In *Making Health Care Decisions*, Sr. Pat Talone cites a Joint Commission statistic that 80 percent of donations are from 20 percent of all U.S. hospitals. Healthcare and organ procurement organizations must partner and engineer specific contracts and protocols for organ donation. Ideally, these support chaplains providing guidance, for instance, by ensuring that living donors aren't coerced.

“Honor walks” are a contemporary ritual in which hospital staff members line corridors as the patient or body is wheeled from the hospital room to the OR, often with family members accompanying to show support. While the practice is almost universally lauded, a presentation at the American Society for Bioethics and Humanities raised concerns about real-life blunders. Failures to emotionally prepare family members, to have informed consent discussions, and to discuss video recording and online posting have all caused harm. Chaplains are uniquely situated and skilled to address these challenges within healthcare organizations.

The direction provided by the U.S. bishops in the *Ethical and Religious Directives for Catholic Health Care Services* exemplifies the mutual complementarity of faith and science. Organ donation directives support the role for medical expertise (e.g., determining death) and “commonly accepted scientific criteria” as well as informed consent, preventing conflicts of interest, and “encouraging and providing means” for donation. Emphasizing this reciprocity can quickly ameliorate misunderstandings, such as the myth that organ donation is somehow anti-Catholic.

Individual

Chaplains may encounter patients and family members who need help framing the decision to donate organs. For living donors, Benedict Ashley, Jean deBlois, and Kevin O’Rourke recommend using the following conditions in *Health Care Ethics: A Catholic Theological Analysis*, 5th Ed.:

- 1) The recipient’s need “cannot be fulfilled in any other way.”
- 2) The donor’s functional integrity “will not be impaired, even though anatomical integrity can suffer.”
- 3) The risk of the donor’s act of charity “is proportionate” to the recipient’s good result.
- 4) Both the donor and recipient have “free and informed” consent.

A useful lens for these terms is a benefits/burdens analysis using Directives 27, 56, and 57. Family members of deceased donors may have misperceptions, sometimes before their loved one’s death. The “Organ donation: Don’t let these myths confuse you” webpage by the Mayo Clinic attends to common myths, including misconceptions that families will be charged for donation and that organ donors cannot have open-casket funeral. Having correct information may mitigate emotional and spiritual distress (see www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/organ-donation/art-20047529).

Patients and family members may have concerns about organ donation, religion, and for some, salvation. The Mayo Clinic says, “organ donation is consistent with the beliefs of most major religions” and specific questions can go to the patient’s clergy. Accurate information may not eliminate all distress, especially in the midst of grief. It is then that chaplains can model Pope Francis’ accompaniment during an encounter so that patients and family members can, in the words of Directive 55, receive “spiritual support ... in order to prepare well for death.”

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Weight of history works against African-American donations

By Daniel Waters

Part Three of the Ethical and Religious Directives states that medical professionals and patients “enter into a relationship that requires, among other things, mutual respect, trust, honesty, and appropriate confidentiality. The resulting free exchange of information must avoid manipulation, intimidation, or condescension.”

Unfortunately, the medical establishment in the U.S. has a long history of the opposite of that relationship with African-Americans. As slaves, African-Americans were regularly subjected to medical uses of their bodies without consent. This included dead black bodies being robbed from graves for medical experimentation. In the Tuskegee syphilis experiment from 1932 to 1972, 399 African-American men were misled about their treatment for this awful disease. Henrietta Lacks was an African-American woman who was the source of an immortalized cell line used for research without her knowledge or consent.

For many in the African-American community, these stories are not simply history – they are the stories of today. The urgent presence of this discrimination leads to a fear that if an African-American is an organ donor, medical personnel will not try to save one’s life but will do nothing in an emergency, in order to “get another donor.” Although this may be true for anyone, the deep mistrust of the medical community heightens the fear around this issue.

There is a widespread thought that “my religion” will not allow organ donation. Tied in with this is that fear that if one donates an organ it will affect one’s status in the afterlife, i.e. if I do not leave this world “whole” I will never be “whole” for eternity. The reality is that most major religions either support organ donation as an unselfish act of supreme charity or that it is the decision of the individual and the denominational stance is completely neutral. Other troublesome myths are that the donation will go to white, wealthy or famous patients; that the donation will be sold; or that the donor will have to pay for the process.

