



Home Dialysis Discussions:

Timely Talks With a Home Dialyzer

Moderator

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Guest

Monica Jemison

Recorded August 2, 2019

Hello and thank you for joining us today for one of three podcasts about home dialysis.

Today our special guest is Monica Jemison, who is going to share her thoughts on home dialysis as a treatment option from the patient's perspective.

My name is Kim Buettner, 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, caregivers, healthcare providers, and the Centers for Medicare & Medicaid Services, also known as CMS, to create resources to help kidney patients improve their quality of life.

Kim

Healthy kidneys clean your blood by filtering out excess minerals and waste products and help balance your body's fluid levels. They also produce hormones that keep bones strong and create red blood cells. When kidneys fail, harmful wastes and excess fluid buildup in the body. This can have an impact on almost all other systems of the body.

There are several treatment choices available when someone's kidneys don't work well enough to maintain health, and a few of those choices include receiving treatment at home. Home treatment options include home hemodialysis and peritoneal dialysis, also referred to as PD.

Our guest today, Monica Jemison, chose to receive dialysis at home with PD before receiving a kidney transplant. Usually, PD is done for several hours a day with the help of a machine. This treatment does not use needles, but, instead, relies on a thin, flexible tube placed in the belly. It uses the blood vessels in the lining of the belly, called the peritoneum, to filter the blood.



Home Dialysis Discussions:

Diagnosed with ESRD in 2011, she started PD in 2015 and continued this treatment for two years until receiving a transplant in 2017. She joins us to discuss her decision to choose PD and the impact it had on her life.

Welcome Monica—May I address you as Monica?

Monica Yes, please.

Kim Thank you, Monica, for joining us. How did you first hear about home dialysis, and when did you first think home dialysis could be an option for you?

Monica Well, I was in the hospital sick and not knowing why and that's why I first met my nephrologist. And after, you know, she got me stable, we met in her office, and during that meeting, she talked to me about what kidney disease is and why I have it, and what the future looks like. And then she scheduled me for a few more appointments and over the next three months. And so after that, I went and met with her nurses who were there in the office so I would have my appointment with her and she would check my labs. And then after that I would sit with the nurse and the nurse would talk to me about all of the different modality options.

Kim What was the most useful information in helping you decide?

Well, the most useful honestly was talking with my doctor.

And the second most would be, of course, those training sessions with the nurse. They showed me plenty of videos, gave me notebooks to take home and read, and all these different resources that I could look at, so when I came back to the next appointment, I was able to ask all the questions that I needed to.

Monica But, the number one thing that helped me decide was when I asked my doctor what would she do if she were in my position. And of course, she didn't want to tell me what to do, so she kind of danced around it a little bit, but eventually she said, "if I were doing dialysis, if I had to do dialysis, I would choose PD." And that let me know that it was a safe option because my doctor would do it if she were me.

Kim Why did you choose to receive dialysis at home?

Monica At the time, both of my younger children were in elementary school. My son is autistic, and my daughter is in Girl Scouts, and I was a troop leader. My oldest son had just had a new baby and so I was a new grandmother. So, my family was real important in making that decision.



Home Dialysis Discussions:

We were also a one-car family and it was just more convenient for my husband not to have to have to worry about taking me to and from around his job and everything.

So, it was a lot less stressful. And, of course, we live in Illinois, so weather was a big thing that we needed to consider, too.

Kim

Describe the discussion you had with your children when you explained to them that you would be doing dialysis at home?

Monica

When my husband and I decided that we would be doing dialysis at home, one of the things that we learned from the nurse is how to talk to kids. And so, we decided that we would use the fish tank analogy, which you know, fish use a filter to filter out all the old food and waste and things like that. So, we used that to describe how the kidneys work and so because my kidneys weren't working very well, we needed to do it at home at night while I sleep, so that my body could keep swimming like a good fish, you know. And so they really understood that a lot and so they were really willing to help out, you know, as much as they could. And of course, you know, I gave them little things that they can do to help out and they were very willing and welcoming, and it didn't bother them at all.

Kim

What led you to choose peritoneal instead of home hemodialysis?

Monica

Well, the biggest difference between the two of course is one, you're using a fistula versus a catheter. And for me, to do it at home, I wanted to be able to do it by myself. You know, because again, we have a busy family, and if you know my husband wasn't home or if my older son wasn't at home, I wanted to be able to do it myself without having to put too much of a burden on everyone else. So that was the number-one thing. And, I know that there are times when you can do "hemo" by yourself, but I really wanted to be able to take care of myself in case of an emergency. So, once we decided to go through the training, and to look at both of them to see which one, my husband said, "you know this would probably be better," because we would not be dealing, you know, with my actual blood, and for him, that was a big concern.

Kim

Describe the discussion you had with your husband about the possibility of treating at home?

