



Home Dialysis Discussions:

Timely Talks With a Caregiver

Moderator

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Guest

Yalonda Moore

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

Today our special guest is Yalonda Moore, who is going to share her experience with home dialysis from the caregiver'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

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. When someone decides to use a home dialysis treatment, a caregiver may or may not be needed to assist with the treatments. Many patients have shared that the role of a caregiver is one of the most valuable.

Today, we are talking to Yalonda Moore, who lives in Anchorage, Alaska, with her husband of 32 years. They have seven children, three biological, four adopted, and 11 grandchildren.

Ms. Moore will discuss the role she played in her husband's decision to dialyze at home and the impact his being able to dialyze at home has had on their lives.

Welcome Yalonda—May I address you as Yalonda?

Yalonda

Yes.



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Kim Thank you, Yalonda, for joining us today. Who started the discussion about receiving dialysis at home, you or your husband, Gary?

Yalonda Gary started that discussion.

Kim What was your role in the decision-making process?

Yalonda As to whether I'd have the time to help support him in doing his home treatment. Because in the beginning, when Gary first became a patient, he had also had a stroke and he had partial eyesight. So, he needed that "extra eyes" to make sure that he was hooking up correctly and things like that. So that there was somebody else to see the process of what was going on.

Kim What led to choosing peritoneal dialysis? Was it the first choice or was home hemodialysis considered?

Well, he really didn't have a choice in the beginning because he became sick all of a sudden.

Yalonda He didn't like having to go to the clinic and be there for four hours a day. He didn't like not being able to control things himself and not being able to just move about when he wanted to.

So, doing the peritoneal when it was suggested to him, it gave him a chance to be able to have control back over his life. Because his main thing is, he likes to say that he's not living with dialysis, he's going to make dialysis live with him. So, it was something where he could control it versus it controlling him.

Kim As both wife and caregiver, what concerns did you have about doing dialysis at home?

Yalonda So, my biggest scare was whether I was going to do it correctly and making sure that I didn't harm him. And then, come to find out it really wasn't as bad as I thought it was because after the classes and what they teach you, it came nice, easy, and smooth.

So, at first it seems like it was overwhelming, but with it, but once the class gets going, and you're going over the machines and seeing that the machine pretty much tells you step-by-step, there's really no way to mess it up.

The classes help you relax and get used to what you're getting ready to have to deal with on an everyday basis. And it left you with a lot of information, and who to contact if you had problems. So, the classes are a big help. And I think every, I think most people that have that do peritoneal, you know, depending on their situation, a care partner is really good because there are sometimes, it's you



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know, there's so much information sometimes to where it's kind of an overload, but as a care partner it was really easy.

Everything they told him they made sure that I knew exactly what they were talking about. So, that if he forgot something or he missed something, I knew exactly what which direction to go and what was missed and how to backtrack to see what happened. So, the classes were really good. You know everyone should be in to take those classes.

Kim

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

At the time that he, that my husband got sick, we had, we still had two teenage girls at home.

It was having to explain to them that he was going to be there, the different actions that had to be taken when he was hooking up his machine, such as explaining to them that you have to knock every whenever you come to the room. If you see the door is closed, be sure to knock on it. Don't open it, because you don't know if he's hooking up, you know. And explain to them why that is, you know, because you don't want the air circulation and things flying around when he's opening his line. Making sure that the animals stayed out of the room that we had then. The animals that we had stayed out of the room, mainly the cat.

Yalonda

But otherwise you know it was pretty easy. For one of our children it was really easy. One of our children, I can't say it was that easy. But I think her problem wasn't as much as the machines or the dialysis. She was just having [an] all-around hard time with the whole thing, you know, because there, like I say, her dad got sick all of a sudden.

But for the most part, it was just talking to them about the process of what he does, how he does it, and the different things that they had to look for when it came time for him to do his dialysis, such as watching the cords on the floors and not touching the tops of the machine and things like that. And seeing how they felt about it, you know. And giving them a chance to work it through and showing them how it works, so then that way, they also had a hand in the process, got a chance to see exactly what he was doing.

Kim

How long has your husband been doing dialysis at home now?