Many in the African-American community experience mistrust, disrespect and lack of honesty with the medical community in general, including organ donation. As a white male blessed with an interracial marriage for almost 38 years (my wife is African-American), I have experienced positive attitudes toward the medical community in general and organ donation specifically from my parents and sibling. But I encounter the attitude described above from my in-laws and my wife’s siblings. My brother-in-law battled diabetes and kidney issues but adamantly refused any discussion of a kidney transplant. He refused an amputation when these issues worsened. He eventually agreed to an amputation, but only with my wife’s intervention. At the time of his death, one of the first questions his daughter asked was if the amputated part would be buried with him.

Research studies in 2001 and 2003 clearly indicate that traditional promotion campaigns will do little or nothing to increase organ donation in the African-American community. However, there are indications that a consistent supportive message from religious leaders can make a

difference in participation. There is a high degree of trust in one's religious leader. African-American physicians and educators who are willing to take the responsibility of dispelling fears seem to be able to make a difference in these numbers as well. The 2007 research article "Understanding the Role of Clergy in African American Organ and Tissue Donation Decision-Making" (www.ncbi.nlm.nih.gov/pubmed/17978944) discusses the challenges and benefits of reaching out to religious leaders.

The need for organ donors remains high, and the need is often higher in the African-American population. An appeal to altruism from trusted sources can begin a slow but necessary process of change.

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End of life and organ donation may look different to Muslims

By Rev. Alejandro De Jesus

The Veterans Affairs Department expects VA chaplains to have a respectable level of knowledge of the major religious traditions, including Islam. Out of over 1.3 million active duty service men and women, a little fewer than 6,000 self-identify as Muslim. The Muslim veteran population (mavanational.org) forms an even lower percentage, but is growing steadily as younger Muslims join the military service. Chaplaincy in both military and VA hospitals, clinics and treatment centers has worked hard to respond appropriately to the spiritual needs of the Muslim population. In some localities, VA medical centers have even hired Muslim imams as chaplains.

A quick recall of what Islam means and requires is helpful before discussing organ donation and end-of-life concerns. Islam means “submission,” and a Muslim understands the life mission of every follower to submit to God (Allah) and Muhammad, the messenger of Allah. Islam is a monotheistic faith that traces its origins back to Abraham. The worldwide Muslim population is over 1.8 billion, and the U.S. is home to several million Muslims. The Qur’an is the Word of God they believe in and rely on, while the Hadith refers to the collection of stories and sayings of the Prophet Muhammad. However, there are also other writings of prophets or followers of Muhammad contained in the Sunnah and the Seerah.

The Islamic tradition has evolved through time, and while there are admittedly many diverse views on numerous issues, there is also consistency on the basic tenets (see rip.hds.harvard.edu/religions/islam/beliefs-and-practices). Faith in God and his prophet Muhammad, praying five times a day, almsgiving, the Ramadan fast, and pilgrimage to Mecca form the five pillars of Islam.

Based on this main creed and on other Islamic laws, the Sharia is believed to benefit all humans. Its major goals are the protection and preservation of life, intellect, progeny, property and religion. The fundamental medical ethic that flows from this is the First Principle of the Qur’an: “Whosoever saves a human life, saves the life of all mankind.” Most Islam believers uphold principles where necessity overrides prohibition; that harm must be removed at every cost, if possible; accepting the lesser of two harms if both cannot be avoided; and upholding public interest over individual interest.

The Islamic Medical Association of North America (imana.org) notes that suicide and active euthanasia are prohibited¹, especially in the face of terminal illness. When death is inevitable, as determined by a team of medical providers, unnecessary procedures are not expected to be utilized². And while medical treatments can still continue, withdrawing mechanical support is morally acceptable.

As noted, Islamic communities around the world do not have a common global leadership. There are, however, regional groups of theologians, medical practitioners, leading intellectuals,

etc., who contribute by their discussion and recommendations on issues such as end of life and organ donation.

