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Desperately Seeking a Kidney

By SALLY SATEL

In the fall of 2005, I started my first online relationship. He was a 62-year-old retiree from Canada; I was a 49-year-old psychiatrist living in Washington. Beginning in early October of that year, we talked or e-mailed several times a week. This arrangement was novel to both of us, so our conversations were tentative at first, but we soon grew more comfortable, and excitement over our shared vision blossomed. After a few weeks, we decided to meet for a uniquely intimate encounter. After New Year's, the Canadian would fly to Washington to meet me — at a hospital, where he would give me one of his kidneys. Thank God.

My own kidneys were failing. On a steamy day in August 2004, I went to the doctor for a routine checkup. I was feeling fine, but a basic test revealed that my kidneys were shot, functioning at about 16 percent of normal capacity. One nephrologist I went to predicted that within roughly six months to a year I would need to begin [dialysis](#). Three days a week, for four debilitating hours at a time, I would be tethered to a blood-cleansing machine. Even simple things like traveling to see friends or to give talks would be limited. This would very likely continue for at least five years until my name crawled to the top of the national list of people waiting for kidneys from the newly deceased. On average, 12 names, the death toll from the ever-growing organ shortage, would be scratched off the list each day.

A much better option would be to get a transplant from a living person. I had tried that and failed. Thus my plans for a rendezvous with a man I had never met. But shortly before Thanksgiving, he disappeared. I panicked. Everything turned to radio silence as my e-mail and phone messages went unanswered. Was I, a psychiatrist no less, crazy to have put my trust in a stranger who goes on the Internet to relinquish an organ?

Friends wanted to know why my kidneys were giving out, but there was no good answer. I didn't have [diabetes](#) or [hypertension](#), the most common causes of end-stage renal disease. My doctor's theory was that my kidney damage may have been caused by a medication I had taken during my 20s. The one thing we knew was that whatever was destroying my kidneys did so stealthily. Like most organs, kidneys have impressive reserves, and the slower they deteriorate, the longer they can keep up a good front, maintaining blood pressure, balancing the salt and electrolytes in the blood and, of course, producing about one to two liters of urine a day. I remembered a line from "The Sun Also Rises," when a drunkard is asked how he went bankrupt. "Two ways," he answers. "Gradually and then suddenly." That was how my kidneys went out of business too.

The obvious place to find a donor is your own family, but that was not really an option for me. My parents were not alive and would have been far too old to help me even if they were. I have no siblings and only three cousins; I hadn't seen two of them since high school; and the third I see maybe once every two or three years. I couldn't call out of the blue with this news. I could just imagine my relatives tsking into the phone, "You only call when you want something." Indeed.

Theoretically, kidneys should be in booming supply. Virtually everyone has two, and healthy individuals can give one away and still lead perfectly normal lives. Yet people aren't exactly lining up to give. At the beginning of 2005, when I put my name on the list, there were about 60,000 people ahead of me; by the end of that year, only 1 in 9 had received one from a relative, spouse or friend. Today, just under 74,000 people are waiting for kidneys.

I wanted my donor to be completely anonymous so I could avoid the treacherous intimacy of accepting an organ from someone I knew. I would have gladly paid someone to give me a kidney, but exchanging money for an organ is a felony in this country. Altruistic giving is the metaphorical bedrock of our transplant system. Organ donation, we are told, should be the ultimate gift: the "gift of life," a sublime act of generosity. The giver — whether living or deceased — must not expect to be enriched in any way.

In late 2004, not long after I learned my kidneys were failing and a little over a year before I met the Canadian online, I told one of my best friends about my diagnosis. She and I first met more than 20 years before at the medical school at Yale, when I was finishing my residency in [psychiatry](#) and she was an instructor in the same department. Dr. Yale, as I'll refer to her to protect her privacy, is a feisty blend of bubbly energy (last summer she made me ride the Cyclone with her at Coney Island) and intellectual seriousness (she is training to be a psychoanalyst). She immediately offered to check her blood type. I needed someone with type A or O, and in uncomplicated cases like mine, blood-type matching is usually one of the biggest hurdles to compatibility. Dr. Yale was type O. Presto!

She said she needed to talk it over with her husband but thought it would be fine. A week later, however, she said it wasn't. "Giving you a kidney seemed a perfectly natural thing to do," she told me. "I had the time, and I wanted to do what I could and in a clear way, far clearer than the vague helpfulness of say, psychiatry. But then I mentioned my plan to donate to a fellow alto at chorus rehearsal one evening." As it turned out, the alto in question was no typical acquaintance: she was a transplant surgeon. My friend continued: "She was very surprised that I was planning to donate to a friend and then pulled an article out of her bag about hemorrhaging after donating." The exchange set off a spiral of [anxiety](#) in Dr. Yale's mind — *What if my brother or kids need my kidney? What if I had complications from surgery?* I'm sorry, she said matter-of-factly, and that was that.

