



National Patient and Family Engagement Learning and Action Network Kidney Caregiver Peer Connection Call *May 27, 2020*

Jerome: Welcome to the National Patient and Family Engagement Learning and Action Network Kidney Caregiver Peer Connection call. We appreciate your interest in this topic. Today's call is meant to be an informal way for caregivers to ask questions of other caregivers and patients who have experience with the kidney disease journey.

Before we get started, there are a few items we'd like you to remember. All the lines are currently muted. The lines will be unmuted after we introduce our panel of caregivers. Please be respectful when asking questions and do not speak over someone else. We also ask you to take the call in a quiet location and mute your line when you are not speaking. This call is being recorded and will be made public on the [National Coordinating Center] NCC website. We will also promote it on social media.

Please do not disclose any personal identifiable information. Do not share any information that you would not want to make public such as your date of birth or the name of your dialysis facility. Please do not ask for medical advice. The role of the panelists is to share their personal experiences of caring for someone with kidney disease. If medical advice is asked or given, the NCC will interject in the conversation. Each person's situation and experience are [sic] unique. The treatment plan for each patient is unique to their personal needs in various factors, including other medical conditions. Before making changes to your health practices, speak with a member of your healthcare team. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding medical conditions.

The views and opinions expressed during this call are those of the panelists and do not necessarily reflect the official policy or position of the [End Stage Renal Disease] ESRD NCC or the Centers for Medicare & Medicaid Services. Any content provided by the panelists is of their opinions and is not intended to substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding medical conditions.

Kim: This is Kim Buettner and you previously heard from Jerome Bailey. We work with a group of patients with end stage renal disease and their caregivers to design and spread practical approaches that can be used to help other patients become engaged in their health and care to improve their quality of life. We have selected a group of three subject matter experts from the [Learning and Action Network] LAN group to answer your questions and share their individual experiences. We would like to thank them for agreeing to join us today. We have Candise Washington from Michigan who has been a caregiver for her father who was a home hemodialysis patient. We have Barbara Hoffpauir from Louisiana, who is a care partner to her husband, and Yolanda Moore from Alaska, who is a care partner to her husband. To learn a little about each of you, we would like to ask you a question, each the same question, "What



three words describe your experience as a caregiver?" Let's start with Candise. Can you give us three words that describe your experience as a caregiver?

Candise: Yes, I can. The three words that come to me are caring, humble, and brave.

Kim: Thank you very much, Candise. And Barbara, what three words describe your experience as a caregiver?

Barbara: Yes, Ma'am. Prayer, readjustment, and gratitude.

Kim: Thank you, very much. Great words. And Yolanda, what three words describe your experience as a caregiver?

Yolanda: [Technical Difficulty]

Kim: I want to thank you both for providing those three words. As you can see, everyone has different experiences just like Jerome had stated. Before we take questions from our callers, we asked for and received a few questions before this call, so we'd like to start off with some of those questions. And as we're going through these questions, if any of you are on the Webex, feel free to use the chat box to submit any questions that you may want to pose to our panelists and we will include those questions, as well. Let's go ahead and start with one of the questions that we received. Has your role as a caregiver changed in this era of [Coronavirus 2019] COVID-19?

Barbara: My role has changed for the fact of having to stay home. My husband goes to dialysis at a clinic three times a week and that means he does have to get out. Whenever he has to go, I usually drive him, but I've had some things happen with arthritis, so now he's driving himself. I can't go in the stores because they want us to stay in because of our age. He's also had to go into the hospital for emergency room, but he's been allowed to come home. They've been able to treat him and send him home. It's just little things like that. It's kind of an inconvenience but I must say that everyone has been very helpful at the hospital as well as at the clinic. We've had neighbors that have helped in a lot of different ways. So that's the way it has changed mainly.

Kim: Thank you for that, Barbara. That's definitely good feedback and I'm sure people can relate to some of those changes as we have all had to adjust. Here's one that we also received. "I'm thinking of trying a support group but I'm not sure of the benefits. Have you used a support group for caregivers and was it beneficial for you?"