The general perception is that Islam forbids organ donation on the grounds that the human body must be protected and preserved with integrity. However, respected regional councils such as Islamic Fiqh Council in Saudi Arabia and the Islamic Medical Association of North America have declared that organ donation is allowed under the following conditions: (1) donation must be specifically indicated by the donor in a will or document (2) for the purpose of saving life (3) with no financial incentive and no cost to the donor's family and (4) cannot involve a donation of reproductive organs. Furthermore, contrary to popular belief, Muslims can donate to non-Muslims.

The Sindh Institute of Urology and Transplantation (www.siut.org) estimates that over 50,000 patients die each year of end-stage organ failure in Pakistan, who otherwise could have been saved through organ donation. Some patients refuse it, even if it will save them, due to a misconception of what they understand as the will of God as expressed in their religious practices.

It is painful enough for patients and their loved ones to suffer from the illnesses they are afflicted with. However, a much deeper pain is involved when one's spirit is torn between what faith tells them (or what they perceive faith to be telling them), and what they need to do in order to be cured from the illness and healed at the core. Chaplains can assist in helping their patients make an informed decision over their goals of care and medical options.

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Notes:

¹ https://yaqeeninstitute.org/maryam-sultan/pulling-the-plug-the-islamic-perspectives-on-end-of-life-care/#.Xkxc_rCP6UI

² [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(05\)67183-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(05)67183-8/fulltext)

Parents choose to share their son with others in need

By Colette Hanlon

Having been a hospital chaplain for many years, I have lots of stories to share. But the most powerful one occurred in the early 1980s and was the first time I was involved in a total organ/tissue donation.

In the large hospital in Wisconsin where I served as director of pastoral care, it was a relatively quiet night until an emergency call arrived from a small hospital in our system. A young college student told his roommate he was hot, stood up, and fell to the floor. The emergency ambulance immediately brought “Shane” across the miles to us. His prognosis was very grim.

His parents – a Protestant minister and his wife who had recently accepted a call to serve in northern Wisconsin – were notified and arrived a couple of hours later. Dad immediately headed two hours south to pick up their daughter at college and bring her back. I remained with Mom for the next few hours and learned about her family. Shane was a much loved son and his mother struggled with the possibility of losing him.

However, with a halting voice she said to me, “Another mother loved him enough to bring him to birth, so I should share him with others, as she did.” She then went on to tell me how her daughter and son were both adopted and were gifts of their birth mothers to them.

Shane, a previously healthy 19-year-old with a massive cerebral event, was eminently able to be a donor. Tests over the next hours showed that there was no hope of any recovery from the brain damage. The medical staff coordinated events once Dad, Mom, and his sister all agreed he would want to be a donor.

Previously, I hadn’t known how many organs and tissues were eligible for donation. Jets flew in from Pittsburgh and Chicago to accept the donation of his heart, lungs, kidneys, corneas, and long bones from his arms and legs. His jaw went to a man whose face was destroyed in a work accident.

The hospital staff had never been present for such a full donation, and some were shocked and questioning. Sharing with them Shane’s mother’s words to me helped them to understand and appreciate her generosity.

Later, Shane’s mother taught me another valuable lesson. Once I received word about the organs given to others, I called her. I began by saying “Because of your family’s gifts, many organs and tissues were harvested.” After a long pause, she quietly explained to me that as a farm girl, “harvesting” connoted a violent pulling up of crops. She did not want to equate that with the reverent removal of Shane’s organs and tissues so others could live.

Since then, any time I am speaking with family members about their generous gift of life, I say the transplant team gratefully accepted the donation of their loved one’s body.

How much we learn from those we encounter in our ministry of pastoral care!

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Research literature sheds light on organ donation process

By Austine Duru

The decision to donate organs or and the willingness to receive donated organs are often influenced by religious, cultural, or social factors.

However, clinicians and transplant teams largely underestimate the importance of these forces. In “Organ donation, transplantation and religion,”¹ the authors highlight the possible knowledge gaps and barriers that hinder effective communication during the organ donation and recovery process. The authors aim to “provide an overview on how the different religions view transplantation and organ donation, with an emphasis on practical points for health care professionals who are involved in transplant listing, organ donation and retrieval, and transplantation itself” (Oliver, M., Woywodt, A., Ahmed, A., and Saif, I., 2011). In a subsequent article, “Donating in good faith or getting into trouble: Religion and organ donation revisited,”² the authors addressed the skepticism and religious concerns that still impact attitudes, and how the organ transplant community can benefit from an open and honest discussion of these issues. This will be valuable reading for individuals who work with a diverse population of patients.

