## Season 3 Episode 4 – Aging with Dignity: Grief, Depression, and the Human Side of Kidney Care

*Guest: Felicia Speed, PhD, LMSW*

**Len Usvyat, PhD**
Welcome to the Renal Research Institute, Frontiers in Kidney Medicine and Biointelligence, where we share knowledge and advances in kidney research with the world. In this episode, I'm joined by Felicia Speed, Vice President of Social Services at Fresenius Medical Care. Felicia is dedicated to improving the emotional and mental well-being of kidney patients. Her work focuses on addressing the emotional toll long-term illness and supporting patients in managing grief, isolation, and fear that often accompany declining health. Together, we're discussing aging, end of life, and depression and its impact on renal disease patients. Felicia, welcome.

**Felicia Speed, PhD, LMSW**
Thank you so much for having me.

**Len Usvyat**
Really my pleasure. Well, Felicia, I think to start off a little bit, can you tell us a little bit about your journey and how you got to this role, what got you interested in and what you do?

**Felicia Speed**
Yes, so I have been in nephrology social work for a little over 26 years and I started out really in hospice as an internship and then I had an opportunity to also have an internship in dialysis and once that happened it really just opened up the door for me to understand all of the facets of the CKD journey.

And that was important to me. I think I had some wonderful nephrologists that would sit down and have those conversations with me. And those conversations allowed me the opportunity to really understand the depth and the impact of psychosocial barriers and just the psychosocial impact that our patients experience every day.

And so, I started out in the facility and worked several, several years, worked on the operations side. And so now I'm in this role after a couple of more hurdles. But I’ve been able to do my research in the beginning when it came to looking at treatment adherence and now, I'm delving into its impact on grief. And so that's where I am right now.

**Len Usvyat**
Yeah, fascinating, fascinating journey. What got you interested in grief? You've done, sounds like you've done some education in it.

**Felicia Speed**
Yes, it really began. I had a patient when I was in, when I was working in a facility and Ms. G, I'm gonna say her name was Ms. G. And I remember I would go and I would sit, you know, I did my rounds and I would sit with her, and she had had cancer before, had breast cancer outside of CKD. And then when she then, she had a hard time breathing and then she got some chest x-rays, and it came back as lung cancer. And so, watching her process that journey really opened up my eyes to the importance of not just looking at the quality of life of our patients, but also the quality of death and her experience in how her roles were gonna change and what roles were gonna be missing in her family's life and how she had to face the end. And literally, all the way to her last day, I was able to truly understand the mortality of life and how she was grieving in her life before her life ended. And then after that, many other patients following her, I began to see that more, even if it wasn't because of a terminal illness, it was because of the loss they were experiencing because of the decline in their health, because of the multiple comorbidities they had, or because there were changes in the dynamics in their family, changes in their financial state.

They were great losses, like loss of my future the way I had envisioned it is not going to be what I had planned. And there's grief connected to that. You know, when they've worked out their life and I'm going to do all these things when I retire. And I remember this one patient, he was so angry, little cantankerous, I guess you have to say. And I was like, why is he so angry? Well, it was because he had worked all of his life, lived the dream of when I retire, I'm gonna travel. And the two days after he retired, he was hospitalized and then told that he had end-stage kidney disease and was gonna have to start dialysis. And he was like; I shouldn't have waited. So dealing with that regret, but then also dealing with that grief that my future that I had planned is now going to look different.

**Len Usvyat**
Thank you for sharing these stories and your experience. Felicia, what would you say is a defining moment in your career that really made you realize this is something you wanted to study more and work in?

**Felicia Speed**
It was really, you know, the Kidney Disease Quality of Life Survey. We started utilizing that, my gosh, it feels like forever now, because I remember it was manual. So, it was very early on, probably like 2001, 2002, somewhere in there, maybe like 2005. And the conditions of coverage came out and we had to start doing the Kidney Disease Quality of Life Survey. And what I started to see is, okay, yeah, we're recognizing and measuring their quality of life, but how do we address when their scores are not great? You know, how do we address getting, what are we trying to get them to? Right? And so, it became a defining moment to me when I recognized that there's a rehabilitative path and then there's a palliative care path, right?