I understood that my friend wanted to spend her kidney wisely. What mystifies me still is how she got so spooked. After all, Dr. Yale was a physician herself, capable of weighing the risks. The operation is done by laparoscope, leaving only a modest three-inch [scar](#); she would have been out of the hospital after two or three nights. Most important, the chance of death is tiny — 2 in every 10,000 transplants — and the long-term health risks are generally negligible.

More baffling to me, though, was the fact that she was talked out of donating by a person who removes and implants organs for a living. I was outraged. A transplant surgeon, of all people, knows how hard it is to find a donor, how grueling dialysis can be and how significant the health benefits of a "pre-emptive" transplant (that is, one received before the patient goes on dialysis) are. Not to mention the fact that hemorrhaging after donation is unusual. How dare she discourage someone who was ready to donate! Or had my friend been ready? It doesn't matter now. But at the time, the surgeon was such a ready scapegoat that I could push the uneasy question about Dr. Yale aside.

I fumed for a week and then got over it because I figured it was early and it wouldn't be hard to find someone else. And sure enough, two more friends quickly stepped forward to have their blood typed. It turned out they were poor matches for me.

A week after my 49th birthday in January 2005, half a year after being given a diagnosis of [renal failure](#), a friend and I were drinking coffee at a Starbucks when I wondered aloud if I would find a donor before I reached 50. I wasn't hinting. I knew she would never offer because she was so squeamish about blood and pain. My friend, whom I met a decade before when we were both new to Washington and worked together on an advocacy project, was a little older than I; she was charming, stylish, smart — and a hypochondriac.

Nor, to be honest, did I want her kidney. Anyone as anxious about health as she was would surely view donation as a white-knuckle ordeal. And the bigger the sacrifice for her, the heavier the burden of reciprocity on me. The bigger the burden on me, the more I would resent her. Then I would feel guilty over resenting her and, in turn, resent the guilt. Who could survive inside this echo chamber of reverberating emotions? Thank goodness my friend would be holding on to her kidney.

But then to my amazement, within a minute or so of my speculating when or if a donor would ever appear, she offered to do it. Later that night we talked on the phone and she rhapsodized about what a “mitzvah” it would be. Yes, her sentiments were lovely, but I felt secretly annoyed because I knew it was her habit to embark upon grandiose plans; when they fizzled, she would just shrug. I told her that giving me a kidney was out of the question — “It would be too weird,” was what I kept saying — but she persisted. I couldn't quite believe it when she told her family of her decision (they were graciously in favor) and then had blood tests and consulted with my transplant team.

Gradually, I began to believe that she meant it, and I decided to embrace her just as you might accept an in-law, as someone who could drive you a little mad but whom you loved because they were the source of something very precious to you — in my case, not a spouse but a kidney. But then after a few months she stopped talking about it. When I finally broke the silence, she said her doctor had advised against it. More likely, I thought, she was scared. I felt sorry to have put her in this position, but I was also bitter: just when would she have gotten around to telling me?

Such near-transplant experiences are not uncommon. All of the transplant candidates I spoke to, as part of my own small nonscientific sample, mentioned at least one person who promised to donate, had some tests done and then developed cold feet. Transplant teams explicitly, and properly, offer face-saving “medical alibis” to potential donors who don't really want to go through with it, which suggests that bailing out isn't all that rare. They might tell the person needing the transplant and the rest of the family, for example, that additional tests on the prospective donor revealed a compatibility problem or some evidence that the donor might be putting her own health at risk.

What's next, I wondered? I couldn't imagine asking friends or colleagues to donate; it was too momentous a request. Not because the risks are great, but because the idea scares the hell out of a lot of people. Also, the recent drama with my friend was a potent reminder of just how suffocating a lifelong obligation might be. Maybe when I began to feel really ill, I would force myself to ask. But not now.

The “tyranny of the gift” is an artful term coined by the medical sociologists Renée C. Fox and Judith P.

Swazey to capture the way immense gratitude at receiving a kidney can morph into a sense of constricting obligation. In their 1992 book, "Spare Parts: Organ Replacement in American Society," the authors write, "The giver, the receiver and their families may find themselves locked in a creditor-debtor vise that binds them one to another in a mutually fettering way."