Anyone who has been part of the organ procurement process at the end of life will understand the importance of balancing persuasion to donate and emotional support for donor families. In “Providing social support in a persuasive context: Forms of social support reported by organ procurement coordinators,”³ Anker, A. E., Akey, J. E., and Feeley, T. H., (2013), investigate several strategies used by OPCs for providing social support to donor families. Some of these strategies will be familiar to chaplains who work with patients and families at the end of life. Professional chaplains who sometimes serve as “requestors” in collaboration with the OPCs have to be careful not to rupture the relationship with families that may hinder spiritual care.

A conversation with the parents of a sick or dying child can be a unique challenge, and “Exploring organ donation with families of pediatric patients”⁴ is a valuable article by Jessica Lee Barr (2017). This is aimed to be an evidence-based resource for caregivers to help grieving parents and families make informed decisions about organ donation for a dying child. The article does a good job of separating the myths from the facts of organ donation and highlights the correlation between consent to organ donation and the positive relationships between caregivers and grieving families. It also introduces certain themes and concepts that are crucial for caregivers to know when dealing with donor parents, including decoupling techniques to help address the disorienting feelings of uncertainty for donor parents.

End-of-life organ donation has been described as a meaningful way to aid donor families in the healing process. Consent to organ donation is obviously a critical first step in the journey. In “Request for organ donation without donor registration: A qualitative study of the perspectives

of bereaved relatives,”⁵ Jack de Groot and his co-investigators (2016) examine situations when a patient did not register in advance and family members are relied upon to make that determination at the end of life. The findings suggest that certain factors inhibit family members’ willingness to donate after death, including “feeling overwhelmed by the notification of death immediately followed by the request; not being accustomed to speaking about death; inadequate support from other relatives or healthcare professionals, and lengthy procedures.” This insight is helpful for chaplains and those providing bereavement support or organ donation support. The authors reached similar conclusions in a closely related article, “Decision making on organ donation: The dilemmas of relatives of potential brain dead donors.”⁶ The authors strongly recommend coaching families through the donation process itself.

Cultural considerations and the role of religious leaders in donors’ decisions about living or deceased organ donation cannot be overstated. Wong, L.P., (2010) addressed some of these issues in “Information needs, preferred educational messages and channel of delivery, and opinion on strategies to promote organ donation: A multicultural perspective.”⁷ The author identifies the gap in information needs among different minority groups, and suggests some culturally sensitive messaging to mitigate the sociocultural barriers to organ donation.

The need for organ donation is significantly higher among ethnic and minority populations, but these populations also have a low donation rate. This leads to increased wait times and higher mortality rates. Morgan, M., Kenten, C., Deedat, S., Farsides, B., Newton, T., Randhawa, G., Sims, J., and Sque, M. (2016) discussed these realities in “Increasing the acceptability and rates of organ donation among minority ethnic groups: a programme of observational and evaluative research on donation, transplantation and ethnicity (DonaTE).”⁸ The findings suggest a need for targeted messaging and training aimed at ethnic minorities for the purpose of addressing cultural issues surrounding organ donation.

The organ and tissue donation community across North America has struggled with the declining rates of organ donations, and the increasing demand for donor organs. Several interventions have been aimed at healthcare professionals to help increase organ donation. Witjes, M., Jansen, N.E., Hoeven, J.G., and Abdo, W., (2019) completed a systematic review of interventions that are most effective. Their finds were published in, “Interventions aimed at healthcare professionals to increase the number of organ donors: A systematic review.”⁹

Best practice standards in organ donation suggest that conversations with families could be improved to support well-informed decisions and potentially increase organ donation rates. Following a gathering of industry experts in Montreal in 2014, their recommendations were published in the May 2017 edition of *Transplantation*, under the title, “End-of-life conversations with families of potential donors.”¹⁰ The experts issued 12 recommendations and corresponding supporting guidelines. Of note are the guidelines around family support, and the skills that are essential in leading donation conversation with families. Also significant is the list of potential research that would extend knowledge and close information gaps in this area, as

well as some system initiatives that require further investigation – such as training, organizational culture, and public awareness.

