



VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Receiving The Gift Of Life:

Stories From Organ Transplant Recipients*

A teaching guide for transplant professionals

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The stories referenced in this study guide can be downloaded for free. Please see the "Receiving The Gift Of Life: Stories From Organ Transplant Recipients" volume of VOICES <https://nibjournal.org/voices/>

Art Frank has written a short reflection piece on learning from narratives for NIB. Please see the Narratives Page under the Education tab on the NIB website to download the piece.

General Questions:

1. How is success defined differently by transplant recipients and transplant centers? Why is there sometimes a discrepancy? What can be done for patients and transplant centers to view success more similarly?
2. Correspondence between a transplant recipient and a donor family is coordinated through the transplant hospital and the organ procurement organization. Writing can be intimidating for some donor recipients. What lessons do the stories contain about how to successfully reach out to a donor family?
3. Many people believe that organ recipients fully recover with no lingering health conditions afterward. In what ways do the stories challenge this idea?
4. Organ recipients often feel they have received a great gift and are compelled to give back. This desire often arises from "survivor's guilt." In what ways is this desire to give back a good thing? When can it become a problem?

*Created to accompany VOICES: Stories from the Pages of NIB, 2022, which contains the narrative symposium from Narrative Inquiry in Bioethics, Volume 12, Issue 2, titled, "Receiving The Gift Of Life: Stories From Organ Transplant Recipients."

Story Questions:

Receiving the Gift of Life: My Kidney Transplant Story

Judith W. Ryan

1. Judith Ryan and her two brothers all inherited polycystic kidney disease from their mother. In her story, Ryan says finding a living kidney donor would be a problem because “how do you ask people to consider being a donor? I had difficulty asking friends for a ride to the airport.” Ryan eventually received a kidney from a live donor who was first tested but not a match for her younger brother. What advice do you have for people trying to find living donors?
2. Judith Ryan's kidney transplant story brings to light that transplant patients may not have the words to express thanks to their donors. Ryan's narrative encourages transplant nurses and social workers to actively assist recipients in understanding that it is never too late to say thank you. What advice do you have for post-transplant patients who are finding it difficult to express gratitude to their donor or donor's family?

Gaining a Heart But Missing Myself

Leilani R. Graham

1. Graham describes her hair falling out in clumps, her skin developing abrasions at the slightest touch, her “explosive and terrifying” mood swings, her inability to recognize her face in the mirror leaving her “caged and alone in my own body . . . angry, hurting, and scared.” What strategies have you employed to get to know your patients and understand what is most important to them in their treatment and care? How can providers manage patient expectations about less severe issues that are often of great concern to patients while balancing the need to convey information about a patient's susceptibility to high-risk issues?
2. Graham felt underprepared for the long recovery she experienced and was surprised by the lack of empathy her providers displayed. She notes that “In the end, there may be nothing [clinicians] can do for a specific issue.” Graham provides an example of how a brief but compassionate response makes all the difference when one doctor responds to her concern about hair loss by turning away from his computer and facing her to say, “I'm sorry. I'm a man. Losing hair is a concern. But I know, especially for women, losing their hair can be extremely upsetting.” What small differences in your interactions with patients have worked to demonstrate empathy?

Managing the Transition from Patient-Centered Care to Protocol

David Slakter

1. David Slakter says that “having a living donor who was also a friend made the transplant experience somewhat less intimidating than it might have been. It meant fewer open questions about what may have motivated [the donor] to be so generous.” Several authors also question the motivation of donors who don't know their recipients.

Why might a donor's motivation be important to a recipient? Should a potential donor's motivation be used by transplant teams to determine if they should be allowed to donate? Why or why not?

2. Slakter says, "Life post-transplant has been a significant improvement from what it was like immediately beforehand. Before my transplant, I regularly weighed food and consulted nutrition charts to gauge how much potassium I was consuming. To prevent too much potassium from building up in my bloodstream, I had to take sodium polystyrene regularly. I had long experienced difficulty with aerobic exercises. Within a few months after my transplant, I was riding a bicycle all over NYC and attained a level of fitness I had not reached since I played soccer as a child." What have patients told you about what life post-transplant is like for them? Is Slakter's remarkable transformation typical of what you see? How do you manage a patient's expectations about what life post-transplant will be like?

Ethical Issues Faced by a Kidney Transplant Recipient

Elizabeth Crais

1. Elizabeth Crais described how medical professionals failed to inform her of the seriousness of her condition. She says "I was completely unaware of the critical situation." She says some physicians use a 'don't tell until it's necessary' philosophy that shields the patient from bad news." Do you think this philosophy serves the patient's or the physician's needs? Why?
2. Crais describes how her husband was allowed to be evaluated to be her donor despite having told the care team about his previous cancer 20 years before. After the final meeting with the transplant surgeon, Crais's husband was told they would not accept him as a donor because of the risk that Crais would develop cancer, passed on to her from the donated kidney. How does such a miscommunication occur, and how can it be avoided? Do you agree with the decision of the transplant team to automatically exclude Crais' husband as her donor without her or her husband's input? Is it responsible to let patients and donors decide what level of risk they are willing to accept? Why or why not?