Barbara: I have not used a support group but at the very beginning when we first started dialysis we had to wait in the waiting room for a period of time and that was very beneficial to us because we got to visit with each other and hear about other's experiences. Some of them were caregivers, some of them were patients. We found that to be helpful, encouraging, even though you might hear scary things, it also had encouragement to it. I thought that it was beneficial and so did my husband.

Candise: I didn't get into a support group, but if I could, I would have done it because it was very hard. I had the support of my family and we all had to learn how to hook my dad and put him on a machine, so that was my support team. When I couldn't do it, I know my brothers had



my back and my mom had my back. If they had a caregiver support team, I would have gone to it, but we didn't have that where we were at.

Jerome: I have a question that came through the chat feature. When you have a concern about being a caregiver, do you talk to anyone on your loved one's care team? I know that would be past tense for you, Candise. Did you talk to someone on your dad's care team when you had a concern about being a caregiver?

Candise: When I first started being his caregiver, I didn't know anything so I would communicate with the nurse all the time because it's a learning step. Every time that I would put my dad on, it was something new or something that might have happened. Even if something didn't happen, I still reached out to the nurse and said, "This happened. What do we need to do? Are we okay? Do I need to take him to the hospital?" I was in constant communication with our nurse. Sometimes, I even had to talk to his doctor that was on his team about what happened and what was going on. It's good to have that open communication and not be afraid to say, "I don't know what's going on. I need help." My father's team was very supportive and made sure everything was good, everything was right. If I needed a break, they even said, "Come on in and I'll dialyze him and you take a break because we know you're in school." I loved my team. To this day, I still can talk to them and get letters of recommendations and things. I am happy and blessed to have a team that supported us that good.

Jerome: Yolanda is now with us. What about you, Yolanda? When you have a concern about being a caregiver, do you talk to anyone on your loved one's care team? I'm sorry. We're still getting some background noise on Yolanda's call. Barbara, do you mind responding to that question?

Barbara: Okay. Yes, I can. As a caregiver, I might first go to the clinic. I have found them very helpful. Then, if I hadn't done it already, I would also perhaps go to the doctor. He would sometimes give us a direction to go in. If I needed to talk to someone just related to my feelings, which I might, if it were brand new to me and if I just was frustrated, I would go to one of my family. Actually, I would say I need you guys to pray for such and such. I've done that a lot. Just to calm down my fears and give me confidence to take the next step, whatever that might be. Because sometimes it was kind of scary to think, what should I do next, this is a big responsibility. That's probably the order I would go in. The team at the clinic have been very helpful, the nurses, and the techs, and even the social worker. Okay, that's probably what I'd do.

Jerome: With COVID-19, we have heard about many caregivers feeling isolated, and if so, what do you think a facility staff can do to help with those feelings? To help caregivers feel less isolated, like they're in it by themselves.

Barbara: Well, you know, there's been times that those people who are actually doing the hands on that particular day or during that week will make comments to my husband. A lot of the times it's helpful. We've also had information sent home which has been helpful on different aspects going on at the clinic and those have been helpful. I would probably, at the



clinic, a lot of times I would go to the nurse first. I think it kind of depends on what situation is happening. I might call the nurse because she would seem to know in most of the situations and what's happening and give a direction to go in. Occasionally, if there's been a social worker I'd call. The tech has been helpful too. I can't rule out anybody. She'll make comments to my husband while she's connecting him or disconnecting him. I've found them to be beneficial.

Jerome: Candise, was there ever a time that you felt like you were in it by yourself and needed someone to talk to?

