

What happens when a living kidney donor needs a transplant?

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Becoming a living kidney donor can be a heroic act, but it has its downsides: increased risks of health complications and occasionally, diseases that may create the need for the donor to have a kidney transplant later in life.

In recognition of these possible consequences, living [kidney donors](#) who are in need of a transplant have, since 1996, been given priority status to shorten their time on the waiting list.

But according to a study published Thursday in the *Clinical Journal of the American Society of Nephrology*, prior living donors do not always receive that priority status in a timely manner. Some had to wait for years and go through dialysis before moving to the front of the line - while some possibly never got to priority status.

"This is a big deal to donors and the transplant community," said Jennifer Wainright, an analyst at the United Network for Organ Sharing research department and the study's lead author. "Living kidney donors should know that they are entitled to priority ... if they ever need a kidney, and also that most prior living donors receive their transplant quickly."

Wainright stumbled upon this issue when she was examining data on donors, wait-list candidates and transplant recipients from the national Organ Procurement and Transplantation Network for another project.

"We put the original project on hold, explored the data, and figured out a way for UNOS to help transplant programs try to prevent the problem in the future," she said.

The researchers sought to characterize how quickly prior living donors were added to and activated on the transplant list. They studied data related to living donors and their transplant needs from January 2010 through July 2015. During that period, 210 [transplant candidates](#) who were prior living donors with priority status were added to the transplant waiting list. As of Sept. 4, 2015, 167 of them received deceased [donor](#) transplants, six received living donor transplants, two died, five were too sick for transplants and 29 were still waiting.

Because of the "priority" designation, most of these patients were able to receive transplants quickly, the study found. But a number waited a long time.

For example, among the living donors studied, only 40.7 percent were added to the transplant waiting list before they needed dialysis, which is a treatment that becomes necessary when the kidneys are no longer functioning optimally. Half of the patients in the study were on dialysis for 332 days or longer before their priority was recognized.

The process of requesting the priority status goes like this: If a prior living donor needs a [kidney transplant](#), the transplant program at the hospital will submit information and contact the UNOS Organ Center to request priority. The center is supposed to complete the request within a day. Patients healthy enough to receive the transplant immediately will be listed in an active status.

The reasons for the delays in this process detected by the study may be, in part, due to a patient's ill health or to paperwork and bureaucratic problems. These can include incomplete data submission and insurance

issues, or a lack of awareness among patients and transplant programs about living donors' priority.

In an effort to smooth out the process and raise awareness among living donors and transplant programs, UNOS since last year has linked their list of living donors with the current kidney waiting list. The goal is to identify transplant candidates who were living donors but have yet to receive priority status. UNOS will then contact the person's transplant program to see that the situation is addressed.

But there are limitations to the data collection. The data tracking living donors only goes back to 1987, and have only included Social Security numbers since 1994. If a person donated a kidney before 1994 and changed his or her name, UNOS wouldn't be able to identify the person - thus still missing prior living donors who may have not been informed of their priority status.

Another solution Wainright identifies is ensuring use of the current Organ Procurement and Transplantation Network policy that requires transplant programs to inform living donors about their priority on kidney waiting lists if they need a transplant after donation.

Between Sept. 2, 1996, and July 31, 2015, a total of 422 living donors were added to the kidney [transplant](#) waiting list. According to the National Kidney Foundation, being a living kidney donor is relatively common - there were 5,538 living kidney donors in 2014 compared with 7,761 deceased donors. Living donors may face a 25 percent to 35 percent permanent loss of kidney function after donation on average, but their risks of getting end-stage renal disease is less than 1 percent 15 years after the donation.

Peter Reese, assistant professor of medicine at the University of Pennsylvania School of Medicine, said his center always makes sure the

[living donors](#) know about their right to a priority status. He was not associated with the study.

"If you tell [kidney](#) donors that, they will remember," he said. "I'm surprised by this UNOS data, I think it's a shame that centers are not getting their donors registered in a timely way."

More information: Delays in Prior Living Kidney Donors Receiving Priority on the Transplant Waiting List, [DOI: 10.2215/CJN.01360216](https://doi.org/10.2215/CJN.01360216)

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