From Coma to Kidney Transplantation: A Flourishing Journey

Abdou Simon Senghor

1. Senghor says that when he was first diagnosed with chronic kidney disease, his doctor didn't give him any information about how serious his illness was because he didn't want to scare him. Delivering upsetting news is perhaps one of the most daunting tasks physicians face. How did your training program prepare you for the complex and emotional responsibility of discussing bad news with patients and families? What advice do you have for new physicians about breaking bad news?
2. After their transplants, several writers were inspired to start new careers in health-related fields. Senghor attributes his kidney transplant as the motivation for pursuing his career

path. "Thanks to my kidney transplant, I obtained a master's degree in public health, wrote a sociology doctoral thesis on my disease, and obtained post-doctoral fellowships that allow me to further my work on health issues." What inspired you to work in transplant?

My Journey Through a Kidney Transplant Procedure

James Moran

1. Moran at first questioned if he should have gone through with his kidney transplant, given the continued health problems he experienced post-transplant. "Unfortunately, I returned to the hospital several times in the next three months with infections leading to sepsis and pneumonia. These months were very difficult, and I was questioning my decision." What advice do you have for patients who continue to experience health problems post-transplant and who question their decision?
2. Moran was reluctant to accept a kidney from his son and waited four additional years for a deceased donor kidney to become available rather than expose his son to the risks of donation. What do you think of Moran's decision? How important is it for people who need an organ transplant to consider the potential benefits that donor candidates may receive from donating (e.g., increased sense of happiness to be able to help, stronger interpersonal relationship with the recipient, relief from caregiving burdens)?

Today We Walk. Tomorrow We Dance

Allen Callaci

1. Allen Callaci writes, "I have not stopped thinking of my donor and their family in the years since returning home from [the hospital], although I only know minimal details about them." Callaci continues, "I have reached out to the family with written expressions of my enduring and unending gratitude over the years through the proper channels but have yet to hear back." In their stories, many of the NIB authors convey a longing to express gratitude to their donor's family. Often they don't hear back when reaching out. Some have difficulty knowing how to express their profound appreciation. In what ways can Callaci and other recipients fulfill their desire to express gratitude and honor their donors?
2. Callaci writes, "I'll be forever grateful to the nurse who, on one of my first brutally painful walks around the nurse's station, lightheartedly told me 'today we walk, tomorrow we'll dance.' I've known fewer moments as hopeful, humorous, and humanizing as that one." Why do you think this nurse's comment was so helpful for Callaci? How do you use humor or lightheartedness in your interactions with patients? How do you know when it's appropriate to do so?

Perspective and the Gift of Life

Todd S. Frantzen

1. Frantzen noted that his relationships have changed since undergoing a triple organ transplant. He says, "At the beginning of my illness, family and friends supported me

with words of encouragement and an outpouring of love. However, as time moves forward, so have they." What should friends and family of transplant patients know about life after transplant? How can they continue to support their loved one who has received a transplant?

2. Frantzen's medical team did not inform him about a policy change that would have allowed him to relist to get a second kidney transplant after his first was unsuccessful. Frantzen must resume taxing dialysis treatments twice a week after the failed transplant. He writes, "We spoke to the kidney transplant team numerous times and were very disappointed with them as they never brought up this policy change." What went wrong in this scenario? How can something like what happened to Frantzen be avoided?

The Right Heart

Ingrid Gould

1. Through her cardiologist's referral, Gould connected with other heart transplant patients with whom she became very close and who helped guide her along the way. "[H]e put me in touch with two women who had received new hearts a few years earlier [. . .] They soon became my invaluable mentors and cherished friends." What advice do you have for transplant patients about finding guidance and community?
2. A huge component of patient satisfaction has to do with the interactions they have with healthcare providers and non-clinical staff. In the hospital, Gould observed those who cleaned and bleached her room, drew blood, took meal orders, delivered food, and wheeled her to and from tests. She says, "The needle pricks less when the phlebotomist calls you 'baby.' Nourishment comes in many forms. Numerous workers provide health care." What strategies traditionally used in the hospitality industry can be used within healthcare to help improve a patient's experience? How can an institution promote a culture of hospitality among its workforce?