Monica

Well, the great thing about him is that he came to every single one of my appointments with me. So, you know, on our way home from the appointment, we would talk in the car about what we have just learned that day, and so, because we learned about it together. You know, we came up with questions



Home Dialysis Discussions:

together and once we realized, “okay this is definitely going to be a real thing that's going to be happening,” we looked at every single absolute possibility.

And you know, we looked at the logistics of it. Where would we keep the equipment? Would the cyclor fit in our bedroom? Or, if we were doing “hemo,” would we be able to do that in a comfortable location in our home? How would it affect the kids? And like, I talked about before, emergency situations. If there's a power outage what would we do then?

So, we really talked a lot about, you know the, from the very minute to the biggest overall picture. How would this affect our family? And so, we went through the whole thing together and we made the decision together.

Kim

What were your concerns before you started, and how did you get past them?

My first thought is never of my feelings. My first thought is always logistics first, and so I was mostly concerned about, you know, how would this work. You know, I knew, umm, I knew that choosing PD was a safe choice. You know, after talking with my doctor and my nurse, I was not concerned about that part at all because I knew that I was in good hands. And I had a good safety net around me. So, if it wasn't working out right or if I did do something wrong, I knew that they were there to take care of me. So, my biggest concern was my ability to do it.

Monica

I felt a lot better once I went through the training. I think it was three or four weeks long and every day my husband and I went and sat with another nurse and learned how to do it.

My biggest concern was can I do it and how can I do it. And so, once, you know, I started doing it each day, I felt more and more confident, and so over time, I just felt better about it. So, it wasn't anything specific that I was concerned about, it was just, you know, getting into a good routine—how to make that routine work for our family.

Kim

What concerns, if any, did your husband have about you receiving dialysis at home?

Monica

Again, he was a lot like me where we felt confident in the actual, umm, in the actual modality. His concerns were more about how can I make this, how can he make it easier for me. So his participation, and it would be to make sure that I had all of the tools that I needed daily to put it all together for me, so that when it was time for me to set up, I would not have to worry about, you know, running all over the house looking in boxes and things like that.



Home Dialysis Discussions:

Because he went through the training with me—he, we both took notes. So, one of the notes that he—I didn't realize that he was thinking about was how to make it more convenient for me. So, another one of the things was making sure that he decided to do was to make sure that he made a sign for me to put outside of my door when I was setting up so that the kids wouldn't come and bother me. Or, he would make sure that, you know, if it starts beeping while I'm asleep that, you know, it's not something that's, you know, a problem that, you know, to see if I need to be waking up or anything like that. Because I am not a sound sleeper at all, so I usually wake up anyway, but just in case I didn't, he wanted to make sure that he understood what all of the functions meant and all the alarms and things like that. So that's the notes that he was taking while we were going through training and of course I'm thinking of how to do it, he's thinking of what can I do to make this better.

Kim

What recommendations would you make to someone who is thinking about a home dialysis treatment?

Research, research, research. You know if you don't get very much information from your doctor, of course, ask for it. If you have access to the dialysis nurse before you start, talk to the dialysis nurse. Get as much information from them as you can.

I would also suggest that you talk to other patients. You know, ask your doctor or your nurse if there are any other patients willing to talk to you about they're... about what they're doing. Another wonderful idea that really, really helped me a lot was to go on Facebook and find a group who are doing PD, or ummm, doing home "hemo" and figure out, okay, what are they struggling with, you know, is that something that I should worry about? You know, because when I did that, I got a lot of extra questions that I wanted to have answered.

Monica

So, being in that group really helped me to learn about some of the other pitfalls that might come my way, so I can talk to my doctor about it, see what we can do to circumvent that, so it doesn't happen. So, umm, talking to other people, getting online, even looking on YouTube. A lot of people post videos of themselves setting themselves up and things like that, was very helpful for me too to see someone doing it that was not staged, you know, provided by say your dialysis clinic, or what have you, but someone who is literally really doing that, you know, on their own, in their life, and that's what they do. Because it's a lot easier when you see someone whose life is truly affected by this, than say, an actor in a video. Not to say that those are not real, but you know first-hand experience is always the best experience.

But, my number one piece of advice is to talk to your team. Not just your nephrologist. Not just your nurse. Talk to your, your, your primary physician.



Home Dialysis Discussions:

Talk to your surgeon that's going to put in either the fistula or the catheter in. Talk to every single physician that sees you. Every nurse that sees you. Talk to them about what you're deciding to do talk to them about, what your options are. See if they have any advice. Sometimes they won't. Sometimes they/we have no clue what you're talking about, but still it puts the thought into their mind so that when they see you like again, you know, they can do a little research themselves, so that when they see you they can say, "so how is that going, how could I help you with that?"

So, that is the number one thing that I would suggest: talk to your entire team. Make sure they're on board.

Monica, 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.

Kim

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