Candise: Yeah, I had those days. It wasn't, what we did on those days, like things like that when I feel like it felt it became too much, I talked to my (undecipherable), I talked to my mom about it, and I even talked to my dad, 'cause we are in a partnership. You need me and I need you, so we both can move forward in life. So, how our relationship is, we talk to each other. We made sure we were comfortable. We made sure if somebody, one of us, was not feeling good or we had a bad feeling about something, we talked it out like maybe we should do it or maybe we shouldn't do it. We kept open communication all through his dialysis, all through every step because it's bad to not have communication because that's when it breaks down and being upset and stuff like that happens. So, we made sure one of us, one of us, wasn't feeling too good or we just weren't feeling bad or sad. So, we would do something like let's go get some ice cream or let's just go ride around town and just smile and have fun or some days it would be 2 o'clock in the morning and be like, "Do you want to go to Don's Bakery and get a donut?" because they used to be open 24 hours. Because of everything that's going on they had to cut their hours, but we'd do a 2 o'clock morning run and go get some donuts and laugh and have fun. So my support team at the dialysis center, they knew I was in school and was taking care of him and they knew I wanted to go see my best friend for maybe a week, so he didn't trust my brothers to hook him up and it's so funny, as much as they could and they had all the lessons and went through training, he just wanted me to do it. So, when I would go out for maybe a week or so, I tell him you may as well go in-center and everybody yeah, you can bring him in here. We love Mr. Washington. He's just a fun man to be around. He makes us laugh all the time. So, I love my support team. They were great. They were wonderful and we rolled it 'til the last day. They even still check on me now, so that's why I really love the team that we had.

Jerome: That's really sweet. That's really sweet. I think I have one more question in the queue and then we'll open up the call to our audience on the call. So, let's get this one last question answered. The question is, what do you do to maintain balance between your life and your kidney caregiver life? So, what do you do to maintain balance in your life and your kidney caregiver life? Do you have any hobbies?

Candise: I can take this. So, what we did was we planned like fun days. So, it could be like every two weeks, we would go out to eat or you want to go see a movie that's coming out. So, we made fun days like you want to go on a mini vacation to Chicago. We made sure we were able to have fun and still get on the machine or pack the machine with us because we were going on a trip. And I had a schedule and I made sure I was on top of things where it gave me time to do my school work, made sure to have time to put him on the machine and talk to him, and be with my little one, and then I had time for my friends and everybody else. I just balanced it as



much I could. Some days I got stressful and some days I was like, easy day. So that's how I balanced my life as being a caregiver and being just a regular person.

Jerome: What about you, Barbara?

Barbara: Well, I'll tell you what. Our family, we don't have any immediate family here in town. So, we often will like, I think it's called FaceTime on the phone, because we get to see them and talk to them at the same time and we always look forward to those. Other things that we would do would be, we're not able to travel at this time, we watch movies. My husband actually can take a walk down the street. I can't read too well because of my vision but I have been using audio books and it's almost like escaping into your own world, or another world. And we have church friends that we communicate with and we do a lot of talking on the phone and other friends here in our area. And that's mainly the way we get out of just going to the clinic. I think probably our favorite is getting to talk to our family through FaceTime. We talk to them on the phone, but it's really special when you can see them and talk to them. That's another thing about this virus, it has stopped, people can't travel state to state. Some of my family is way in the East and part of them are in just the neighboring state. So anyways, they're not in the state. So that virus has kind of interfered.

Jerome: That's great. Seeing your loved ones face[s] even if they are only minutes away using FaceTime or using whatever mobile tool you have; you can still create special memories. Thank you both for sharing. We are now going to open up all the lines, so that we can hear from some of the participants on the call. If you all have questions for our panelists, again we are going to ask you to take the call from a quiet room. If you're not speaking, we are just ask[ing] that you mute your line to avoid as much background noise as possible.

Kim: I know Yolanda was going to try to call back in.

Yolanda: I did call back in.

Kim: Welcome back to the call.

Jerome: Hi Yolanda. Glad to have you with us. Do any of our callers have a question for the panelist[s]?

Caller: Well, what would be the hardest thing about being a caretaker would be my question.

Yolanda: I think the hardest thing about me being a caregiver was having patience with my husband because having to go to the doctor and not overstepping him and putting it to the point where he would forget who he is. In other words, not smothering him, because as a caregiver, you have the tendency when you go to the doctor you want to answer all the questions, or you have the tendency to even though you're not thinking of them as sick or something, your mind kind of does, so you have the tendency to overstep them a little too much, so you kind of have to step back and let the patients do it for themselves. That's the hardest thing that I had to deal with, just stepping back and letting him be himself.