A Trial of Patience

Christopher Lewis

1. Twelve years after his mother donated part of her liver to him, Christopher Lewis required a second transplant. This time he needed a multivisceral transplant. The transplant team that Lewis initially worked with did not offer multivisceral transplants. They explained that he would have to be re-listed at a new center 300 miles away from his home, requiring Lewis to move close to the transplant center for several months. How does your transplant team support patients who require a move? What could be improved with this process?
2. After waiting for nearly a year for a multivisceral transplant, Lewis advocates for himself and asks to pursue an isolated liver transplant instead, despite the risks. Lewis writes, "To my surprise, the idea was not met with a stark no." How do you respond when a patient desires a different plan of care than the one you recommend?

The Transformative Journey of Transplantation

Valen Keefer

1. In her story, Keefer kindly reminds us that “Healing is not linear, nor does it involve all physical wounds. There is the mental health journey as well. It isn't just the recipient who is emotionally impacted; transplantation also affects the caregivers.” Based on your observations, in what ways does the transplant journey affect family and friends? What resources are available to help family and friends engage in self-care?
2. Keefer, who was diagnosed with polycystic kidney disease when she was ten years old, says, “Some may think of transplantation as a singular event when in reality, it's a lifelong journey that can start with a diagnosis many years prior.” What differences do you notice in patients whose transplant journey is put into motion when they are young, like Keefer, in contrast with those who may need a transplant after something more abrupt or unexpected happens?

The Courage To Live

Antonella Colace

1. Colace highlighted how caring for her young daughter, who needed a pediatric liver transplant, changed their bond. “Over time, I became my daughter's personal nurse, almost at the expense of our mother-daughter relationship.” What advice do you have for family caretakers?
2. When recalling the wait for a liver for her young daughter, Colace writes, “The most dramatic thing to overcome and accept was hoping for someone's death. For Elisa to live, someone else had to die. I felt like an executioner. I didn't think of anything else; I didn't sleep at night.” What would you tell patients who struggle with these types of thoughts?

My Gratifying Testimonial of My Extended Warranties of Life

Danette Ragin

1. Ragin had several unsuccessful calls to be transplanted—the donated kidneys could not be used or were accepted by another patient first. What advice do you give patients who have just been listed to manage their expectations and circumvent disappointment?
2. Ragin encourages readers to register to become organ, eye, and tissue donors. She adds that individuals who want to donate should discuss their wishes with their family members. How would the transplantation field change if more people discussed their wishes with family?

Blessed Beyond Measure

Barbara Bischoff

1. Bischoff says she struggled with guilt over the death of her donor. During a conversation about it with one of her nurses, the nurse tells Bischoff, "Your donor didn't die so you could live. You're alive because they died." Bischoff says the nurses' words resonated with her, and she was able to refocus on gratitude. What wise words have you said or heard others say to patients who struggle with guilt?
2. Bischoff says, "During my recovery time in the hospital, volunteers who were recipients themselves would visit to give support and share their stories. It was inspiring." To what extent does your transplant program enlist the help of past recipients? Who does this type of volunteer work help the most?

Lemons to Lemonade

Cindy Conrad, Mike Conrad, Katie Johnston, Crit Conrad & Doug Hanto

1. Conrad's physician, Dr. Hanto, says there was added urgency and emotion with Conrad's case because she was young, had just delivered a baby, and had a husband and daughter that loved and needed her. How do you cope with the added stress and perhaps pressure of caring for younger patients like Conrad?
2. Dr. Hanto says that he has maintained a friendship with Conrad and her family for over 34 years since she underwent a liver transplant. Do you have patients with whom you have developed and maintained friendships? What boundaries should be in place concerning physician-patient friendships?

How Do You Decide Who Saves Your Child's Life?

Meghan C. Halley

1. Halley's three-year-old son needs a liver transplant from a living donor. Her sister is a match and offers to donate a part of her liver. However, her sister is a recovering alcoholic. Halley worries that the surgery and subsequent physical challenges could cause her sister to relapse based on the rates of depression in living donors following surgery. What concerns would you have about a living donor who was a recovering alcoholic? How would you decide whether or not to do the transplant?
2. Halley asks, "Were we selfish to let my sister take my husband's place?" Halley still feels guilty about the decision, though she admits that even posing the question of whether she and her husband should have "let" her sister donate feels unfairly dismissive of her sister's active role in deciding to offer such a gift in the first place. Do you agree? Why or why not?

Metaphors and the Transplant Experience

Madalina Meirosu

1. Meirosu says she did not want her father to donate because of the shame and stigma of being chronically ill in Romanian culture. Meirosu says, "Being ill meant not being useful or worthy." Have you observed shame and stigma with being chronically ill in your patients? How have you responded to patients vocalizing these feelings?"
2. Meirosu expresses concern to her doctor that the dose of cyclosporine she is taking is too high and causing her uncomfortable symptoms. Meirosu says, "Though she was understandably resistant to bucking standard procedures concerning normal ranges of immunosuppressant medicine, she still listened to me, thankfully, and began to trust my insights into my own body. Slowly but surely, we reduced my cyclosporine to a minimal dose." How comfortable are you with trusting your patient's insights?