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Organ Donation Has Consequences Some Donors Aren't Prepared For

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by GRETCHEN CUDA-KROEN



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July 2, 2012

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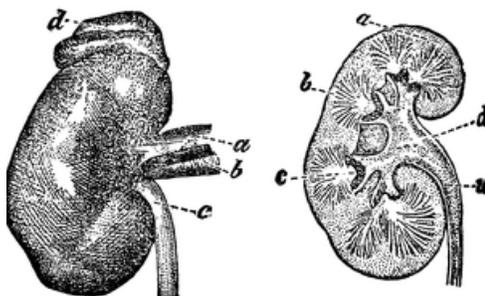
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Most living kidney donors return to their daily lives in a matter of weeks, but for some, unforeseen physical and financial complications arise.

Nearly a year and a half ago, Jeff Moyer [donated a kidney](#). It's something he says changed his life forever. "Transplant surgery is a miracle," marvels Moyer. "I mean, to think that my kidney [saved someone else's life](#) — that's staggeringly wonderful."

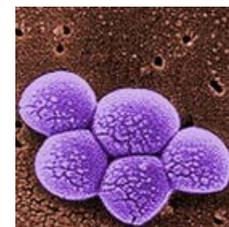
His reaction is surprising given all he's been through. Like most surgical patients, when Moyer awoke, he was in a lot of pain. He was reassured that the post-surgical pain was normal and he'd be back on his feet again in a couple of weeks. But weeks, then months went by. His scars faded, and the pain didn't.

Today, Moyer says he has daily pain that leaves him virtually doubled over. It has affected his relationships and his ability to work. And yet doctors tell him they can find nothing wrong.

It's a story familiar to Vicky Young, who donated her left kidney to a friend seven years ago, only to develop kidney disease herself.

"All of a sudden I'm plummeting down to stage III chronic kidney disease, and that scared the hell out of me," says Young.

Moyer and Young represent only a small fraction of donors, but donors like them say they were [unprepared financially](#) and emotionally for the prospect of lifelong health problems. And they are frustrated by a transplant system that is primarily focused on the organ recipient, but isn't prepared to care for donors.

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Young's kidney function eventually improved, but like Moyer, she suffered from chronic pain, numbness in her left leg and groin complications she says no one ever told her could happen.



[Enlarge](#) Gretchen Cuda Kroen/NPR

Jeff Moyer suffers from chronic pain. He says the pain began after he donated a kidney a year and a half ago.

"Death, pneumonia, blood clots — that was what I was told, so I didn't think that there would be anything else," Young recalls. "I figured if I was in the hospital and didn't have a blood clot, didn't have pneumonia and was still alive, then I was going to be fine."

Young eventually discovered that her symptoms were a result of nerve damage during surgery, but it took her years and she estimates as much as \$15,000 in out-of-pocket medical expenses to get a diagnosis.

Moyer and Young's experiences aren't typical. More than 100,000 people have donated a kidney to a friend, family member or stranger in the six decades since transplantation became possible. Most of them return to their daily lives in a few weeks — and have few if any complications.

"I don't think the transplant community really respects donors as individuals that are going to be impacted by this," explains Moyer. "We're sort of treated like living cadavers."

Donna Luebke, a former nurse who donated a kidney to her sister in 1994, now works as an independent donor advocate. She says there's no way to really know how many Jeff Moyers or Vicky Youngs there are — no one is keeping close track.

Living kidney donations have been successfully performed since the 1950s, but it wasn't until 2006 that the [United Network for Organ Sharing](#) began asking transplant centers to report on the health status of its donors. According to reports by the [Organ Procurement and Transplantation Network](#), however, transplant centers have lost track of more than one-third of their donors one year after their donations, two-thirds by two years, on average. Furthermore, few centers report any laboratory results on their donors, and some centers consistently fail to report any data at all. That's something Luebke says is unacceptable.



[Enlarge](#) Gretchen Cuda Kroen/NPR

Vicky Young (left) with her mother. Young developed kidney disease after donating one of her kidneys to a friend seven years ago.

"I think that, as donors taking this risk, we deserve the highest scientific standard, and that means data — and they don't have data," says Luebke. "I'm sort of tired of hearing that donors are fine. You can't tell us that, because you don't know."

Some argue that many donors simply don't return the forms — and that the cost of tracking down all of their donors and maintaining their records is prohibitively expensive. But critics say they can and should do better.

