



National Patient and Family Engagement Learning and Action Network Kidney Caregiver Peer Connection Call *July 9, 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 who have experience with the kidney disease journey.

Before we get started, there are a few items we'd like you to remember. All 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 phone line when you are not speaking. This call is being recorded and will be made public on the NCC (National Coordinating Center) website. We will also promote it on social media.

Please do not disclose any personal[ly] 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 dialyzing at home. If medical advice is asked or given, the NCC will interject in the conversation. Each person's situation and experience are 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. For those of you joining by WebEx™ and you have a question at any point, please send it to all panelist by using the chat feature. We will read your question in the question and answer period.

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 ESRD NCC (End Stage Renal Disease National Coordinating Center) or the Centers for Medicare and 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 a medical condition.

I will now turn the call over to my teammate, Kim Buettner.

Kim: Thank you, Jerome. For those of you joining us by WebEx™, you now see a photo of the NPFE-LAN (National Patient and Family Engagement-Learning and Action Network) team. I am Kim Buettner, as Jerome introduced me, and 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 healthcare and to improve their quality of life. We have selected a group of three subject matter experts from the LAN group to answer your



questions and share their individual experiences. We would like to thank them for agreeing to join us today. We won't go into their history or stories as caregivers too much because we want them to be able to share their experiences directly with you. First, I'd like to introduce Brenda Taylor from Illinois who was been a caregiver to her husband and her daughter, both of whom experienced in-center hemodialysis and transplantation. Donn Bellmore is from New York and was a caregiver to his wife who began with in-center hemodialysis, and through her journey used peritoneal dialysis, transplantation, and home hemodialysis. Natasha Bress from North Carolina is a care partner to her husband, Keith, who is using home hemodialysis. I'd like to welcome everyone to the call and, again, thank you for your time.

Before we take questions from the callers, I'd like to ask each of you about your most memorable moment as a caregiver. I thought we could start first with you Brenda. What was your most memorable experience as a caregiver, Brenda?

Brenda: Can you hear me?

Kim: Yes, we can hear you.

Brenda: Ok. Thank you, Kim. I would have to say my memorable experience as a caregiver was the satisfaction and the gratification that I got having the opportunity to take care of my family. Oftentimes, caregivers are driven by the heart of compassion and they want to support their loved ones in their health journey. We know that caregivers tend to experience higher level of mental and physical health than most people do. On the one hand, I was really happy, and I was grateful I had a chance to be there for my family and provide them with the support that they needed. On the other hand, I found myself battling with the mixed emotions that came with that and my own emotions of caring for my family. Finding a way to balance that process was by far the most memorable experience in the journey.

Kim: Thank you for sharing that Brenda. And hopefully as we go through some of the questions, we can find out how you balance some of those emotions. And this time, I'd like to ask Donn if you wouldn't mind sharing your most memorable experience as a caregiver. Donn?

Donn: Oh no, not at all. I think my most memorable time out of the whole journey was when we started home hemodialysis. Elaine as very sick. The training was totally overwhelming the first day. The second day, I learned how to access her fistula. The third day I accessed it. I was pretty scared. I got everything ready and at the last minute I stopped and said a little prayer. She asked, "what are you doing?" I said, "I'm saying a little prayer," and she said, "well stop, I trust you." And I did it. And that was the start of us treating her at home dialysis.

Kim: That's a great story to share. The relationship and trust you two built together. Thank you, Donn, for sharing that with us as we kick off this call.

Donn: You're welcome.

Kim: And Natasha, what is, or was, your most memorable moment as a caregiver?



Natasha: Well, I guess I have a couple. But, one would be the first time we had to train for home hemo[dialysis]. Before that, we had done in-center or PD (peritoneal dialysis) and I'm terribly afraid of needles and blood. Going into training, my husband downplayed a little bit part of my involvement. That I wouldn't be very much needed as far as the needles were concerned. His nurse let me know that I would need to know some things. And I had to practice with helping him with the (inaudible) taking out the needles and the cannulation and it was very serious, and I did almost passed out. But since then, I'm pretty comfortable with it now and I would never thought I would be at that place where I could be comfortable around needles of any sort.