I had read of a brother who was so overwhelmed by feelings of obligation that he could "not even stand to look at" his donor sister. And I was also aware of the lengths people went to to avoid the vise: the son who refused a kidney from an overbearing mother, telling his surgeon, "She's devoured enough of me already"; the young man who chose to remain on dialysis rather than accept a kidney from his long-term girlfriend lest he be forced to reciprocate by marrying her.

Maimonides, the 12th-century Jewish physician and philosopher, believed that anonymous giving was nobler than charity performed face to face because it protected the beneficiary from shame or a sense of indebtedness. He was onto something. I ruminated constantly about what it would mean to be related to someone "by organ." Would my future donor assume a proprietary interest in how I lived my life, since she had made it possible? Would she make sure I was taking proper care of "our" kidney or lord her sacrifice over me? Or would I hold it over my own head, constantly questioning whether I might have said or done anything that could offend or disappoint my donor, anything that might be taken as ingratitude? How could a relationship breathe under such stifling conditions? It was exhausting to think about; I wanted no part of a debtor-creditor relationship. I didn't want a gift, I wanted a kidney.

Naturally, I was preoccupied with the ways in which the gift might tyrannize me, but for every patient who wonders, "Do I want to accept?" there are many more prospective donors who ask, "Do I want to give?" News that a patient needs a transplant quickly leads to anxious glances among relatives, wondering who the future donor will be. "I and others had seen refusal of donation lead to ostracism within a family or donation made as a reluctant sacrifice to someone for whom there was little or no affection," wrote Thomas E. Starzl, the pre-eminent transplant surgeon, in his memoirs. "If a prospective donor was deficient in some way, usually intellectually, the family power structure tended to focus on his or her presumed expendability." This so troubled Starzl that he stopped performing live kidney transplants in 1972.

Donors can have their own agendas, too. The academic literature on donor [psychology](#) offers many examples, like a man who sought the adulation of his community by offering a kidney to his minister, a daughter who competed with her own mother to be the rescuer of another family member and a woman who told researchers that her motive for wanting to give a kidney to a stranger was to become "Daddy's good girl." Then there is the "black-sheep donor," a wayward relative who shows up to offer an organ as an act of redemption, hoping to reposition himself in the family's good graces. For others, donation is a sullen fulfillment of familial duty, a way to avoid the shame and guilt of allowing a relative to suffer needlessly and even die.

By comparison, friends are better insulated from emotional pressures; their compassion is less likely to be tinged with obligation, let alone tainted by it. And the rare Good Samaritan donor who cold-calls a transplant center to donate to the next suitable person in the queue, not even knowing who will get his kidney, surely embodies the purest form of altruism. In the end, though, people who don't want to donate usually manage to extract themselves. They miss appointments for screening tests or just drop out of the process.

People who actually do become donors, however, usually regard it as a supremely gratifying experience: they were given a blessed opportunity to save a life, a chance that relatives of a dying [cancer](#) patient can only dream of. I've read of siblings jousting to give an organ to a cherished parent and of adult children who were heartbroken when doctors ruled them out on medical grounds. According to a review of published surveys on donor attitudes by Mary Amanda Dew, a psychologist at the University of Pittsburgh Medical Center, about 95 percent of donors say they would do it again. Most experience a boost in self-worth and enjoy feelings of deep purpose, while only a small minority regret having donated or report that their relationships with recipients changed for the worse.

From my medical training, I was familiar with some of the ins and outs of end-stage renal disease. I had an especially morbid dread of dialysis. The playwright Neil Simon received a kidney from his longtime publicist in 2004 — “The Odd Donor Couple,” as *The New York Times* put it — but before that he endured 18 wretched months on dialysis, suffering cramps and [vomiting](#) spells that kept him largely confined to his house. His [memory](#) deteriorated, and he hated the time away from his writing. Shortly before his donor came forward (unsolicited, it should be noted), Simon's doctors said he might have to start spending more time on dialysis. If that were necessary, he said, he had decided, “I didn't want to live my life anymore.” Neither, I thought, would I.

It is possible that I was overestimating how miserable I would be on dialysis. An avalanche of psychological data shows that people are far better at handling adversity when it actually befalls them than they expect they will be. Still, I was quite sure I would flout the longstanding evidence attesting to human adaptability. On dialysis I would be disconsolate and maybe even [suicidal](#) if the wait for an organ were to stretch for years. As dispiriting, I would lose all my friends. Not that I expected them to abandon me. I would abandon them out of anger for not rescuing me.