[Lainie Friedman Ross](#), a physician and professor of bioethics at the University of Chicago, has been outspoken about the

need for a similar national comprehensive registry of kidney donors.

"I think it should be morally required," says Ross.

Ross says the consequences of organ donation might not be apparent for decades — and the risks are not the same for everyone. Young or minority donors have a higher rate of kidney failure than the general population.

Additionally, transplant centers are increasingly willing to accept donors that are older, obese or have high blood pressure. And while Ross says that doesn't necessarily mean they shouldn't be donors, getting long-term data can help answer questions about how these donors will fare.

"We need to be able give more particular information to living donors. It's not just 'On average, two out of 1,000 go into kidney failure'; it's 'What is my risk as a potential kidney donor?' " says Ross.

The [Living Organ Donor Network](#) has proposed a solution: an insurance policy that also tracks donor health. The policy costs a one-time fee of \$550 and has been around for more than 12 years — yet few donors know about it.

Thomas McCune, a kidney specialist who directs the program, says only six of approximately 260 transplant programs [currently cover](#) all of their donors with the insurance policy, in part because drawing attention to the small but real risks of donation might scare people away.

"Transplant programs are comfortable with the idea that, well, we've never had this problem before, or it's so rare that we don't really have to worry about it, when in fact every single donor who walks into a transplant center needs to worry about these potential complications, including the possibility that they could die. It's very rare, thank God. It hasn't happened that often. But it has happened," says McCune.

Case in point: the kidney donor and young mother who died on the operating table last month at [New York's Montefiore Medical Center](#) after her aorta was accidentally severed during surgery.

Surprisingly, almost every donor asked — even donors with complications, like Jeff Moyer — say they have no regrets. They simply want to make the system better.

"It's among the most important things I have ever done in my life," Moyer says. "And I would do it again."

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Recent First



Don Gillam (dgg) wrote:

I hate it that I am this selfish, but I really don't want anyone taking parts of my body as long as I might need them myself. When I'm dead, you can take anything of value, I don't care.

Monday, July 02, 2012 12:06:45 PM

[Recommend \(0\)](#) ↑

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kay pett (keekee) wrote:

@Elizabeth

No, you are criticizing people as evidenced by your angry post. You hold those who donate above those who don't. But you also miss the point. People who are not willing to put themselves in harms way for a person who expects just that, are no less a part of "humanity" than people who do.

There is a lot of bullying in the organ donation business and some people resist and it doesn't make them any less a part of "humanity" than others.

You did what was right for you. Fine, good for you. But you slam others who question the wisdom of living organ donations and the ethics of it.

So you do in fact consider your choice to be superior as much as thou protest to the contrary.

Monday, July 02, 2012 12:05:48 PM

[Recommend \(0\)](#) ↑

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Pam Silvestri (sparkledakota) wrote:

I donated a kidney a year and a half ago to a good friend, and we're both doing great...we also both take care of ourselves at an extraordinary level, which is our own responsibility. The hospital did every imaginable test on me to be sure I was a good candidate. Any potential medical risks were assessed and I was advised. Yes, I agree good docs and support are important, but I also think potential donors need to bear some responsibility. I've seen potential donors pushing to donate when they knew their health was not sufficient. And I've seen potential donors pushing docs to transplant someone who clearly was not a good candidate. There is a lot of pressure on transplant hospitals to have near perfect outcomes, and there is a lot of pressure from families to save all lives at any cost. The potential donor should do research and should interview the transplant team to be sure they support and follow donors. Not every hospital is a top hospital...for any procedure. But if someone you love needs a transplant, or if you do, then this becomes more real to you and you may change your thought process.

Monday, July 02, 2012 11:53:04 AM

[Recommend \(1\)](#) ↑

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Elizabeth Walsh (TrixieinDixie) wrote:

Again -- so sad to see that someone who writes (brags?) "I'm entitled" gets recommended 7 times.

It's hard to have faith in humanity when people are so willing to belittle the decisions of others. I clearly stated that my decision was right for me -- I am not at all critical or disapproving of others who make decisions that are right for them. I only ask the same respect.

Monday, July 02, 2012 11:51:17 AM

[Recommend \(0\)](#) ↑

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kay pett (keekee) wrote:

@Aimee, as a mother, I cannot imagine in a million years, expecting one of my children to put themselves in harm's way to save me. I'm sorry, but maybe it's just her time. For her to expect you to do that is selfish.