So if I have a patient that is having a hard time, the questions were like, can you push a vacuum cleaner? Can you go upstairs? Okay, when I'm talking to someone who is a double amputee, they have uncontrollable diabetes, they have hypertension, they have congestive heart failure, and an ejection fraction of 15%. And then what am I really supposed to say? Well, let's just try to see how you can have a good quality of life and get you active and get you moving. And that was not the path they were looking for. And I had to pause and stop trying to tell them what I think they should do but really listen to what their desires were in that moment. And when I began to do that. And it was, again, always the patient for me. And there was one patient that did not want me to ask the questions again, because the questions were hard, because it caused them to have to face and remind them of what they could not do. And I was like, you know, I think we need to look at this differently. And that's when I began to dig into anticipatory grief.

And I began to dig into aging and how patients are aging and what their needs are. Are they trying to get out and do a marathon? Is that what they're trying to get to? Or are they just wanting to connect with family and find a way to kind of resolve some of the fragmented relationships that they have? Is that more important? And how does that improve their life or how they see it? And when I began to shift with that, and it wasn't always exactly when I was in the field, it was more after I took other roles and I had to have those conversations with people who were disruptive had disruptive behavior. That's when I had to start listening.

**Len Usvyat**
You know, this is fascinating as I'm listening to you. You are so interested in doing research and investigating these areas. How is how do you think research is incorporated in social work in general? I mean, I think, as you know, Rena Research Institute, of course, is focused on doing research. So how does that tie to our social workers and others, others in the field?

**Felicia Speed**
Oh my gosh, there's so much, you know, I believe that, you know, I love mixed methods, but I love qualitative. I didn't think I did. I think I wanted to quantitate because I didn't want to have to listen to people too long. But what I found is with qualitative and capturing the narrative, it allows you to extrapolate those themes when you're listening and from, you're able to really begin to develop some frameworks and then can shift into that quantitative. But oftentimes understanding how to understand various perspectives, right? Because our death is not created equal. Our grief is not created equally. Our age is not created equal. So, to me, it was how we can capture their stories, find things, but also celebrate the differences because then that helps us to know how to customize the care that we provide. So as social workers, you know, when I look at the quality outcomes that we look at every single month, I want to know what psychosocial barrier is connected to anemia. Like if someone is dealing with anemia, and they're experiencing a lot of fatigue. How does that affect them mentally and emotionally? And

so why is it important that we address the anemia from a perspective of how they live from day to day? When I look at the phosphorus and we're wanting them to stop eating certain foods, but recognizing culture, recognizing that we're emotional eaters.

**Len Usvyat**
Mm.

**Felicia Speed**
How do we connect stress to phosphorus? How do you look at depression and phosphorus? And maybe there's a correlation between those two that we have overlooked. So, I believe that when you look at any quality indicator, there is a psychosocial component that we can't ignore. If you're looking at catheters, what is it about their perspective of self-efficacy?

What is their perspective when it comes to their self-esteem, their image? What are their values? What are they prioritizing? What are some things that are going on that keep them from not wanting to get the catheter removed? And is it because we've used the terminology end stage and permanent catheter? If we were to really explore the terminology that we use every day that is not a part of our everyday vernacular, how do our patients process and understand that and internalize that? Because then we can begin to understand what changes we need to make. And so that's why I feel like social workers, the social work research must be more utilized because the changes that we need to make have to look at the whole person.

**Len Usvyat**
Yeah, yeah. It reminds me little bit of, I think there's this book out there, The Human Face of Data, behind every person and behind every number, there's a real human being with their feelings and their emotions and their needs and their ethnic backgrounds that maybe they like certain food, or they don't like certain food. it's a wonderful topic.

