

February 2024 Peer Connection Call
All About Me: I am more than my diagnosis

Patient Spotlight:

Barbara Briggs, transplant recipient

Please note, there is no link to the recording for February's Peer Connection call spotlight. Patient Spotlight is transcribed below.

Barbara Briggs: "The first thing I want to say to everyone is know your medications, know the color of your medications, and when you're supposed to take your medications. I say that because I have autofill on my meds, and so one of the nurses had taken my Prednisone and given me a 90 day supply with no refills. And for the past month, I have just been not taking it. I couldn't imagine what was wrong, so I went to the doctor. They took X rays and everything, and then finally one of my doctors said, are you taking your Prednisone? And I came home and looked through my medicine box and there was no Prednisone. So that's why I say that, and you can memorize your medications, I've memorized mine. I even know the colors. If you get a bottle with your medication in there and it doesn't look right, call the doctor because I have gotten some prescriptions before that did not look right so I called the transplant center and they called me up and looked at it and it came from the manufacturer, but it was the wrong pills.

I have also done my dialysis at work and I've also done peritoneal and with peritoneal you really, really have to be careful not to mess around and get peritonitis and whatever I did, I always carried Clorox wipes with me and I would wash my hands. Didn't even touch the doorknobs, that's really important. I was also always afraid I was gonna lay on the tubing from my medical equipment at night, but I had enough tubing to roll around in my bed.

The other thing I found out that was really helpful, you need a friend if you can't share with someone in your family, find someone that you can share with. I had a friend that looked after me like I was her big sister or little sister and she was from Florida. And I remember when the 9/11 hit, I was lying in bed just turning my dialysis off, and she called me. And she said, hey, girlfriend, get up. Are you watching TV? I said yeah, and that was one of my lazy days and she said get out of the bed. She looked after me during that.

I have another story I'd like to share. There's twice I've gone to the hospital and they said that I wouldn't make it and I had a stoma in my stomach and I went to the hospital and my family was in church and they called him out of church. And when my mother got to the hospital, they said that we don't think she's gonna make it. So my mom went to the doctor, pointed her finger in his face and she said you don't have the authority to make that decision. So the doctor looked at her like, who's this old lady thinks she is? So they went into the Chapel and they prayed. And my daughter said if you mess up, I'll sue you. He called in another surgeon and then they came out and they said everything went fine. My mother said I told you, you didn't have the authority to make that decision. So I'm always focusing on my family support.

Another time when I went in, I think I had filled up with fluid and you know that's something else you have to watch is your fluid, my son took me in and he came to the hospital. He was expecting me not to be there because they had told him that it was critical and he said if you could eat anything right now what would you like if you had your choice? And I said a strawberry malt, so I was up walking around

when he wasn't expecting it and he turned the corner and he said he almost dropped the malts on the floor!"

Barbara also shared some amazing tips on how to remain focused on yourself and not letting your diagnosis run the show:

- Owning your new normal, treatment is going to change things for you.
- Memorize your new medications, be aware of any changes.
- If someone else is picking up your medications, or if they help you manage your meds, you could print out a picture or send them a screenshot of what the medication looks like so that they know as well.
- Barbara used to treat on Monday, Wednesday, Friday, so she would utilize her off days by actually doing something that's just for herself and it would help her get her out of the house as well. For example, on Tuesdays, she found out that a local movie theater would do discount tickets. She would go to the movies just by herself, and that was accomplishing two goals: It was helping her get out of the house, but also again focusing on something that she really enjoyed. On Thursdays, she would volunteer with various groups.
- Remain active in your community and surround yourself with support.
- Utilize your time on the machine by reading, writing, knitting, and planning your next trip.