



Are You Afraid to Be an Organ Donor?

Don't be led by fear. Get the facts.

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You know how many of us act when the subject of organ donation comes up—particularly when there are older people in the room. It's often a swift and negative series of comments out of fear and general distrust of doctors. Stories of unethical experiments from darker times in history where Blacks unwittingly were misused and abused by science and medicine have left some generations gripped with fear for what could happen if they let their guard down.

Loretta Jenkins knows that fear all too well. When her husband Lee, 54, was on the verge of having to go on dialysis because his kidneys were totally gone, she decided to become a living donor. On the day of the surgery, her 70-year-old aunt was terrified about what could happen.

"We arrived at the hospital early, in the morning. My aunt called into my room. She was so upset. I was trying to tell her that it's okay, that I have to do this. I have to save my husband. My children need their dad. I can restore him. She was like, 'I'm so scared.' She almost wanted to say I shouldn't do it. But me and my husband have been together 28 years and she knew how I would have felt had she said it. But she said, 'I wish you could wait because I'm not there,'" recalled Loretta, who said her aunt was afraid that something would happen to her by donating. "It's a big thing with Black people. They think that they shouldn't donate or if you go to the hospital, they're going to take more than they should. They think they won't try to heal you, so they can take your organs, and it's not like that at all."

Pam Graves, 51, can relate. Her name was on the organ donor list for a long time, but she just took it off last November when she renewed her license.

"After my father died and I saw how my family was during that time, I thought they would fight it or be upset if I did it [donated organs]. Nothing bad happened, but the elders are old school tradition-

al. They'd consider it extreme," said Graves, whose father died in 2014. "Organ donation would be out of the question for them. My father's family always seemed to be worried that someone was going to take something from them or do them wrong. I think it was a trust thing ... didn't trust doctors or 'the system.' He was definitely a product of his era."

So, with fear holding us back, what are we to do to support our community when, of the 4,345 people waiting for an organ in Illinois, 1,630 are Black, according to the U.S. Department of Health and Human Services. That's more than any other ethnic group in the state — even White people, who aren't that far behind at 1,542. The situation is especially jarring when you consider Blacks only make up 14.7 percent of the population in Illinois, according to the most recent census. Experts do say we can improve those numbers with better education about organ donation. But even with extensive outreach, there's still the very real issue of trust among Blacks and the doctors who want to serve them.

Dr. Dineen Simpson, an African American transplant surgeon at Northwestern Memorial Hospital, says the onus is on the medical community to do a better job of explaining things to patients and making sure they understand their disease, all of the options, and the risks and benefits of those options.

"I've been a patient. I know what it's like to fear the unknown. What's going to happen next? What's going on with me or with my family member? What is available out there to help? When those options are explained to you, your mind is swimming with all sorts of questions and it's a lot to take in," said Dr. Simpson. "Trust is definitely a two-way street and I implore the patients and their families not to shut the door on hope because of fear. Don't just stop because you're afraid and not pursue [organ donation]. Ask questions -- ask as many questions as you need to ask to understand fully what is going on with you or your loved one or your friend. There is a lot of misinformation out there



Loretta and Lee Jenkins participated in an organ swap.

that will perpetuate fear and myth and cheat someone out of an opportunity to pursue transplant and therefore prolong life. More knowledge means less fear and less fear makes it easier to be a partner in your own health care rather than a victim. Don't be afraid to advocate for yourself."

Weighing Your Options

People on the wait list for an organ can get one from a deceased person or from a living donor. To be a living donor, you don't have to be an exact match with the person you care about, you just have to be willing to donate your organ to someone else. That's the option the Jenkins couple chose.

"I put up my kidney in honor of my husband. If a match came for him, then he would get the kidney he needed, and then my kidney, which didn't match him, would go

to someone else that it matched, and we would cross swap on down the line. Actually, when my husband got his transplant so did several other people," Loretta Jenkins, 47, explained.

Jenkins' husband suffered from undiagnosed high blood pressure. He appeared young and healthy. But in the spring of 2011, he got really sick and couldn't hold anything in his stomach -- they thought he had the flu. When he kept getting weaker and weaker, it was time to head to the hospital. That's when they found out about his condition and learned that his heart and kidneys were declining. For the most part, he turned things around over the course of five years by eating better, exercising and taking medication. But his kidneys never did improve, and they knew it was time to look at other options or

face dialysis, which Lee strongly opposed.

"I heard a lot of bad stories about it. My wife's grandmother and her uncle were on it and it was painful and it drains you and you don't have the quality of life. It takes a lot of your time. It takes away a lot of the quality of your life," said Lee, who got on the list for the kidney swap in February of 2017 and by June of the same year, he had a donor and the surgery. "Everyone I know in the Black community knows someone who needs a kidney or they're on dialysis. I love the fact that the donor [in the swap] is saving two people as opposed to just the person who they're bringing to the table. They are saving someone else also. This should be a really big thing in the

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Pam Graves and her father, Lawrence, at her graduation from the University of Illinois.

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Black community. We should tell about that more on TV. People don't talk about that a lot. It's a non-invasive surgery. In one day, a donor could be back home. I was only in there two days."

Alece McFadden was diagnosed with diabetes at the age of 11. She knew that living a healthy lifestyle would keep her from having to undergo an amputation, need an organ donation or go on dialysis in the future. But she was young, and it was challenging to do so. Alece's blood sugar would spike, and she'd head to the hospital, but she didn't take warnings from the doctors seriously. When she got older and finally did start to take care of herself, it was too late. By age 26, her health was deteriorating rapidly.