The medicos will minimize the risk but they will inflict what amounts to a gunshot would on

your liver. Most likely you will never really be the same.

It's a shame you've been put in such a position by your mother.

Monday, July 02, 2012 11:44:59 AM

[Recommend \(1\)](#) ↗

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Rebecca King (RebeccaKing) wrote:

I am an organ donor. Of all the things I've done, this is among the ones that make me most proud. I *was* informed that I could have serious consequences, including death. It did not change my decision to donate, because I can handle pain, but I cannot live the rest of my life knowing I was too much of a coward to help someone's infant survive. Even if I had known I'd have complications (which I did not), I would have chosen to do it regardless.

I do think that compiling solid information about donors is critical, because if more substantial chances of consequences exist, donors should give INFORMED consent. The "informed" part is critical.

I respect the choice of anyone to donate or not, but for those who criticize the people who do--shame on you! I hope you never have to beg a doctor for your child's life and no one will help you. It is my sincere hope that one of the generous people who you criticize today will help you. I wish that no one would ever be in that situation, because it changes your perspective with lightning speed.

Monday, July 02, 2012 11:44:12 AM

[Recommend \(5\)](#) ↗

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Claudia Harrison Hall (claudzilla5) wrote:

jen schiff - you say the article is terrible because it scares people away from donation. I think if you read it carefully, you can see that the risks of these consequences are very low. the article is informative about the realities, and urges people to ask questions, while also highlighting the need for a better way to follow-up with donors after surgery. The fact that some folks are taking away only the negative is not the fault of the article. Being informed is better than ignorance, isn't it?

Monday, July 02, 2012 11:44:10 AM

[Recommend \(2\)](#) ↗

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kay pett (keekee) wrote:

@David "LifeSharers is a non-profit network of organ donors who agree to offer their organs first to other organ donors when they die . . ."

Uh, it's organizations like yours that put me off organ donation. First of all, since when are dead donors or their families considered when parceling out organs? Can donors designate organs? Really? Because my understanding is that providers have some bizarre, nonsensical system for prioritizing organ donations. A neighbor of mine received a kidney when she was 76 years old. Somebody explain that one to me.

I personally would take to my front porch with a beer when I got the news, instead of clawing and scratching to live by undergoing organ transplantation. So I don't care if I get an organ. I also have no intention of being a donor in a system that is as dysfunctional as the medical industry where a person like Dick Cheney gets a heart at 72 years old.

Explain to us our your registry is enforceable please.

Monday, July 02, 2012 11:37:38 AM

[Recommend \(2\)](#) ↗

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Amanda Brown (amanduhb) wrote:

"You are noble. I am not. I'm entitled....it does not make me a lessor person." I would argue that it does. That's why people who are willing to face risks and dangers to save strangers' lives are called "heroes", not "people who aren't any better than the lessor people who just stood and watched". I'm perfectly fine with people not wanting to take part in organ transplants, for whatever reason. But when you repeatedly insult sick and dying people while simultaneously talking about how you're "entitled" to respect even though you chose to insult rather than help...well, you just kinda look like a jerk.

Monday, July 02, 2012 11:35:28 AM

[Recommend \(0\)](#) ↗

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Lisa Bloomquist (Bisa) wrote:

The pain that Mr. Moyer is suffering from MAY (emphasized, because I don't know his medical history at all) be due to the antibiotics that he was given during or after the surgery. Fluoroquinolone antibiotics (common brand names are Cipro, Levaquin and Avelox) can have SEVERE neurological side-effects including chronic pain, anxiety, weakness and tendon problems, especially when taken with NSAIDs (ibuprofen, aspirin, etc.). These severe side effects can occur weeks, even months after the patient has taken the antibiotics. For more information, look up "PBS and Levaquin" to see a horribly scary story. The negative adverse reactions that are possible with this class of antibiotics is largely unacknowledged by the medical establishment and tests will show that everything is "fine." However, the pain, weakness, anxiety, etc. is real and can be debilitating. I know that this story isn't about antibiotics, and my intention isn't to detract from the issue, but it is a possible reason why some people suffer severely after a major surgery such as organ transplant surgery.

Monday, July 02, 2012 11:32:27 AM

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community host

Scott Hensley



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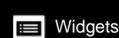


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