



Home Dialysis Discussions:

Talking Kidneys – Timely Talks with a Caregiver

Moderator

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Guest

Tina Gee

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Recorded August 2019

Jerome

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

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, patients—to create and share resources that help kidney patients improve their quality of life.

Most people are born with two kidneys, each are about the size of a fist, and pack a powerful punch in terms of the amount of work they do for the body. Healthy kidneys clean waste from the blood and make urine.

They keep elements in the blood, like sodium and potassium, in balance. They also make hormones that control blood pressure and red blood cell production.

When the kidneys stop working properly, it can lead to kidney failure. There are more than 100,000 Americans living with kidney failure who rely on a kidney transplant to keep them alive.

Most of those individuals count on the support of a loved one or friend to help get them through the transplant process.



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Today I am speaking to Tina Gee. Her husband received a kidney transplant in 2017. Ms. Gee was her husband's caregiver both before and after his transplant surgery.

The caregiver plays an important role in the transplant process, helping his or her loved one, friend, or family member in a variety of different ways. The caregiver may help with ensuring that medicines are taken at the right time or coordinating doctor appointments. Their most important job may be to provide emotional support. The role of caregiving is often said to be one of the toughest and also most appreciated.

Ms. Gee, Tina—May I call you Tina?

Tina

Yes, but at this point in my husband's transition, I prefer to be called the care partner. That denotes an agreement between the person who has a chronic condition and I'm just helping him along, and we agreed to help one another in his transition.

Jerome

Thank you, Tina. Welcome to the podcast!

How did you learn a kidney transplant was an option for your husband, Patrick?

Tina

Patrick and I had discussed all the options that were available to him at that time and what our future plans would be. He wanted to live a fuller life to be with, not just me, but all nine of our grandchildren. So, after more discussion and research and reviewing all of our options, we both carefully agreed on a kidney transplant.

Jerome

What was your role in the decision to seek a transplant?

Tina

I kind of shared with him what I wanted our future to look like— what our future to look like as a married couple. We both minister to the sick and the shut-in pertaining to those suffering with kidney disease and the support systems. We maintain a very involved partnership in our decision-making when it comes to our health. So whatever impacts Patrick, also impacts me.

Jerome

How involved were you in your husband's care before he received a transplant? While he was on dialysis? How did that change after the surgery?

Tina

Patrick was very independent, and he had to be. My work schedule had me traveling a lot. But, on those days when he was either too sick or too fatigued to move and lost the strength, I'd have to step in and be the caregiver that he needed to assist him with his care. After his surgery and the constant challenges that we endured after the transplant, my care became more pronounced. Excuse me, his care became more pronounced. He had his surgery for his transplant on April 21, 2017. Five days later, he had a blood clot in his neck. But, then he had another



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surgery. So, three-days after that surgery, he was bleeding internally. So, he had a third surgery. Seven days, 17 days later, he had a fourth surgery! That's a lot of surgeries going on just for a kidney transplant. But everybody is different. When he had the fourth surgery, they removed a J-tube and created a peritoneal window so he could drain internally.

About 33 days in the hospital, his kidney finally woke up on the 47th day. Now, his needs became more intense because he needed to go through home therapy to come home. He came home with an open wound. He had to wear a wound-vac and he needed to be changed every few days. He needed bandages changed as well as assistance learning how to walk and get up and down our stairs in our home. So, my role was very important then.

Jerome

So how did those complications impact to you?

Tina

If I wasn't healthy, how could I be a good caregiver for him? It was a lot of stress on both of us. But, we both had to learn how to endure both my stress and his stress. He understood that, yes, he was the patient. I understood that he was the patient, but we gave each other plenty of space to just be us. So, with good communication, telling each other, "hey, I'm having one of those days. I don't think I'm going to make it." The other person would pick up the slack and do what needs to be done throughout the day.

Jerome

Now, were you able to get help from family and friends as well?

Tina

There was no help from family and friends for me. Most of our family live out of state, so there was [sic] no family and friends. The only time we did get assistance was when he came home with the wound-vac and I had to go back to work. There was a nurse that was not given, that was assigned to us through an organization, and she came out that week I was out and changed the bandages and big things that I would do as a caregiver.

Jerome

What changes have you noticed in your husband since his surgery?

Tina

He's had more energy and stamina. He's more cognitive of his health challenges. He's encouraged, not just me to be a better manager of what's going on in my life, but both of us. We eat cleanly now and exercise more and we just kind of want to be healthy for one another. Our relationship is thriving better than ever. All that we have endured individually and collectively.

My role is changed and I'm no longer the caregiver. I became his care partner. Now, I had a front-row seat access witnessing his transformation from peritoneal



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dialysis, five times a day, seven days a week, 2.5 hours a day obvious [*sic*]. And then he received his gift of life. And dealing with those challenges that the organ, you know, presented to us. We're much happier, healthier, and active in our advocacy.

Jerome	What advice would you give to a caregiver whose loved one is thinking about getting a kidney transplant?
Tina	Keep in mind, everyone is different. If you're...if you can't care—you can't care for anybody if you're not healthy. Your care for yourself and your needs comes first. It isn't being selfish, but you can't fill an empty cup if you can't pour anything into it. You need to find your balance with all that you have going on. Always keep the lines of communication open. Don't take it as a sign of weakness to say you can't handle a particular situation. And if you need assistance, ask for it. You're only one person and you need to remember that at all times. Just don't do anything, do what you can and understand that you need to care about your well-being just as much as you care for your partner. Or that person that you're giving care to.
Jerome	Tina, it has been a pleasure to speak with you today. We are grateful for your time and dedication to improving the quality life and experience of care both for your husband and for all those touched by ESRD. Thank you.
Tina	Thank you for having me. It was a pleasure.
Jerome	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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