Kim: Thank you, both Donn and Natasha, for sharing that moment. We've heard from patients about the fear of needles and you brought in a different perspective of caregivers and a fear of needles and how you've been able to overcome that and working with your loved one. Before we get started, we received a few questions ahead of time, but I wanted to check in with Jerome to see if we have received any questions through the chat box so far. And we wanted to remind any of you who are on WebEx™ that you can submit any questions that you might have, to just send them through WebEx™ using the chat feature. We will ask those questions as well before we open the lines for conversation. Jerome, have we received any questions so far in the chat?

Jerome: Yes, Kim, we received one. That question is, "what do you do to maintain balance in your life?"

Brenda: I'd like to speak to that a little bit. This is Brenda Taylor. That happened to be one of my biggest challenges. When I started caring for my husband, it was years ago and there certainly was not a lot of resources available to caregivers at that time. A lot of the things I did was by trial and error. Just checking in with myself to see what I needed, what I felt like I had, I was at the other end of the spectrum. I would implement small things. I would begin by ... I didn't feel comfortable leaving my husband or daughter. I would go into another room and just listen to music. Eventually, I would feel comfortable with that. I would go outside and take a walk. Eventually, I felt a little more comfortable with that and then I was able to take a respite break. And so, it was small things I was able to do to just take care of myself that I needed to do during the process.

Jerome: Donn or Natasha, would you like to answer that question as well?

Donn: I would, yes. I felt the opposite. When my wife first started her journey—I should say our journey. She was on home PD. She was quite capable. As a caregiver, my biggest job was moving supplies and helping her get things ready. But she took care of pretty much everything herself and I had stuff shipped all over the country as we traveled. But she did pretty much everything herself. But as we got older, and she got worse, you know, on in-center dialysis and then home hemodialysis, I couldn't leave her very long. So, I had to find a way to take care of myself while taking care of her and that might be just quiet time every day. Maybe just before dinner or, you know, just something that I could do by myself to relax and think. Music, read a



book, whatever for half an hour, minutes. And that's how I maintain balance. You have to take care of yourself.

Jerome: Thank you, Donn. Natasha?

Natasha: For me and my husband, a lot of how we try to find balance is to sometimes separate the care-partner-like relationship and being like, you know, a normal married couple and doing things outside of dialysis. Sometimes we do get bogged down, I think, by it. It's a big part of our life, and as it should be, but just making that space for the two of us is important, separate from that, as well as for myself. Also, just like being able to, like Donn mentioned, having those moments away from everything and just that quiet time. Both me and my husband also see a therapist separately and together. And that helps as well.

Kim: Thank you for sharing that Natasha. We just got a comment in the chat box and it stated, "good reminder, Donn, self-care is so important, especially when you are caring for someone else." So, thank you Kimberly for sharing that with the group. We also received another question and they asked, "have you, have any of you, used a caregiver support group?"

Natasha: I have not. This is Natasha. I didn't even know—I guess when I became a big part of this—about any other caregivers at all. I don't really have any close by, so that's why I was really interested when I was asked to be a part of things like this—just to get to speak to other people who are going through the same thing. So, for me personally, no, I have not been a part of any support groups.

Kim: Okay. Like you said doing something like this does help just getting out there. Talking and sharing with others and learning from others. So, excellent point. Brenda or Donn, is there anything you are going to add or share?

Brenda: I've actually been a part of a support group. I actually have a support group that we would, we meet virtually, and we meet in person. Just to kind of get together and talk about the challenges of caring for our loved ones with end stage renal disease and to, you know, talk about informal conversations, and so that we can support each other. So yes, I do have a support group and I am a part of a support group.

Donn: I didn't have a support group. There wasn't any available to me at the time. I found the biggest support was within the in-center dialysis of caregiver family. I mean, we always ended up waiting there together having lunch, talking, and sharing. And when I left, that I mean, when Elaine and I left and went to home hemo[dialysis], there was no support group. So, I recently started one on Facebook for a lot of the caregivers in this area now. We share experiences and stuff. This is not that real active because I think a lot of people just you know, they don't want to take the time for it, but there's a few people that are pretty active in it. It helps. It helps everybody.

