

Whaddaya have to do to get a kidney around here?

My search to find an organ donor taught me just how generous my friends are -- and how flawed the current transplant system is.

BY FRANCES KISSLING



It was almost a year ago that I found out my kidneys were slowly but ineluctably failing. I'd been diagnosed with kidney disease a few years earlier but the beans had been stable at 50 percent. Then a consult at Mass General concluded with the news that it could be as early as a year before I would need what was euphemistically called "renal replacement therapy." Doctors are often discreet in the way they describe things, but the message was clear. I would face three choices: death, dialysis or transplant.

I am an odd duck, but I was energized by what was now to be a great adventure. I was going to have the opportunity to face my own mortality. At 65, I had a wonderful life, a public voice and made a modest contribution to a better world. Twenty-five years giving the Vatican and the U.S. bishops a hard time for treating women like dirt had helped build a feminist movement in the Catholic Church and resulted in some extraordinary bonds of solidarity. I loved my life and would enjoy more if it were available, but death was OK. I would take it as the last wonderful journey. I'd

also do what needed to be done to continue to live a long and fruitful life, free of infirmity. That meant finding a person who would donate his or her spare kidney to me before mine failed. It was not, the doctors said, too soon to begin the search.

I think I instinctively knew what I had to do. I'd spent a lot of my time raising money, and I had that Bible verse "ask and you shall receive" burned into my consciousness. I decided to compose an e-mail about my need. In it, I shared my sense of the adventure before me and asked if anyone would like to give me one of their kidneys. I noted:

"To be dependent on the generosity of others is a new experience for me and I am thinking a lot about what it means to share one's body with another person. Also trying to figure out how I ask for a gift that I really want without expectation or making friends and colleagues uncomfortable."

I sent this off in batches to about 150 friends and colleagues whom I thought would want to know and might fit the criteria for donating. Within three days I had five offers. Within a month, 24 people, some I did not even know, came forward to donate. I was in the midst of a new phase in my life's journey. I have always seen myself as an open person, but I have also been pretty circumspect about sharing my life. I never married, and I have no children. Now, not only was I planning on being part of the remarkable biotechnological revolution in which a part of someone else's body would become mine, but I was also engaged with others in reflecting on the meaning of friendship. I was bowled over by how people responded. One friend wrote:

"I want you to know I am willing to consider being a donor. I am facing a different kind of provisional diagnosis of a rare inherited form of dementia, one that would take my life in the next two decades. Since I probably won't need a kidney to last more than another 15-20 years, I am happy to share one of mine. I planned to donate my useable organs anyway, and it would be a blessing and a joy to see one of them help you."

I had offers from an Episcopal woman priest, Roman Catholic nun, ACLU lawyer, Pulitzer Prize-winning author (OK, it is Anna Quindlen, who said she thought if we ever had to share an organ, it would be our spleens, but if it has to be a kidney, that's fine). **Susan Wicklund**, a Montana physician who rides the circuit to provide abortions in states where there is no provider, offered a kidney. Former co-workers came forward. Many said I still had important work to do, and they wanted to be sure I got to do it. Most who offered, offered quickly, spontaneously and firmly. A few thought a longer time, asked for more details. Some said I will do this if you come down to no other offer, but I hope I don't need to. Almost all who offered were women. Two men, Andy Merton, who wrote the great 1980s book "The Enemies of Choice" (he has a strong feminine side), and the director of a local NARAL chapter, whom I did not know, were the only exceptions. I am convinced that this is not just because I know more women than men. I think women, who carry life in their womb, are more attuned to sharing their bodies, and men -- well, men are just weird about medicine and bodies. (Statistics seem to bear this out. Women are more proactive in seeking donors, and they provided 58 percent of living donations in 2007. The statistics reverse with cadaver kidneys.)

Just as touching as the people who offered to donate were the people who took the time to say no. One friend wrote:

"I know that is not what you would like to hear from me, but I believe I owe you a full disclosure; perhaps it might be good to help you to allow yourself some self-pity, not a very constructive feeling admittedly, but empowering nevertheless, in the sense of acceptance of weaknesses. I was also sad because I realized how limited my solidarity is. I know you also do not want me or anybody else to feel guilty but I was disappointed with myself to realize how unlikely it is that I will give you my kidney."

I am crying as I read this, for indeed, this is solidarity. I was not the least disappointed. This friend is a cautious person, and her willingness to share how she felt about herself was very brave. I understood my own decision to share my need and my feelings widely as an intimate act on my part as well. I had succeeded in my desire to offer people the opportunity to share in my life without coming across as demanding or needy, and that taught me something.

But most people are not so lucky. They have no viable offers. My nephrologist told me the story of a senior surgeon at the hospital who had recently had a transplant. His kidney came not from a family member, friend or colleague -- but from a Web site.

Some basics: According to the National Kidney Foundation, there are 485,000 Americans with end-stage renal disease. More than 341,000 are on dialysis; 140,000 have functioning transplants. About 87,000 people die each year from end-stage renal disease, some on the waiting list, others who could benefit from a transplant but never get on the list. Each year, through death or transplantation, more new people go on the list than get off the list. For example, in 2007 there were only 16,629 kidney transplants; 10,588 were from organs donated by 7,241 deceased people and 6,041 from living donors. In spite of all the heart-rending stories about the lady from Dunkin' Donuts who gave her kidney to a customer and the millions of dollars the federal government has given to nonprofits charged with organ procurement to educate the public about the social good and medical ease of donating organs, the number of kidneys donated has risen only modestly over the last decade. In 2007 the number donated was the lowest since 2000.

