



Kidney Transplant Discussions:

Transplant Times

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Guest

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Recorded

Hello, and thank you for joining us for one of three podcasts about kidney transplantation. Today, our special guest is Timmy Nelson, who is going to share his thoughts on transplant from the patient's perspective.

Jerome

My name is Jerome Bailey, and I'm the associate director of patient and family engagement with the End Stage Renal Disease (ESRD) National Coordinating Center. We partner with patients, healthcare providers, and the Centers for Medicare & Medicaid Services—also known as CMS—to create and share resources that help kidney patients improve their quality of life.

According to the United Network for Organ Sharing, kidney transplant is the most common organ transplant surgery performed. In this surgery, kidneys that are not working are replaced by a kidney from an organ donor—living or deceased. If the transplant is successful and the kidney continues to work, the recipient no longer requires any kind of dialysis. There are more than 100,000 Americans thriving today with a donated kidney.

Our guest today, Timmy Nelson, was diagnosed with kidney failure in 2013. He received a kidney transplant from a deceased donor in 2017. After retiring from the United Parcel Service after 38 years of service, Mr. Nelson now volunteers his time educating patients about their kidney disease treatment options, including transplant. Mr. Nelson, may I address you as Timmy?

Timmy

Yes, please do.



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Jerome	<p>Timmy, welcome to the podcast!</p> <p>How did you first hear about kidney transplant as a treatment option for kidney failure?</p>
Timmy	<p>My first visit to my nephrologist, we talked about a quandary [<i>sic</i>] of things, and he concluded the conversation, with the optimal treatment for me was going to be a transplant.</p>
Jerome	<p>How and when did you decide that it was something you wanted to pursue?</p>
Timmy	<p>Once again, I had a great nephrologist. He educated me on all the avenues for dialysis and how that process worked. He explained to me that there was no total treatment for kidney failure. He said the best option for me to manage this disease I have is the transplant. We talked about how the process worked. We talked about what I would need to do afterwards as far as after care, as far as my immunosuppressants that I'd have to take. There was no decision for me other than to seek a kidney transplant.</p>
Jerome	<p>What was the role of the dialysis facility staff in the process of becoming listed and maintaining an active listing status?</p>
Timmy	<p>Once again, I was very fortunate. The staff that I worked with walked me through the entire process for dialysis first of all, but then they were totally supportive of what I needed to do as far as getting a transplant. They also shared at the same time with me that our goal was to not just maintain you on dialysis. Our goal is, if you are willing to do so, is to prepare you for a kidney transplant. So, in addition to talking to me about my treatment for dialysis, they also talked to me about healthy things that I needed to do to maintain my health as far as eating properly, taking the medication I needed to take, having a decent exercise regimen...to make sure I did all the things that I needed to do to get prepared for that first evaluation.</p>
Jerome	<p>What were some of the challenges you faced getting on the transplant waitlist?</p>
Timmy	<p>There really were not any challenges for me that I can think of. In my mind, the biggest challenge for me was to make sure I was the best possible candidate. So, I took to heart everything that was shared with me by the professionals. They are professionals for a reason and if I'm going to be treated by them, I need to listen to them. I took every piece of advice that they gave me and followed it to the letter.</p>
Jerome	<p>Did you ask relatives or close friends to be a living kidney donor?</p>



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Timmy I did and I struggled with that. And here is why I struggled with that. My mother also passed away from kidney disease at an early age. I was diagnosed at 57. She passed away in her early 60s. Around the same time, she got diagnosed, I got diagnosed. And they really have not been able to determine totally why my kidneys failed. It might be genetic. It might be hereditary. So, my fear was with my four children, was to have one of them become a donor. They were all willing—they all got tested. I was concerned about that because for me personally, if one of my children were to have the same issue as they got later on in life, then the toll on me mentally, would have been probably more than I wanted to bare. So, I chose not to have my family members to become donors, or strongly consider being donors. As I got adjusted to my life as a PD (peritoneal dialysis) patient, I kind of accepted the notion that if this is my destiny, then I can manage that.

Jerome What was the conversation like when you told your kids that you would not be accepting a kidney from them?

Timmy I have four children, and like me, they are very strong-willed. So, that was not a very easy conversation. There was a lot of opposition. It got to a point where I said, “I love you all, but that is something that at this point in time I cannot see me doing, so let’s table that conversation.” But I also assured them that I was in very good health considering my kidney disease, and I was doing everything that I needed to do. That relaxed them a little bit too, knowing that their dad was doing everything that he needed to do. They were still adamant about it. In fact, I talked to my oldest son recently who was a perfect match for me. He said, “Dad, I said I understand, but that’s not something I wanted to do.” It was a difficult conversation, but I think I made the right call in the long run.

Jerome Tell us about the experience of getting the call that a kidney was available for you.

You talk about euphoria! That was probably one of the greatest points of my life to be honest with you. As I mentioned, I had decided that if for some reason I could not get a kidney transplant, I was able to manage my life on dialysis. I managed it, I did not let dialysis manage me. I did all the things that I was supposed to do, but I built it into my lifestyle.

Timmy We were preparing to go to a family reunion when we got the phone call and they shared with us that they found a kidney and it was a perfect match for me. However, I was the number four person in line for that kidney, but they would keep me posted throughout the next couple of days. Every 10–12 hours I would receive a phone call. After that second phone call, telling me that I was no longer number four, I was now number three, I cancelled my plane ticket to Kansas,



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which is where the reunion was taking place, and said, “I’m going to take a chance that this kidney might be here for me.” And it turned out that it was. When I got that last phone call saying the kidney is yours, you need to get here, excitement, answers to my prayers, realization that hope was coming true—I guess that’s the best way to describe it. I’ve been euphoric ever since then. Every day is a blessing. And every day is an opportunity to share my story with others with the hope of giving them hope.