Kim: Thank you. Thank you for mentioning that Donn when you started you talked about how you connected with people within your wife's facility and there may not have been a formal support group. As the question had asked, you were able to connect with others and find that



support there. And it sounds like you're able to kind of do that within your community now as well, too. Those are good suggestions, too, to kind of reach out to people who might just be available and talk and share experiences, just as what we're doing on this call. So, thank you all for those suggestions. Jerome have you received or were there any other chat questions?

Jerome: Yes, we did get one. And this is for all the caregivers on the call. “How can others show you that your care is appreciated?”

Brenda: Can you repeat that Jerome?

Jerome: Sure. This person wants to know how can others show you that your care is appreciated? So, is there something, you know, the person that you're caring for can do or say to let you know that what you're doing for them is appreciated?

Brenda: Well, during my process, and I think that's why it was such a positive experience for me. Just hearing those words mean a lot. There was probably not many days that would go by, especially because my husband has been on dialysis and had had renal failure for a long period of time and to work the like the last 10, maybe 5 to 10 years of his life, there was never one day that went by that he wouldn't say something like, “You know I really appreciate you doing this,” or you know, “Thank you for this.” So, a lot of time just hearing those words really makes a difference. At one time, he knew that there was a, was a challenge to leave them alone and he would suggest, “you know go take some time for yourself, you know take a day and go out and spend it with your family—with your sister.” So, you know, just like that really shows that the person is aware of what you're doing and, you know, and their ways of saying thank you.

Donn: For me, it was fairly similar. I mean, when I had to start taking more care of the Elaine, she always made an effort to let me know how she appreciated it. And when I didn't quite want to leave her alone too long, she would insist that I would. I would go do something, even if it was to go to the store. At one time, she even made arrangements for the kids to take turns coming in so, and the nurse, so that I could go on a weekend getaway. And I hated to say no to that, but I did. But the thought of her doing that for me was tremendous. But she never failed to let me know how much she appreciated it.

Natasha: Well for me, it's more, I think Brenda might have mentioned it, but just the thought, the word, you know. My husband tells me all the time that he really appreciates everything, you know, I do for him, you know, that I'm there. And I've had people kind of ask that as well. And honestly when people are like, “You know it must be a lot of work,” or “It must be a lot of this,” you know I don't really think of it that way. It's definitely great to be appreciated, but I wouldn't be anywhere else but with him and by his side through any of it. So, he's very thoughtful about everything, when his treatments are if we want to plan something he definitely makes sure, you know, that his treatments are done, and we can enjoy ourselves without that having to worry about it. He makes sure to get everything, so yeah things like that.

Jerome: Well, it sounds like you all have some very generous and loving people in your lives. Thank you for sharing that. We did get another question in in the chat and it says, “What type



of support do you need from your adult children or extended family members? What specific things have your family done that you found especially helpful?"

Brenda: Well for me, during the time when both my husband and daughter was on dialysis, probably the last couple years of his life, it became very extreme and so I've always had a problem during this process of asking for help. But, a couple of my sisters I reached out to [me] because things got really rough. And they would do things like ... uh ... because they both went to dialysis on the same day during the same time and they would have doctor's appointments. She would call me and she would be, she would say, "Well, you know can I take one to the uh," she would take my daughter to her doctor's appointments or she would go and pickup a prescription. There was a time when she needed a procedure done, a patient procedure done outpatient. I'm sorry, procedure done, and she went and she sat with her. Things like that meant so much to me. It was priceless. And just having someone there, you know, to know that you know if they need, if I needed them, that they were there. And you know, those gestures went a long way.

Jerome: Donn? Donn you're muted now.

Donn: Can you hear me?

Jerome: Yes, we can hear you, Donn.