**Felicia Speed**
Yes. Yes, absolutely.

**Len Usvyat**
Felicia, guess I wanna, let's talk a little bit more about aging, which I think many of us probably think about periodically. What do you think are some of the biggest misconceptions that people have about aging?

**Felicia Speed**
What I hear most about some of the misconceptions about aging, one is that their life, that there is no future. They're not thinking about their future, right? And they don't necessarily have plans.

Yes, they do. And we also make us, so it's like when they want plans, it's just that their plans have been re-imagined. It’s kind of like; there was this book I'm reading called Falling Upward. And so, it's just that their perspective has changed, right? And so instead of what I can take, or what I can move my way up in, you know, from career-wise or what's being invested into me. When you get to a certain place in your seasons of aging, you're looking at how can I contribute? How can I, what legacy can I leave? You know, what can I leave behind? And so, you want a place to deposit. And so, when I look at our population, one of the best things we can do is create opportunities for them to invest, for them to deposit, to share their wisdom, to share their journeys, to share what matters most, to share their history and the richness of that. That is so fulfilling to those who are aging. I think another myth is just assuming that all people who are aging want to be surrounded by people. And yes, there's isolation, but there's so many ways to be able to do that. That's something I've learned just dealing with my aging people in my family is they don't always necessarily want to go anywhere.

But they do want to have connections. So, they want you to come to their house or they want to do FaceTime. You know, they want to have ways that they can connect. So it's not always that I want to be around 20 people. I really want to be around one person at a time so that I can have that intimate connection with that person, which I think oftentimes we see manifested in our facilities, which is why oftentimes our direct patient care staff become so close to our patients because our patients get that undivided attention at times with that one person that's willing to listen to their journey. And they're not a loss for words and they can hear and they can see, but it's not always necessarily the physical hearing, but it's what do they hear in their heart? And it's not always the physical seeing.

Yes, you know, their eyes may be going dim, but what have they seen? You know what I'm saying? That they want to share with someone else. So don't be dismissive because we have to work a little bit harder to communicate with them. And, I think we should learn in our culture to embrace aging. It's not something we should be afraid of.

**Len Usvyat**
Hmm. Well, I do think, I think you're right. I think there's often a misconception or cultural barrier to aging being negative. And I think you're right. I think we shouldn't look at it that way. I agree with you.

**Felicia Speed**
Yes. It's And I'm like, you know, hey, I'm seeing my gray hair and they were like, you gonna color your gray hair. No, I am not. I have earned gray hair. I have earned every strand. And I'm gonna walk into, instead of seeing it as an end, I'm just moving from one season to another season.

**Len Usvyat**
There you go.

**Felicia Speed**
Right? And so I get to my fine lines. I'm not trying to necessarily fill them in. If they show up on the camera, they show up on the camera. I am fine with that. These lines mean something to me. They are a representation of my journey. So I'm not trying to fill in my lines. I want to be able to share the stories behind my lines. Right? I think there's just one way, a perspective that we can have about aging that can shift us so that we can still enjoy life in its totality without dread. You don't have to dread it. It's just taking more time to enjoy the moments and being present even more now, which is what I find when I'm around aging adults is that we, I guess I put myself in this category, we are present. We wanna savor every moment that we're in, we're not rushing, we're slowing down. But the slowing down is not just the footsteps, it's the slowing down of I want to savor the moments, right?

**Len Usvyat**
Mm. Yeah, what a beautiful way of thinking about it. Thank you, Felicia. This is wonderful. I know you talked to a lot of not just patients, but also families of course. And what are some of the fears and concerns people have that come up the most often about end of life and end of life care? What are some of the most common things you hear?