By the end of the summer of 2005, a year after the diagnosis, there was no donor in sight. I was mentally preparing myself to undergo the standard predialysis operation to create “access” to the machine. A vein and artery in my arm would be joined to create a large superficial vessel for the insertion of needles and tubing that would carry my blood to and from the machine. I resisted, but I knew that soon I wouldn't be able to put off dialysis any longer.

The “tyranny of the gift” now took on a new meaning for me. It was no longer about moral debt; it was about the very fact that an organ had to be a gift, about the tyranny of the system. I heard of people trying to persuade strangers to give them organs. They put up bulletin boards or started Web sites ([GordyNeedsAKidney.org](#), whose opening page carried the plaintive headline, “Please Help Our Dad”). I flirted with the idea of becoming a “transplant tourist” in Turkey or the Philippines, where I could buy a kidney. Or going to China, where I would have to face the frightful knowledge that my kidney would probably come from an executed prisoner. Grim choices, but I was afraid I could die on dialysis if I didn't do something to save myself.

In October 2005, I stumbled across a Web site called [MatchingDonors.com](#) that helps link potential donors and recipients. Once a match is made, the process follows the standard path, with physicians at a transplant center determining whether to proceed. I was given space to describe myself and to post photos. I read a few of the requests. There were parents wanting to see their young children grow up; a new husband hoping to

have children with his wife before her kidneys failed; a 70-year-old grandmother yearning to see her only granddaughter get married.

My God, how could I possibly compete with these people? I wouldn't leave children motherless or miss the milestones of life; were I a prospective donor, even I wouldn't have picked me. I took a minimalist approach to my statement, hoping it would attract a no-nonsense donor who appreciated reserve. I wanted to stand out as the "applicant" who wasn't begging; no emotional blackmail here. Of course, I would have poured out every detail of my moribund state most operatically if I were living on dialysis or near death. I thought of boosting my stock by mentioning that I was a psychiatrist at a methadone clinic, but the prospect of heroin addicts bereft of their shrink might not conjure a poignant Hippocratic tableau. In the end, I simply wrote: "Type A blood. 49 yr old female physician . . . idiopathic kidney failure. Otherwise healthy. Aug 2004 discovered [chronic renal failure](#) during routine blood test. [BUN](#) 80, Cr 7. Not yet on dialysis. Doctor predicts organ would be needed by Jan. 06."

Three days later, the Canadian called. He told me he considered becoming a donor five years ago when he heard through his church about someone who was failing on dialysis. That was the most personal thing I ever learned about him. Well into November, we were in regular contact, yet our phone calls rarely lasted more than 10 minutes. He asked about my health, and we would talk about logistics — whether my insurance would pay for his tests, whether he could take time away from a project he was working on and so on. I ended the calls blubbing with gratitude, and he would tell me to stop.

Although the Canadian seemed kind and steady, he had enormous power over me. I deliberately kept our calls brief to minimize my chances of saying something that might antagonize him. I wondered why he chose me, but I dared not ask, lest his decision was based on a misconception of who I was. Would I then be morally bound to set him straight so that he wasn't giving a body part under false pretenses? What if he loathed conservatives? After all, he was involved in politics, and I was associated with a right-of-center think tank.

This is ridiculous, I told myself; a person whose inspiration to donate is forged in church is surely above partisanship in such matters. Still, until both of us were snug in our adjoining operating rooms, I could never relax — everything was tentative, conditional and prone to collapse. I prayed the Canadian wouldn't talk about his decision to donate (and the identity of his recipient) with his family or friends. They could look me up online and not like what they saw or think I wasn't sick enough to warrant heroics on his part or turn him against the idea of donating altogether.

Yet from what I could tell, the Canadian's only agenda was the act itself. Had I detected any hint of ambivalence, I would have cut him loose immediately, since each false hope ate up irreplaceable time. But, it turned out, I misread him. About a week before Thanksgiving, the Canadian went dark. By then I was fatigued most of the time and fluid was pooling in my ankles. I took four antihypertensive drugs a day and had injections of a hormone that stimulated my body to make more red blood cells. Dialysis was closing in.

Around Christmas, the Canadian finally called. The conversation went as if nothing had happened. I didn't dare ask about his silence; instead, I forced myself to sound upbeat and touched on the few things I knew about his life: that he was volunteering on a political campaign and that his father had been ill. He swore he

was still “raring to go with the transplant,” which my transplant coordinator, a young woman named Julie, had tentatively scheduled for January. I wanted to press him for a firmer promise, but I worried that if I betrayed my irritation, he might be offended: “That’s it!” I imagined him saying, just before he slammed down the phone like a twisted character in a “Seinfeld” episode. “No kidney for you!”