Donn: Okay, for me, my kids are all grown and when Elaine started getting pretty bad and what have you, a lot of times one of the kids would feel free to provide support to [ac]company what have you a lot of times, they would help out around here, around the house, with me and do things like that to free me up for other things. And then they had no problems coming and visiting their mom and allowing me to do a couple of things that I had to do. Go to the store, go shopping or whatever for my doctor's appointments. So, to me, that meant a lot. They couldn't help treat her, but they could allow me to have free time so that I could get other things done. So, to me that meant a lot.

Jerome: Thank you Donn. Natasha, do you want to answer that question?

Natasha: Sure. We don't have any children, but our extended family have been really great. Keith's mom, her fiancé, has been on dialysis and has had a transplant. So, she was a really big help with everything and especially when I and Keith started dating and, you know, engaged and got married. You know, she was a really great source. My aunt also was a caregiver to my cousin for dialysis as well. So, she's also a great source of just someone to talk to about everything. And then, our friends are really great and whenever Keith has a procedure, especially if it's a few nights in the hospital, or something like that, you know, my friends are definitely, and his friends, are willing to, you know, if I need to go home to just take a break and come in and sit with him and stay with him or bring food. So, we don't have to worry about someone watching our dog if we need it. So, just that kind of [support] has been really great.

Jerome: Great. We are now going to open up the lines to give all of our call-in users an opportunity to ask questions. So again, we ask that you take the call from a quiet location. If



that's not possible please mute your lines so that we can avoid as much background noise as possible. I am now going to unmute all the lines. The lines are unmuted. Does anyone have a question for our panelists?

Caller: Jerome, I do want to ask them this. When the caregivers have attended family events like family or going to someone's home, say after church, or go to a party, how have you helped the patient with the dietary restriction?

Jerome: So, I believe the question is, once when you've been invited to a family event or an outing, how have you helped your loved one with the dietary restrictions?

Donn: I would offer gentle reminders, but my wife was a stubborn Irish woman, who pretty much followed the rules most of the time. But, when it came to a special occasion or something special like that, she pretty [much] did what she wanted to do regardless of my relationship. So, I couldn't argue with her because she was good all the other times. So, you gotta live once in a while.

Jerome: How about, Natasha, do you have to sometimes step in and, I guess, help your husband [with] about what he's eating?

Natasha: Yes, often. He is a very big snacker. So, he really likes a lot of sweets and things with sugar and his nutritionist gets on him all of the time. So whenever we like go out, I do try to, like, make him aware of, like, the things that he's eating or just make sure he's taking his binders like he should be, as well with his meals and every time he eats. It's still a work in progress though, I will say for sure.

Jerome: Okay and I think this question is also for Natasha. This came in through the chat feature. "How has COVID-19 impacted the caregiving, your caregiving routine?"

Natasha: It really hasn't impacted us too much. I will say as far as me, I'm more anxious to do anything. I still am, you know, my job has been open the whole time. I work in property management. Our doors have been locked, but I've been very outspoken with my job about, you know, meeting with residents and things like that. What I'm not willing to do. Just for the sake of, like, I still have someone at home who is compromised. So, I get—I have a lot more anxiety when it comes to going out grocery shopping and things like that. As far as, like, just our normal day-to-day, it hasn't been too bad. It's just kind of the things that we were used to doing and things we still have to do, like, go out into the world. I just tend to get a little bit more anxious about that, but we're just trying our best to just to stay safe with everything.

Jerome: Any more questions from our call participants? We do have another question in the chat box and I believe this is for any of our panelists. What general comment would you make to caregivers to encourage them when things may have gotten tough.

Natasha: Can you repeat that? I'm sorry.

Jerome: Sure. What general comment would you give to a caregiver to encourage them (sic) when things may have gotten tough?



Natasha: Oh gotcha. I would just tell them that, you know, there will be tough moments. That is not a maybe, it's a fact. But, just making sure that the lines of communication are open and that you feel okay to ask questions. That you feel okay to ask questions to the dialysis team. I ask questions all the time. I don't care if they sound silly. I want to know and sometimes just in regards to, you know, being a caregiver, it can seem like a large weight sometimes and it seems heavy. But that, you know, you're doing this and you're here for that person that you love and, you know, it's gonna be okay.