Afraid of dialysis after seeing her grandfather endure it, she started learning as much as she could about her options, attending an event at the University of Chicago that gave her insight on what she'd need to do to get on the list for organ donation.

"My thing was, I did not want to go into dialysis unless my name was on the list. So, I had a great nephrologist who said it was just kind of up to [me], how I felt. I had no energy, and I was laying down all day, I couldn't get up. You can feel your body just dying. That's the way it feels. I just remember one day, when my mom and I went to



Alece McFadden

the planetarium and my name was already on the list at this time, and I was just like, "You know what? I think I'm ready."

After a few months of dialysis, her name started to move up on the list. But knowing that it could take around three years for someone like her to get an organ donation, she decided that it wouldn't hold her back.

"I'm like, 'Okay, well do you know what? I'm going to go to school, get my degree. I mean, I've got three days a week for four hours, I can study,'" said McFadden about her time in dialysis. She only had to wait around a year instead of the three she anticipated because she was a good candidate for a transplant -- young, healthy aside from the kidney disease, and a good weight. She got

the call, it was a good match and she had the procedure, receiving a kidney and a pancreas from the same deceased donor.

Life after Surgery

For Loretta and Lee, the surgery was life-changing. Lee says he's doing well, is happy, and back to his old self again.

"I see my husband every day, his skin color has changed. There's just so many changes from that kidney. The guy I gave my kidney to, he keeps in touch with me and he sent me a text saying he's traveling. He has amazing stories. He was his parent's only child and his mom died the day after Christmas, but she got to see her son get a kidney and he's been living life," said Jenkins.

McFadden, now 32, has had more challenges. At first, things were great. She was traveling to Europe and Jamaica. Got in a great relationship. Earned her bachelor's degree in social work from Northeastern University. But then a medication change had an adverse effect on her kidney and it started to fail. She has chronic kidney disease all over again. But she's anything but bitter.

"Now I'm getting my masters from Loyola. I graduate May 9th in mental health in social work. I want to do therapy with those who are on dialysis and help them make sure that they get everything that they need," said McFadden. "It's like giving back to pay it forward."

Organ Donation – What You Need to Know

Many of the more common questions about organ donation can easily be found online by going to websites like DonateLife.net, Unos.org, OrganDonor.gov, or GiftofHope.org.

To help, we asked Dr. Dine Simpson, the first Black female transplant surgeon at Northwestern Memorial Hospital, a few questions that may be myth-busters for Black people in particular.

Is race a factor in determining who gets an organ?

When I receive an organ offer for my patient, it's not generated based on race. White organs don't only go to White patients, Black organs only to Black patients. Organ offers are based on several factors such as how sick the recipient is, how long they have been waiting, and how well the organ matches. Race is not considered. The reason why it's important for Blacks to donate is that there is a shortage of organs overall. We aren't even close to meeting the need. So, we need to reach out to all communities to increase the number of people who are willing to donate organs – living and deceased. That's the only way we're going to make up this difference.

What about people who are concerned that being an organ donor will keep them from getting the necessary, life-saving treatment during an emergency at the hospital?

The emergency team is not even related at all to the transplant team. The transplant team is completely separate. When a patient comes for an emergency operation, the people who are caring for them are emergency physicians who are charged with treating the patient and saving their life. It isn't until all lifesaving efforts have been offered that organ donation is brought in as a discussion. The emergency treating team is not even aware of whether the person has designated that they are an organ donor.

How long does it take to get a kidney in Illinois?

We have a lot of people waiting for organs and kidneys specifically. The waiting times are very long. For a kidney, the waiting list is kind of prioritized by how long you've been waiting. In Illinois, the wait times for a deceased kidney

is 7-8 years. When you have a living donor, you skip the wait and it doesn't have to be a family member. If more people were to come forward as a living donor that would be transformative.

If you choose to be a living kidney donor, won't that put your own health at risk?

We have an incredibly strict process to screen people for donation. We screen them for things that would put them at risk for developing kidney disease down the road. If a potential donor has any of those things, we would not allow them to donate because the last thing we would want to do is speed up that process or put them at higher risk by going through the donation process. They have to be otherwise healthy. We see many more people each year who want to donate than we actually allow to donate. We turn a lot

of people down because we are so strict about who is suitable to donate and who isn't. Experience and research has shown us that our donors do just fine with one kidney. The risk of someone needing a kidney transplant as a donor is extremely low when you follow these people years and years down the road. Now suppose there was some circumstance where someone was a kidney donor and they had a freak accident that injured their remaining kidney. Because they were a living donor, they would move up toward the top of the list for getting a kidney themselves. But, again, the risk of this is very low.

What if the potential donor isn't healthy? Should they still consider organ donation?

As a deceased organ donor, there is much more that can be donated beyond the heart, the kidneys, or the liver. There's tissue, cornea – a whole bunch of things. I don't think that a patient should be deterred because they are unhealthy. The actual assessment doesn't come until after all life-saving efforts have been exhausted. Then you have a conversation. Is this person an organ donor? It's a pretty short list of conditions that would prevent someone from being a donor of anything. Everyone can sign up to be a donor and then the actual assessment doesn't come until all life-saving efforts have been exhausted.



Dr. Dine Simpson