**Felicia Speed**
It's the burden of caregiving. As someone is declining, it's not knowing that you need to ask for help. And I see that not only with patients, but my peers who have aging parents. You don't want to necessarily ask for help. You feel like, they took care of me. I should just take care of them. And that should be the end of it. And it doesn't have to be that way, right? Just like when we were growing up, they put us in daycare. They got breaks, right? Okay, so we can still have breaks too, and that's okay. I think that oftentimes there's this, need to feel like I got to fill all the gaps for this person, but it is absolutely okay to utilize your resources because it's so important that as caregivers, whether formal or informal, that we are taking care of ourselves so that we can take care of that person. Because again, that person does not wanna see you running around the entire time that you're with them. If they feel rushed, that's going to make them feel more of a burden than it is if you have someone else come in and do the cleaning. And when you come, you're sitting and you're having a conversation. And so, you take the help, utilize the help where you can, find the resources that are out there. That's the social worker in me. Find the resources that are out there. Find the grants, the scholarships, what you have, so that you can capture on time.

**Felicia Speed**
Because I think that's where we feel more weighted and we feel more burdened and you know, we have this fear as we're watching others age that is this what's going to happen to me? And so we impose our fear onto them by you know, doing more than what's necessary and don't take away independence, right? By doing so much, you know, because at the end of the day, when it's your turn, your grace to age, if you have the privilege to be able to age, then you want to be able to maintain your level of independence, whatever that is.

**Len Usvyat**
What a beautiful phrase, privileged to age. That's a beautiful way of putting it. I love that. That's a wonderful way. So let's talk a little about depression. And I think I'm sure depression affects different people differently and shows up differently in different people. How do you think it varies between younger and older people? mean, obviously people may have depression for different reasons, also at different age. What are your thoughts?

**Felicia Speed**
Yes. Right now, what I've observed is the depression that I see in our older adults as they are exposed to more social media outlets than they ever have been before, they have so much history that their depression, and I'm just communicating firsthand. They are anticipating what they've already experienced before and so it creates that level of depression for them, right? Of the hopelessness and that depression, especially clinical depression, it starts to happen with persistent hopelessness and helplessness that they experience and especially if they were change agents and then they're trying to figure out how can I make a difference now and they don't feel like they have the bandwidth or the space or the proclivities to be able to do that. They don't feel like they have those things that they need to be able to do the things they need to do. Also, I think the depression that we see with aging is the lack of communication because everybody is so moving at such a fast pace. There is some isolation, but like I said, it's not the isolation that they can't live by themselves. They want to live on their own. It's more of the isolation of no one's checking in, right? And no one's communicating with them. So that creates that helplessness, that hopelessness, especially the older they age, the more age that comes, the less people, the less friends they have.

I had an aunt who lived to be 94, beautiful matriarch in our family. And when I watched her depression begin to happen, it was when many of her friends were dying. And so her circle was getting smaller and smaller and there were no people to fill in those gaps that understood. For our younger generation, their depression, what I see is not knowing how to handle current events, not knowing how to handle current pressures of life. Especially in various generations where everything came easy. You know how you know, back in the day, there was a first, third, and a fourth place. And then it was just like, you're not getting a trophy. You're in fifth place. You don't get anything. Okay, well see now it's first, third, fourth, fifth, and then you still may get some type of toy. You're still going to get something because you did something great. So it's, you know, they don't get to experience loss. And then they come into the world and they get rejected or they don't get exactly, you know, they was like, wait a minute, so I'm not going to get anything and how to handle those pressures of rejection and how to handle the cancel culture that we're in. All of those pressures of wanting to be liked, wanting to, and because there's this facade of friendships, they're not really true authentic friendships and those things cause them to be isolated and, in that isolation, it leads to some clinical depression or depression as well.

**Len Usvyat**
Felicia, can you maybe explain to us in our audience what's a difference and distinguish between things like grief and sadness and, you know, more formally clinical depression? What are the differences? I know some viewers may not.