Brenda: And one of the things that I would always do, also when things would get rough, to bring myself, I would always bring myself back in by asking myself, by reminding myself why I'm doing this. That would always give me perspective and just kind of keep me centered as to why, you know, why I'm in this situation. Or why I chose to do this. It would, you know, it gives me, it would always give me perspective. So that's always a good question to ask yourself, too.

Donn: Yes, if I may add something, I always believed that the best way to help my wife was to be a patient advocate for her. She didn't always understand some of the medications and stuff like that. So, I always tried to help her out with that, but when things got really tough, I was never afraid to reach out to family members just to talk—our pastor, you know, friends at dialysis. Sometimes just having somebody to listen to you is very meaningful. Don't be afraid to ask and don't be afraid to talk to somebody.

Jerome: We have one last question and we're going to start with Brenda. We'll go Brenda, Donn, and then Natasha. What advice would you give someone starting their caregiver-caregiving journey.

Brenda: The first thing I would say would be to get as much information as you can. Become informed on what the process is going to look like. Ask plenty of questions and to also get an understanding from the patient's care team on what's expected. What you think is expected from them. And, to see what sort of support is needed. I think that it's very important for you to build a relationship with the care team, especially if your loved one has in-center dialysis. So that you can ask the right question, so that you'll know about their labs, and their diets. And, just having that communication is extremely important. And, then educating yourself as a caregiver is very important.

Jerome: Thank you Brenda. Donn?

Donn: I agree with everything that Brenda said. I would emphasize being involved with the care team and educating yourself and the patient with everything concerning the process, the illness, and make sure to use of all the resources available. Knowledge is power and a lot of times that's very helpful with the care team. And, to remain active with your patient. The care team will answer your questions more enthusiastically and show a little bit more care if they know that you are very active in your patient's care.

Jerome: Thank you, Donn. Natasha?



Natasha: Pretty much everything that both Brenda and Donn say, you know—educate yourself, just being informed. Get close with your care team. I have multiple people's phone numbers and if I feel like I'm at a loss for something or scared about something or need assistance, I am quick to call, and they are nothing but great and are willing to answer any questions. Again, just, you know, it's a lot of, you know, going to the appointments and being available and, you know, just learning that sometimes you might be flexible because it's always changing and things are always happening, but just being open-minded.

Jerome: Well, Brenda, Donn, and Natasha thank you all for being with us this afternoon. We really do appreciate you taking the time to share your experience, your thoughts, your words of wisdom. I'm sure they will be and are helpful to the many patients that (sic) are on the call and who will review this recording. So, thank you very much.

Natasha: Oh, thank you.

Donn: Thank you. You're welcome.

Brenda: Thank you.

Jerome: For more information on caregiving options, please visit any of the websites listed on the screen of the websites include the ESRD NCC, the American Association of Retired Persons, Family Caregiving, Caregiver Action Network, ESRD Rockstars, Family Caregiver Alliance, and the National PACE Association.

Kim: The ESRD NCC has developed, with assistance from patient subject matter experts, the KidneyHub.org. This is a secure mobile friendly web tool for patients and professionals, so we invite you to visit thekidneyhub.org today on your mobile device and access links important to important resources such as COVID-19, infection prevention, transplant, home dialysis, as well as new ESRD patient education. We also have new features added regularly and we recently added access to the Patient Grant Library and included informative videos about understanding high Kidney Donor Profile Index (KDPI) and increased kidney risk. So when you visit the mobile device or when you visit this on your mobile device, rather, please be sure to bookmark it on your device's home screen, and then this way, you'll have easy access to all of these resources right at your fingertips.

Jerome: There are several ways to contact the ESRD NCC. Our email address is NCCinfo@hsag.com. Our telephone number is 844.478.4250. Our address is there on the screen (3000 Bayport Dr., Suite 300, Tampa, FL 3307). We also invite you to follow us on social media. You can find us on Facebook by liking ESRD National Coordinating Center or follow us on twitter @ESRDNCC. We are also on YouTube. You can search ESRD NCC. Thank you all for joining us. Have a good day.



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