

The Kindness of Strangers
And the Cruelty of Some Medical Ethicists
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Imagine you are hooked up to a machine three times a week for hours at a time. The machine extracts deadly bodily toxins from your blood that your kidneys can no longer clear themselves. You come back from these dialysis sessions exhausted and depressed; meanwhile, dialysis itself takes a toll on your heart and generally shortens your lifespan.

This is the life of Lisa Cunningham, a 40-year-old mother and former social worker who lives outside of Boston. Her kidney failure was caused by Type 1 diabetes that she's had for years. Her only hope for better health and the semblance of a normal life is a kidney transplant. Until then she must continue to wait on the national list--which pairs deceased (cadaver) donors with potential transplant recipients--for at least five more years, because the demand for organs far outstrips supply. Lisa tells me her doctor says she might not live five years.

Many people in this position turn to living donors. Such donation is possible because people have two kidneys, and a healthy person can lead a normal life with a single good one. Lisa turned to relatives, but they too had diabetes or wanted to preserve their kidneys in case their children developed it. She was desperate.

So when Rob Haneisen, a reporter at the *MetroWest Daily News* in Framingham, Mass., who has written about people in situations like hers, asked Lisa if he could interview her for a story, she jumped. Perhaps former colleagues, long lost friends, or a Good Samaritan would read about her and volunteer to donate. Lisa had even begun coordinating with Beth Israel Deaconess Medical Center to prepare for a transplant, should a donor come forward as a result of the News article that ran on April 16.

Enter Dr. Douglas Hanto, head of the transplant division at Beth Israel. He had heard about Lisa's circumstance when Haneisen called him for an interview as part of the story. Before speaking to the reporter, Hanto had his staff phone Lisa right away to deliver shocking news: Beth Israel would flatly refuse to do her transplant if the only donor she could find was a kind-hearted stranger who responded to the article.

"We are in favor of donors coming forward and donating to the next person on the waiting list," Hanto told Haneisen. And how many have done that so far over the years, the reporter asked? "Just a couple," Hanto admitted. Also puzzling is Hanto's assertion: "We have hundreds of people on the waiting list. If we support some favored status for one patient, how can we really say we are being fair and looking out for all our patients?"

The fact is that Lisa harms nobody if a stranger responds to her story and comes to her aid. In fact, she helps people on the list because she is taken out of the cadaver-waiting queue and others can move up.

The real story here is the sorry state of the waiting list, maintained by the nonprofit United Network for Organ Sharing (UNOS) under a monopoly contract with the Department of Health and Human Services. About 92,000 Americans are on the list, most waiting for kidneys, yet only one-fourth will receive transplants within the next year. Eighteen people die every day because they have not found a donor in time.

That is why Lisa and so many like her have resorted to public notice or have joined websites aimed at pairing recipients with altruistic strangers who go online in the hope of literally saving someone's life.

I know because I appealed to one of those websites. In 2004, I learned I had end-stage renal disease, and in order to stave off dreaded dialysis (which my doctor predicted would be necessary within a year or less), I searched for a donor. I have no siblings, and friends did not pan out, so last fall I turned to a website, MatchingDonors.com. The site is supported in part by fees from patients who post their profile. A 30-day membership, for instance, costs \$295. But fees can be waived with a showing of financial need.

As I investigated web-based donation in general, I was stunned to read of Hanto's stance. As a member of UNOS's ethics committee, in addition to his Beth Israel appointment, Hanto is quoted regularly on the topic. For example, I read about him in the tale of Alex Crionas. Alex was on dialysis in Orange City, Florida, and started his own website in 2004 to attract potential donors. Hanto was appalled. During his tenure as head of the ethics committee at the American Society of Transplant Surgeons in 2004, he went so far as to ask its members to boycott privately arranged transplants.

Hanto is not a lone obstructionist. Arthur Caplan, bioethicist at the University of Pennsylvania, told the *News* that web-based donation and ads amount to a "high-priced begging campaign," and he disapproves. After all, he says, such efforts comprise an "attempt to subvert the waiting list." Benjamin Hippen, a transplant nephrologist in North Carolina, believes this concern sidesteps a crucial issue. It is the broken system that makes "begging" necessary.

"A commitment to equal treatment is key to maintaining our patients' trust," Hippen says, "but if recipients view the waiting list as simply an equal opportunity to die, we will lose that trust, and deservedly so."

New York University medical center is another place that refuses to perform transplants for patients who meet their prospective donor through *MatchingDonors*. The staff fret, incredibly, over the fact that some people have the means to afford Internet access and others don't. Never mind that these days almost anyone can get access for free at a public library. The message is clear: A slowly dying patient must not take any initiative to save

his own life, even though the status quo, inexplicably extolled by Hanto and others, is pitifully inadequate.

Good news for Lisa came just days after *MetroWest Daily News* ran her story. A woman with the same blood type--the only requirement for a healthy, interested donor--told Lisa she would give her a kidney. Now the two are going through the required medical testing for the transplant--at another hospital. (Good news came for me when a generous friend heard about my situation and proved to be a good match.)

This is a blessing for Lisa, and for those behind her on the waiting list. But tens of thousands still languish on the list. We need imaginative pilot projects that increase the number of organs for the purpose of saving lives. The stewards of the waiting list should learn something from initiatives like *MatchingDonors.com*--not decry them. We need physicians and bioethicists with better ideas about extricating us from a system that lets people needing organs die every day. Dr. Hanto should welcome the next Lisa and thank the kind soul who offers her a kidney, not lock the doors of his operating room to keep them out.

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