Candise: I think the hardest thing about being a caregiver is when they get sick. That was my biggest battle because when my father got sick, you never know what it is. You don't know



where that infection might have come from, who you might have been around, any of the things or factors. So, when he gets sick and is in the hospital, I sometimes would blame myself, because I'm like, "what did I do wrong?" Even though I know it has nothing to do with me. I'd think, "Okay, maybe he just caught a bug and it got worse" or he had a blood infection one time [and] I thought that I might have poked him wrong, maybe I did this, but it was none of that. So, my biggest thing is when the patients get sick, is it my fault? What did I do wrong? What can I do to make it better? I had that battle and the majority of the time, when he gets better, and we find out what happened, it usually doesn't have anything to do with me. Just the fear of I don't want anything happening to him and I don't want to be the reason this is happening to him, or maybe I should've done more or should have done less, so that was my biggest battle when it came to being a caregiver.

Barbara: Probably the hardest thing I found was not really going to the doctors, but at home. I have a tendency to go from doing lots of hands-on care, to not doing any and allowing him to do for himself because I would want to go ahead and do it. I don't know if it's because I was rushing and trying to get things done too fast. So, I had to really think and still do have to think, well, am I being mean by not helping? And then you see little things that's he's doing for himself, but it's difficult to step back and let him do these things for himself. That has not been easy.

Jerome: Do we have any other questions for our panelists?

Lisa: I have one more.

Jerome: Okay, Lisa.

Lisa: While I was on dialysis, I had to be a caregiver, and I was wondering if anyone else had to be a caregiver while being seriously ill yourself.

Barbara: I have never been on dialysis myself, but I have had lots of problems with arthritis, which makes me be dependent on him more so at that time. It is also difficult to know who to turn to. Like these other folks, my friends and my neighbors and I have a cousin in town, and these kinds of people have been helpful to us there. But, I have seen another side of my husband and we have become closer. It puts us on a different kind of level from depending on each other for different things.

Yolanda: For me, my husband, we're at home [peritoneal dialysis] PD, and I had a total knee replacement and trying to help him when he was sick and then having to go to the doctor and on top of him doing the PD. He had a stroke, so he had a short-term memory loss. So, him going to the doctor and me having to be at home and him calling with the doctors to ask me different questions because he couldn't give the answers. You know, so that made it hard. I was trying to do what he needed me to do from home because I couldn't go with him. But at the same time, taking care of myself at home.

Lisa: Wow, thank you. My husband had colon cancer. Wow, so I appreciate that, thank you.



Candise: I would say, what we mostly had to deal with was my school when it came to my father getting sick and stuff. So how we worked it is sometimes I would have to go take my test a little later on in the week or later on in the next few weeks. So that's how we had to work it. I had to still schedule times and made sure, today I'm not putting you on because I gotta do work, tomorrow you gotta get on. So, we managed like that. It was a give and take. Sometimes, he liked to take more and then sometimes I liked to give more. We [are] both Aries so I'm basically his little clone. We know when we had our days. We had our good days and sometimes we had our bad days, but even with the bad days, we still made some fun out of it.

Jerome: Do we have any additional questions for the panelists? Alright, we do have a question that was submitted in the chat feature. Is anyone's partner using telemedicine and if so, what is your role with the telemedicine visit as the caregiver?

Yolanda: Gary, my husband, is using telemedicine. For us, for the most part, when he does his appointment, they make sure that myself and my daughter are involved so they can find out, especially with this virus going on, ask us what else they can do to help us get through it. They make sure we are involved so they can give us suggestions about things to keep him away from. His doctor explained, it's better for you guys to go to the store and when you get home to instantly change your clothes and wash up. So, the telemedicine helps us to be able to get in touch with his doctor and ask what's the easiest way for us to handle the different things going on without him going in and what's the easiest way for us to keep him safe.

Jerome: Thank you. Barbara, any telemedicine?

Barbara: My husband has had appointments over the phone with the doctor. He had previously had an echocardiogram done and like his doctor told him the results of that and reviewed his medicine and did a checkup over the phone. Mainly my role, anytime he goes to the doctor or have any contact with him, we both try to go so we can verify what we hear to make sure we got the information right. We really didn't have any other issues with telemedicine. It was a good visit over the phone. It was better than going into the office.

