



VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Receiving The Gift Of Life:

Stories From Organ Transplant Recipients*

A teaching guide for patients and organ recipients

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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. If you have reached out to your donor or their family, how did it go? What advice do you have for other 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. Leilani Graham, a heart transplant recipient, discusses what outcomes matter to patients and suggests that professionals in the transplant community should focus on patient-centric goal setting rather than on graft survival metrics tied to transplant center success and funding. Graham writes, “What did I care to only survive a year? I wanted years. I wanted decades. It felt I wanted more than anyone was willing to pay attention to.” What metrics did your transplant center provide to you? Were these metrics in line with issues that were important to you? What information was missing that you would have liked to know?
2. 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 side effects did you experience that surprised you? Did you have a conversation with your physician about these side effects? If so, what was helpful about the conversation? How do you wish your provider would have responded differently? How can providers better manage patient expectations about less severe issues that are often of great concern to patients while balancing the need to convey information about critical issues?

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? Was it important to you? If you asked your donor what their motivation was to donate, how did they respond? How did you feel about the reason they provided?

2. Slakter says, "I had the opportunity to choose another doctor on staff whose bedside manner better suited my needs and who was willing to hear out my concerns and provide answers to my questions. My advice to other transplant patients is to take charge of their own care." The search for a provider who better suits you can be daunting and some patients may not have other options due to their insurance or the availability of providers where they live. What advice would you give to someone who feels their current provider is not serving their needs but has limited options for finding other care?

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. 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. Think of a time when a physician had to break bad news to you. What went well? What could have gone better?
2. After their transplants, several writers were inspired to start new careers in health-related fields. Senghor says his kidney transplant motivated him to pursue a career in health care research. Has your transplant changed the trajectory of your life or your interests? If so, in what ways?

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.” Did you continue to experience health problems post-transplant? If so, what advice do you have for people who have yet to undergo transplant or who have recently had a transplant?
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.” Is there a time when a healthcare provider said something especially meaningful to you? What made the interaction so special?

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, “In 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.” How have your relationships changed since undergoing transplant? 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." Did you experience any communication breakdowns when waiting on the transplant list? What advice do you have for transplant teams on how communication could be improved?

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." Who did you rely on for guidance while going through the process of organ transplant? How did you connect with this person and how did they help you?
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?

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, to replace his liver, intestines, spleen, and stomach. 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. Did your transplant experience require such a move? How did the transplant team support you with this move? How could they have supported you better?
2. After waiting for nearly a year for a multivisceral transplant, Lewis advocates for himself and asks to pursue an isolated liver transplant despite the risks of not receiving the multivisceral. "To my surprise, the idea was not met with a stark no." How much did you have to advocate for yourself during the transplant process? Were you successful? How did your transplant team respond?

The Transformative Journey of Transplantation

Valen Keefer

1. Keefer writes about how the experience of receiving a transplant changed her. While camping and admiring nature and “the gift of life,” Keefer reflects, “This moment would not have possessed such deep meaning if it wasn’t for the journey that came before it.” Despite the hardships of a prolonged medical journey Keefer says the transplant journey also had some positive aspects. Do you feel the same? What positive aspects do you recall from the transplant journey?
2. 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.” In your observation, how has the transplant journey affected your family and friends? What would you like them to know?

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.” How did relationships with family or other close people who cared for you during your transplant journey change? What challenges did you face with these changing dynamics?
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.” Did you struggle with similar feelings of guilt? How did you overcome these feelings?

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. How important is it to manage expectations when waiting for an organ transplant? What advice can you give those who have just been listed?
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. Have you had this discussion with close family? How have their views changed since you received an organ transplant?

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. Did you struggle with guilt? If so, what advice were you given that helped you to overcome it?
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." Did you read or hear stories from other transplant recipients during your transplant journey? If so, how were these stories comforting? What do you tell others about your transplant journey?

Lemons to Lemonade

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

1. Conrad's physician, Dr. Hanto, says that he has maintained a friendship with Conrad and her family for over 34 years since she underwent a liver transplant. Are you friends with any of your physicians? Why or why not?
2. One of Conrad's children writes, "I realized the toll that the transplant, medications, and subsequent hepatitis C took on [my mom]. I watched her organize pills, suffer through exhaustion from Interferon, and try to rest when she could amidst her commitments to keeping our household afloat." What resources and support do transplant patients and their family members need to better promote well being after transplant?

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. Halley's sister ultimately convinces her that giving the gift of life to her nephew will be part of shaping her own recovery. If you are in touch with your donor, what did they tell you that donating meant to them? If you had more than one offer, how did you decide who would be your donor?
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 explains that she did not want her father to donate his kidney to her because of the shame and stigma associated with being chronically ill in Romanian culture. Meirosu says, "Being ill meant not being useful or worthy." Is there shame and stigma associated with being chronically ill in your culture? If yes, what false assumptions exist? How has stigma or shame affected you? What have you done to overcome this?
2. Meirosu did go on to receive a kidney transplant from her father. After his death some years later, she says, "I have read accounts of transplant patients feeling an ongoing connection with their donors. Given the close relationship that I had with my father, I would expect if a donated organ can mediate the presence of the donor, I would be able to feel something." Do you feel an ongoing connection with your donor? How so?