A few days later, Julie contacted him. Straight-talking and bright-eyed, Julie spoke to the Canadian in a way I could not. “We need to know how to proceed,” she told him firmly. “There is no time to spare. Can you be here in January for the surgery?” He conceded that the campaign he was working on was too unpredictable. Julie said he seemed to feel genuinely bad about renegeing, but he did not tell her to convey that disappointment to me, and I never heard from him again.

I was astonished at the Canadian’s . . . what? Negligence, cowardice, rudeness? It was a sickening roller-coaster ride: hope yielding to helpless frustration, gratitude giving way to fury. How dare he reduce me to groveling and dependence? Yet I assume he intended no such thing. I think the Canadian was actually quite devoted to the *idea* of giving a kidney — just not necessarily now or to me. Then, again, it occurred to me that one of the most brilliantly cruel games a sadist could devise would be to promise an organ with the plan of later snatching it away.

The Canadian knew that I was relying on him, that I suspended my donor search when we settled on a date for the transplant. At the very least, he owed me an apology — not so much for backing out, although by now I was frantic over that, but because he led me on for weeks. And would have continued doing so had Julie not pushed him. The truth, naturally, was that I had no right to anything of his, let alone something so absolutely and intimately his as a kidney. Who could dare to presume — or even appear to presume — that his kidney was meant for me? I was thoroughly confused about how entitled I was to hate him. Meanwhile, my kidneys were deteriorating, and I didn’t have time for more cycles of commitment, silence and rejection.

Salvation came out of nowhere. In early November 2005, a few weeks before the Canadian withdrew, I received an e-mail message from a friend — a fond acquaintance really — whom I knew from the think-tank circuit. “Serious offer” was the message in the subject line. It was from Virginia Postrel, a 45-year-old author and journalist. (She has written for the business pages of *The Times* and for this magazine.) Known for her original mind, she is especially popular within libertarian intellectual circles. Virginia ran into a mutual friend at a meeting, who told her about me, and she sent an e-mail message within days: “If I’m compatible, I’ll be a donor. Best, Virginia” Two weeks later, she sent this: “By the way, I absolutely promise you that I will not back out.” Intuitively, she had grasped the golden rule of responsible donorship.

Mercifully, Virginia was the right blood type; even better, she was the right personality type. In early March, four days before our operations, she came to D.C. from her home in Dallas. On March 4, 2006, I became the proud owner of Virginia’s right kidney. She was out of the hospital after three nights; I was home after seven; our recoveries were uneventful. I require no drugs except medication that prevents my body from rejecting the new organ.

Though Virginia never before gave blood or even signed an organ donor card, the decision to donate, she told me, was quick and sure: “I felt intense empathy and imagined how desperate you must feel,” she said. “I liked the idea of being able to help in a straightforward way — to be able to cure a sick friend rather than just bring

food or send a card.

Virginia was the perfect donor for me. For one thing, she lives far away. She also has an ingrained respect for personal privacy. She never suggested that I might owe her a thing beyond the extraordinary gratitude that decency demands. And she is bracingly pragmatic. “I have a very instrumental view of my body,” she told me, “so when you needed a part, I was happy to give it. I knew you had no family. I wouldn’t have done this for a stranger, but I would do it, I *did* do it, for someone I cared about even though we weren’t close.”

My story, it turns out, is a triumph of altruism. Looking back, I see that my anxiety over my future donor was a neurotic luxury. I worried about finding the ideal donor, but thousands of people have no donor at all — no relative who will do it out of love or obligation, no friend out of kindness, no stranger out of humane impulse. Alas, I have no kidney to give away. Instead, I am urging wherever I can — in articles, in lectures, from assorted rooftops — that society has a moral imperative to expand the idea of “the gift.”

Altruism is a beautiful virtue, but it has fallen painfully short of its goal. We must be bold and experiment with offering prospective donors other incentives for giving, not necessarily payment but material reward of some kind — perhaps something as simple as offering donors lifelong [Medicare](#) coverage. Or maybe Congress should grant waivers so that states can implement their own creative ways of giving something to donors: tax credits, tuition vouchers or a contribution to a giver’s retirement account.

In short, we should reward individuals who relinquish an organ to save a life because doing so would encourage others to do the same. Yes, splendid people like Virginia will always be moved to rescue in the face of suffering, and I did get my kidney. But unless we stop thinking of transplantable kidneys solely as gifts, we will never have enough of them.

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