Jerome

What were the biggest challenges in recovering from the surgery?

The biggest challenges were just understanding what I needed to get done. I don’t even want to call them challenges, because as I mentioned, I’m very disciplined, and I feel as though the professionals were in my life for a reason, and if I’m going to listen to what they say, I’m going to follow what they say. So, the greatest thing that the professionals shared with me was to maintain my diet, to maintain my medications, but also to start to get more and more exercise. In this case, that meant walking. Probably the greatest challenge was me realizing that the day after surgery, I need to start walking. I wasn’t walking very fast at first. In fact, I was thinking, how could I be walking right now? I just had major surgery. The three days I was in the hospital. Day one, day two, day three, and it got easier and easier. And of course, I continued that once I went home. But that was probably the greatest challenge, if you want to call it a challenge. It’s a matter of following the instructions— I guess I’m stressing that—it’s so important that anytime you’re talking to medical professionals about your personal health, they are giving you their advice for a reason. I think it’s so, so important that you adhere to that advice.

Timmy

Jerome

Who was your care partner after the surgery?

My wife was my care partner. Lorraine did a great job. I have constant praise for her—how she nursed me through this process. There are things that you just can’t do afterwards. In fact, through the entire dialysis process, she was right by my side, every step of the way, totally supportive. We may have disagreed on some things that I wanted to do. There were things that I wouldn’t do—for instance, my kids being possible donors—but totally supportive every step of the way. I tell you what: I owe her a great deal of gratitude.

Timmy

Jerome

How important was having a care partner with you after the surgery?



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Timmy Once again, I am a very strong-willed person and I mean that in a positive way. I'm not a raving lunatic, but I'm a very strong-willed person. This was a time in my life when I had to realize that I could not do things on my own. And to have a care partner that was totally focused on what you needed. And also understood how difficult it was for me to ask for help. It got to a point where she was like a mind reader. She knew the things that I needed to do. She could tell when I wasn't feeling well, when I was having mental anguish. It was as though she was inside my mind and she could read my mind and know the things that I needed. That care partner is so important because it's not just for them to take you back and forth to the doctor. This is the person that you share your concerns with—this person is really focused on you. They can read what you need and have it before you need it. So, the care partner is a huge key for this process because without a good care partner, it would be very, very difficult, if not impossible.

Jerome What have been the benefits of having a new kidney?

Timmy I'll tell you what. I call it a new lease on life. The organization that secured my kidney is called Gift of Life and that's exactly what it is. Because without having a functioning kidney, as I mentioned before, I managed my kidney disease, I didn't let my kidney disease control me, I managed it. Having a new functioning kidney has given me the opportunity to do things better than ever before. It also makes me very conscious of my need to give back, and hopefully, support others. I know what it's like to be in the world of dialysis and to live that life. So, when I talk to patients, I share with them those things that they need to do to become the best possible candidate for a kidney transplant. I also share with them, after the transplant (post transplant) that you got to do all you can to make sure that you maintain that kidney. The best thing for me, each day, I think about what it means to have received a kidney, and also this presents to me an opportunity for me to share with others.

Jerome Was there anything that surprised you?

Timmy You know I was surprised at how quickly I recovered. They told me it would be about three weeks before I'd be able to drive again and do things on my own. In my mind, I'm thinking this is pretty major surgery. How can you have an incision like this, have a major surgery like this and be up and mobile in about three weeks? After about two and half weeks, they said, you're ready. You're all set. You've done what you're supposed to do so. You've beat the projected time by half a week. That's been my goal with everything that I've done with this whole process though—is to be the best possible patient I can be. Again, those medical professionals are in my life for a reason, so I need to do what they say.



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I was surprised about that but when I look back on it and I talk to the medical professionals that took great care of me, I'm not as surprised because if you do what they tell you to do, your chances of recovery are great.

Jerome

What advice would you give to someone thinking about getting on the transplant waitlist?

Timmy

There are a couple things that there are not exceptions to things that you must do. The first thing is you must maintain your current dialysis prescription. Everything you need to do to maintain a good healthy lifestyle on dialysis, taking your medication, eating right, not drinking excessive fluids, getting exercise—those are the things that you must do to get prepared for that transplant. Because in my case during my first evaluation, my coordinator shared with me that based on my results that they saw from my first evaluation that I was a great candidate there that day. But, then they also shared with me that you're a great candidate now. Now, your goal is to become an even better candidate. Each day, I woke up with the focus of what is it that I need to do to make myself a better candidate than I am already. So, what I would tell a person considering a transplant, stick to your dialysis prescription 100 percent, take your medications like you're supposed to, eat like you're supposed to, drink like you're supposed to, and you also have to do the exercise thing, like you're supposed to. After you get that transplant, maintain that regimen. You have to make sure you do everything that you're asked to do to maintain that kidney.

Jerome

Timmy, it has been a pleasure to speak with you today. We are grateful for your time and dedication to improving the quality and experience of care for all those touched by ESRD. Thank you.

We thank you for listening to this podcast. To listen to the rest of our podcast series on transplant or for additional information on the kidney transplant process, visit the End Stage Renal Disease National Coordinating Center website at www.esrdncc.org, or talk to your healthcare provider.

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