**Felicia Speed**
Yes. And that's one of the things that when I did my dissertation, I really wanted to dig in the difference between depression and grief because for years and years and years, we focused on the symptoms of depression. And what I was finding is they were answering the questions, and it was like, no, no, no depression here. And I was like, but you're but you're sad. But you know, this is going on and some of the symptoms, you're not sleeping well. And they were demonstrating or manifesting some symptoms of depression. And then when I looked at grief, grief has similar symptoms. So the question is there, what is the difference? Well, it's not that. Grief usually happens because of an event, because of a situation, whether it was a loss of a loved one, a loss of the cloud of physical to club, you know your physical activity there's something that transpired now and where in Depression is more of and it's temporary. Sometimes it's temporary. It kind of theirs ebbs and flows I'm not going to say that grief always goes away. I've learned it in my personal life It doesn't always necessarily go away, but there's ebbs and flows it comes and goes depression stays it becomes constant, right? Because it's not based on a particular event. Not saying that some events can't trigger that, but oftentimes it's persistent sadness, but it goes a little further beyond sadness to what I said about helplessness and hopelessness, and it's very dismal. There is no light at the end of that time.

So for grief, there's a light at the end of the tunnel. I see a little light, it's a flicker. For someone with depression, I see no light. I see nothing, there's just complete darkness. And in that darkness, I can't see what my future is gonna look like. People who are experiencing grief don't necessarily feel they don't have a future. They're just trying to figure out how to reimagine their future after a loss. Not that they won't have one.

Someone that's dealing with depression doesn't see a future. And if they do, they don't see it being something that they want to live in. And that's why we have to be so careful with suicidal ideation because of that. so I think with grief, it's more about just listening and not necessarily wanting to medicate or to numb that experience because that grief came from a place of love, whether they loved their significance, they loved their identity, they loved the person that they lost. Whereas depression, we need to dig in and find out what is the root of that, you know, saying what are the true root causes? We got to do some digging to really get to what are causing the thoughts that you have and then recognize is it clinical? Is it hormonal?

You know what saying? Is it because there's a chemical imbalance and you need some assistance with that? And understanding how to be able to treat that appropriately and then helping that patient understand or that person understand the difference between that. So it's very important that we do not medicate grief.

**Len Usvyat**
Really fascinating. Felicia, you've mentioned already a couple of patient stories, but I'd love to hear if there's particular patient story that has always stayed with you and really maybe changed how you approach your work today and your life today.

**Felicia Speed**
Now you may make me emotional. Okay. A patient that really meant a lot to me. I'm gonna call Miss E. And Miss E, it was just her and her husband, they had no children. But they were so happy and they were so in love. Her husband would sit out in the lobby and we would sit together and I would go around and I would do my best. I always try to make sure I saw each patient at the same amount of time. Because I didn't want one patient to feel like they were being left out. But she would pull me on to try to get me just an extra few more minutes.

One of the things that she shared with me from the very beginning caused her to grieve, she wasn't depressed. She was grieving because she was like, no one will know that I was here. After my husband leaves, if he dies, no one will know I was here because I haven't been given the opportunity to pass something down. I haven't been given and she had a beautiful voice and but one of the things I noticed is Outside of all of her amazing stories was that she crocheted most of the time when she would sit there she would crochet So I said, okay what I'm gonna do as your social worker I'm gonna let you teach me how to crochet I said I know how to knit but I don't know how to crochet and so each time once a week.

During my rounding, she would use that time and I would sit there and I would only have like a little piece because of infection control. I would have like a piece of yarn and my needle and I will let her show me how to do a loop or patch, you know, and I would do like pot holders or whatever. Oh, it gave her so much joy, right? But guess what? To this day, I have, and she's already passed on, but I still do blankets and

I still, you know, do shawls and I do all those things and I remember Miss E. So, in my heart, she was able to still pass something down that, and in some way she still lives in the art of my crocheting. And so if I was able to touch or impact her life, that she was able to have some closure in her aging and in her, you know, and in her last days, if I was able to impact her in that way, then I'm grateful. Because I've taught other people how to crochet. So it's like her legacy lives on.