Having had such a positive reaction to my own need, I was left wondering: What the hell is going on? Why are so few people donating kidneys to people they know? And is anyone doing anything about it?

Answers to the first question are hard to come by. As I talked to people and read more about the issue, there were clues. People wanted to save their kidneys for their kids or their spouses. Some friends reported that other family members discouraged them from giving. Transplants are still a little creepy, and the idea of sharing your body with someone else is still science fiction. It's scary. It's not a simple procedure. And people who need kidneys stay quiet about it. A recent study of people considering transplant showed that 54 percent of them had not asked anybody to donate.

Publicity about improvements in dialysis has probably made people think it's not so bad. We imagine people go sit in a nice chair for four hours three times a week, read a book and then go about their daily lives. In fact, as nephrologist Benjamin Hippen notes in the scientific journal *New Atlantis*, "Life on dialysis is a fragile, vulnerable existence." Far too often, things do not go well, and people on dialysis are unable to work, experience multiple complications and die quickly. The average span of life once one goes on dialysis is eight years for a person 40-44 years old and 4.5 years for someone 60-64.

The "is anyone doing anything about it" question is easier to answer. Some leaders in the field -- transplant surgeons, nephrologists and policy analysts -- have suggested that it's time to provide donors with incentives, from health insurance to tax credits and pension contributions to promote donations. My friend Sally Satel has been in the forefront of promoting this idea, and she has been a thorn in the side of the kidney establishment, which has been moving around the deck chairs on the Titanic rather than face the core ethical questions in the debate: Do potential donors own their bodies and have a right to decide? Do we treat potential donors fairly? These questions take on special urgency when you realize that 23 percent of Medicare expenditures go to treating kidney disease and the number of people with end-stage renal disease in the U.S. is projected to reach 712,000 by 2015.

Even without incentives, no group of do-gooders is treated with more suspicion by the medical community than living organ donors. Even a free glass of orange juice or an unnecessary lollipop given to a donor is interpreted by some leaders in the field as a "bribe" or a crime. Appropriate concern for the international organ trafficking problem (WHO estimates that the annual total of internationally trafficked kidneys is about 6,000) has so distorted the concept of altruism and eroded the principle of mutual respect that potential kidney donors are denied the basic safety net that a just and giving society should provide people who offer to risk their own lives to save the lives of others. And let's be clear. The best way to stop first-world people with money from exploiting poor people by bargain basement organ trafficking is to procure more organs from well-informed, healthy and autonomous people in the first world.

This insanity is so widespread that a new and creative transplant practice, known as daisy chains, needed federal legislation to assure hospitals and donors that they would not be arrested for performing them. In a daisy chain, two or more people who need kidneys but have potential donors who are not a match, trade donors. Those concerned worry that the 1984 National Organ Transplant Act (NOTA), which prohibits the sale or transfer of human organs for "valuable consideration" would be invoked. Would my trade of my donor's kidney for another be a form of "valuable consideration"? Legislation to clarify this was introduced and failed in three successive sessions of Congress. It was not till 2007 when Rep. Charles Norwood died and the bill was named after him that Congress could get this bill passed.

Far more disturbing is the attempt by some transplant professionals and ethicists to so constrain government benefits to potential donors that the large number of low-income and minority candidates for transplant are almost automatically precluded from receiving kidneys while they are healthy enough to benefit from them. Almost half of those on the kidney waiting list are African-American or other ethnic minorities. African-Americans wait twice as long for kidneys as white people; other ethnic minorities wait longer than white people but not as long as African-Americans.

The donor costs of the kidney transplant are covered by the recipient's medical insurance (most often Medicare) and the recipient can reimburse the donor for medical costs, travel and lost wages. Low-income recipients may not have the money to do that. Charitable funds for this purpose are woefully inadequate to meet the need and when they apply for funds donors wait months to find out if these costs will be paid.

More important, we financially abandon the donor almost immediately after we take their kidney. There is no provision for comprehensive long-term health insurance for donors, or for life and disability insurance. Opponents of any form of compensation or benefit to donors beyond costs directly attributable to the transplant itself fight efforts to provide these benefits. One example of such stinginess is the current "End the Wait" campaign of the National Kidney Foundation. In a grudging concession, the NKF supports post-transplant health insurance, but insists that it only cover medical expenses directly related to complications from the transplant. How mean can you be?

No matter. This over-scrupulosity has to stop. It's time to rescue the debate about organ transplant policy from the deck chair rearranging and simply treat potential donors with the same generous spirit with which they have offered their kidneys. No donor should spend a single dollar in the process of giving an organ. And donors should have the safety net they need to stay healthy, to support their family if they cannot work and life insurance should

they die. We can and should do even more; but health, life and disability are bottom lines. One member of Congress who gets it is Arlen Specter, who is circulating the Organ Trafficking Prohibition Act of 2009. The bill increases the penalties for really buying and selling organs, but makes clear that state and federal government can provide the kind of benefits donors deserve without going to jail. Anyone disagree?

My own story? I'm still waiting to hit the magic number when the transplant will be needed. Two potential donors were found to have kidneys not quite strong enough to share and are very sad. A third, my buddy Rita Nakashima Brock, is in the final stages of the rigorous testing, and it is looking good. I have no idea whether taking better care of donors will result in more kidneys available for transplantation, but I am very certain it is the right thing to do. My search has changed me and made me more willing to share myself. Rita and I have talked about writing a book that will guide people through the process. The 54 percent who could benefit from transplant and don't ask anyone to give need all the encouragement they can get.

-- By Frances Kissling