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Notes:

¹<https://academic.oup.com/ndt/article/26/2/437/1894177>

²<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3782236/>

³https://www.researchgate.net/publication/235755371_Providing_Social_Support_in_a_Persuasive_Context_Forms_of_Social_Support_Reported_by_Organ_Procurement_Coordinators

⁴<https://www.myamericannurse.com/wp-content/uploads/2017/10/ant10-Pediatric-Organ-Donation-919.pdf>

⁵<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940748/>

⁶<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4574465/>

⁷https://www.researchgate.net/publication/49632314_Information_needs_preferred_educational_messages_and_channel_of_delivery_and_opinion_on_strategies_to_promote_organ_donation_A_multicultural_perspective

⁸<https://www.ncbi.nlm.nih.gov/books/NBK355264/>

⁹<https://ccforum.biomedcentral.com/articles/10.1186/s13054-019-2509-3>

¹⁰https://journals.lww.com/transplantjournal/Fulltext/2017/05001/End_of_Life_Conversations_With_Families_of.2.aspx

Dementia communication tools will benefit professionals

By Anne M. Windholz

Ian A. James and Laura Gibbons. *Communication Skills for Effective Dementia Care: A Practical Guide to Communication and Interaction Training*. Philadelphia: Jessica Kingsley, 2019. 142 pp.

I come to this book as someone who has worked with dementia patients in lay ministry and as a professional chaplain since 2003. I am also primary caregiver for my mother, who has lived with me and my husband since being diagnosed with Alzheimer's in 2016. I open its covers with the awareness that I could develop Alzheimer's in the next twenty years. I cannot, therefore, claim to be an objective, disinterested observer. Like many of you, I read works like James and Gibbons' *Communication Skills for Effective Dementia Care* looking for answers to questions that are as personal as they are professional.

That said, this book by two British healthcare researchers and clinicians is most directly intended for paid caretakers and particularly those who provide hands-on care to people with dementia. It explains communication and interaction training and how to apply it. James and Gibbons offer a person-centered approach that focuses on the basic needs that motivate all human interaction. When we lose our ability to communicate or reason, we can act out or react with what they call "BtC" for behaviors that challenge.

Communication Skills is a rich resource: it offers cogent summaries of studies in the field, provides useful tables and diagrams, and presents case studies to show practical applications of theoretical approaches. Its extensive lists of references will be a boon to any researcher. As a chaplain, I very much appreciated the authors' emphasis on knowing each individual's story and using that knowledge to help assess needs and determine interventions. They accentuate *creating a relationship with* a person rather than *doing tasks to* a person, a reframing that they hope frees healthcare workers to explore and experiment while reducing patient stress. The value of empathy is celebrated, but James and Gibbons wisely note that empathy by itself does not meet a need. They are above all practical, presenting the features of effective interventions and discussing the evidence-based benefits of various allied therapies. They describe how to approach each patient depending on the extent of their dementia; how to speak to them and how to touch them; how to earn trust and learn to love.

This useful reference book should be on the shelves of all skilled nursing facilities, hospices, geriatric wards, and behavioral health hospitals. However, while its style is straightforward, *Communication Skills* is not an easy read. The writers depend too much on acronyms, which becomes distracting rather than helpful. The book's strength is its conciseness – and that is perhaps also its weakness. Like a soup that has been boiled too long, all the rich content becomes jumbled together with little broth to smooth digestion. I would only guardedly recommend it to family caregivers, who might find it overwhelming. For professionals, it is a must-read – but I advise judicious use of the index to most efficiently find needed information.

I learned a great deal from James and Gibbons' research and practical insights and was immediately able to apply their lessons in my spiritual care with patients. But *Communication Skills'* most meaningful passages were those that taught me how to better see the world through my mother's eyes, how to better connect with her, and how to be a better daughter to her at this stage of our lives. As the authors note again and again, the most important thing is to create and nurture relationships. Because the heart knows even when the mind cannot.

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