Yalonda

He is going on his seventh year.



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Kim

How involved are you with your husband's home dialysis regimen?

In other words, what type of assistance or support do you provide?

Now, within the past three years has gotten less. When he first started, whenever he had to have heparin injected into his into his bags, I took care of that. Trying to, you know, making sure that he had the right bags when he was first connecting the cassettes and setting up the machine and things like that. For the most part, I did a lot of that because of his eyesight and trying to make sure that, you know, he could see everything correctly. Other than that, I didn't have to be involved too much. You know, it was mainly just when it came to having to look at things where you had to deal with certain measurements and having to make sure that you don't touch the tips of the bags when you're doing injections. Things that would be hard for him to see on his own. So those are the things that I had to deal with.

Now, for the most part, he does pretty much everything on his own now. It's, you know, now that his eyesight is cleared up and things like that. I don't have to deal with too much of anything other than, you know, being at home when his dialysis supplies is delivered. That's about it.

Kim

What benefits to your husband's health and your family dynamics have you noticed since he started peritoneal dialysis?

We used to have to take and schedule everything around him going to the clinic and then also having to put off things because he was sick quite often when he was going to the clinic. So, when he got home he didn't have any energy.

But since he's been on peritoneal, he has more control of when he hooks up, when he, you know, when he unhooks, and where he does his dialysis, but when, you know, what it's on the machine or whether it's manual.

Yalonda

We don't have such a tight schedule. You have to deal with, you know, we're going, you know, they have a kid performance. Well, he can't go because he's at dialysis. He's now able to go because he does it at night now and it's not during any time when somebody needed him to be someplace else. And so, that's how it's made it easier for us, because he has more control of his time and his schedule and the things that he's doing without us, having the heaviness being restricted to the timeframe of in-center.

Kim

Gary works full time while on peritoneal dialysis. Can you talk to us a little bit about what that's like for him and for you as a caregiver?

Yalonda

Gary is a workaholic, so there. Also, peritoneal did great with that for him.

He didn't work for like about five years. He just started back to work last year.



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He normally works from seven o'clock in the morning to five o'clock in the evening. If he has his way, he's there six days a week versus just the five. He's able to, you know, he has his time set to where he is up and out of the house by a certain time, and if for some reason he has to work late, he just calls and says, you know, in order to make sure that everything is set up and ready to go, the solutions are warm. He gives a call, "can you set the machine up for me?" You know, things like that.

But it's left him being it was with him working and everything; it's not interfering with him. He has the energy to work because it's not as extreme on his body.

Kim

You and your husband like to travel. What is it traveling like on a home dialysis treatment?

Traveling on the home dialysis treatment is not bad. Because he's not having to call to schedule at somebody else's clinic to try and make sure he has a chair Monday, Wednesday, and Friday, the only thing that he has to schedule for the most part is when you call, you got a call in like 40 days ahead of time to have some solutions sent ahead to wherever your destination is. And then you just load up the machine and take it with you. You know, they give you a suitcase, everything to put the machine in. You take it with you.

We've taken a cruise. And with the cruise, he ended up doing manual, which was very easy, you know. The Fresenius, or the clinics that you deal with, most of them have contracts with the different cruise lines when they have a contact person that will help coordinate the time that you'll be out of water and getting the solutions to the correct cruise.

Yalonda

And on top of that, my husband and I, we drove just two years ago. We literally drove from Alaska all the way to Florida. And then, that was seven days in our truck, you know, drive. And part of the time, you know, he, when he were [*sic*] just driving, he would stop and he would just do an exchange within the car cuz [*sic*] it was just us. We just cut everything off, so that he could hook up.

He took his machine and some cyclor bags with us so that, you know, the two or three times that we stopped to get a hotel room, he was able to do a complete cycle exchange at the hotel.

But, he travels quite often and we have no problems, you know. It's really easy to get with everyone to make sure that the solutions and everything are where they need to be at [*sic*] the most part. They'll even send your cartridges along with the solution and any other extra supplies you need on to where you're going, so you're not having to travel with a whole lot of stuff.



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Yalonda, 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]

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