Jerome: Any other questions from the audience? I see that we have one last question in the queue, and it is for each of you, and we can start with Candise. What advice would you give to a new caregiver just starting their kidney disease journey?

Candise: The new advice I would give is ask questions. It is never wrong to ask a question. If you don't understand it, if it's not making sense to you, or you want to know more information, ask questions. The doctors and the nurses are there to help you understand, to make this an easy journey for you and an easy journey for your family member. That's what I did. I asked many questions. If something didn't look right, medicine wise, or they changed his medicine, I asked, "Why are you doing this?"; "What would happen if this happened on the machine?" I don't think there is anything wrong with asking questions. That's what I think. Ask as many questions as you got.

Jerome: Thank you, Candise. Barbara ...



Barbara: I agree with Candise. Ask all your questions and if you leave and you have some more that pop up, because you've thought about something or something else has come in, I would either call them back or as soon as you can, write that question down and ask them when you go. As far as the medicine, I definitely agree, find out why it's changed, or why it's added, and what it's for. When you pick it up, ask the druggist, also read the literature. I would also read up. They give you a lot of paperwork when you first go into the clinic. Well, I'm not familiar with how it is when you first start in the home, but we received a lot of paperwork. It was beneficial to read that, to look through that, and to reference it as you can. All of that is very important. And like she said, talk to the facility. Also, the doctors, when they come by, get as much information as you can. And of course, your patient, the one that you're caring for, they should too. And keep an open communication between you and the one you're caring for. That's very important because they are going to see things, especially if they go along through the process, they're gonna see differently. You may both be seeing the same things, but what they perceive may be different than what you perceive. So, it's extremely important to keep those communications good between you and the one you are caring for. Okay. That's it. Thank you.

Jerome: Thank you, Barbara. Yolanda ...

Yolanda: One of the things as far as being a care partner that I look at is when they go to the doctor, understand that you are there to help support them. So, when you see something not right, you know, because they don't always catch it, question it. Like they've been saying, ask questions. We've always said in our Network, the patient, you are your first doctor because you have to know the treatments. So, as a care partner, you need to know what they're going through so if you see something not going correctly, question it. So, as someone going into it and starting off, learn the process. Learn everything that they are going through so that you're able to help them watch and keep an eye on everything that they're going through because you're also that first defense with them. So it's them as the first, you as the second. So, you need to know and understand everything that the patient is going through because you need to watch because not everyone is perfect, and you need to be able to question anything that they don't see that you don't feel is correct.

Jerome: Yolanda, thank you very much. Kim?

Kim: I want to thank everyone for all their great feedback and their participation and how they shared their caregiving expertise with us and everyone on the call. So, now that we have been able to go through the questions, we want to go ahead and share a few caregiving resources with you. For those of you on Webex with us, for more information on caregiving options, you can visit any of the websites that are listed on the screen. A few of those resources include the ESRD NCC, the National Coordinating Center. You can visit us at www.esrdncc.org/npfe-lan. We have several caregiving resources on there, one of which was created by patients for caregivers. You can also visit the American Association of Retired Persons (AARP) Family Caregiving at www.aarp.org/caregiving. There's a Caregiving Action Network, ESRD Rockstars, Family Caregiving Alliance, and National PACE Association. All of these will be available on the [National Patient and Family Engagement] NPFE-LAN website when we post this recording later. Also, you can contact the ESRD NCC. We have our contact information up there. You can email



us at NCCInfo@hsag.com. You can call us at 844.472.4250. We also have our address up there as well. We invite you to follow us on social media. You can find us on Facebook by liking ESRD National Coordinating Center or following us on Twitter @ESRDNCC. We also have a YouTube channel, so please visit us on YouTube at ESRDNCC. And again, we would like to thank everyone for joining us today. Please keep an eye out for the recording of this and we will post the slides as well so you can see this information. Thank you again to our panelists. Everyone, please have a good day and stay safe. Take care.