**Len Usvyat**
Beautiful. Thank you. Felicia, thank you for sharing that. Many years ago, you've mentioned something in one of your presentations that certainly told me and I'm sure many others about always having something to admire in life and be appreciative of something. And so I can tell you, I always have a little reminder in my notebook to think about this and it's thanks to you. So thank you. Well, Felicia, I know where I feel like I could talk to you for hours, but maybe a couple of other kind of thinking more about advice and some reflections moving forward. Is there any advice you can give to families that are caring for somebody who is aging and you know has depression for example, what would it be? What is one or two pieces of advice you would give to family members?

**Felicia Speed**
Listen for the need and don't assume what the need is. Oftentimes we think, if they have the right food, they have, long as they have all of their needs, they're tangible on the Maslow hierarchy. If they have their basic needs met, that's the tangible support. Then we're like, we've met it. They shouldn't be depressed because they have everything they need.

And, but ask them what they need. Because you'll find that sometimes their taste buds have already left them anyway and the food doesn't even taste the same that it used to. So it doesn't really matter. It's not necessarily the meal, it's who they're eating with. That means even more. So ask them what their needs are and create opportunities to journal with them or to allow them to journal, capture their stories, capture, allow them to go back in time and share with you tidbits of their stories and be able to have that in a place that can be shared. One of the patients that we had, every dialysis treatment, she would be there and she would just be writing the entire time. And so when she passed away and I spoke with her, her daughter, she had two daughters, two young daughters, like 15 and 18. And I was like, hey, you know, I'm so sorry to hear about your mom. She was a beautiful lady. You have the notebooks, right? And they were like, what notebooks? And I said, no, no, they're green. There's one green, there's one pink, and there's a blue one. And I said, you need to go find those notebooks. And they went searching and they found them. And she was speaking to them and she was talking to them through those journals. Just simple, you know, composition notebook, just different colors. But she was having conversation with them and was able to tell them how she felt, that she felt like she couldn't do verbally, but she had something that she could share. So allow them to be able to share their narrative, share their story. People love, just like I'm enjoying sharing my story now, people love opportunity to share their story with undivided attention.

**Len Usvyat**
Nice. know, as you know, at Reno Research Institute, we're always interested in doing more research. And I think maybe one of the questions I have for you is, again, you're very involved in research as well. And how do I make sure to involve more of our social workers and others into doing? Yeah.

**Felicia Speed**
Ask us. I cannot tell you how many social workers have approached me or have submitted, have said, know, hey, how can we get more involved? I've gotten, you know, I've attained my PhD. I'm really into research. Several of them have submitted abstracts to, you know, various NKF and things of that nature and have had posters and things. I think we need to, you know, they started it, but you know, it was recognized, but we didn't go any further. So it would be great if we would just take what has already been established and move further. Like for myself, I am so interested in patient burnout right now. And I am looking for an opportunity to validate a tool for that because we don't have, it does not exist, Lynn. I have done my research. There is a gap.

There is not a patient burnout tool. And imagine if we were able to see that, identify that as create the tool and use that as a predictor for home therapy. You know what I'm saying? For home therapy retention. And I'm just like, social workers are sitting around thinking about things like this all the time. We're always looking at how can we improve the patient's quality of life, but how can we have some standardization, how can we predict, how can we tie in our theoretical frameworks with research and data so that we can bring about change in a lasting way.

**Len Usvyat**
Felicia, I certainly think sending the voices of our frontline staff is so incredibly important. I think you, social workers, dieticians, nurses have so many ideas and so much to say. And as I think you said, we just need to make sure we listen and we give it our opportunity or ask if they don't raise those concerns. So fascinating.

Well, Felicia, I could talk for hours but thank you for your time today. I think it's been incredible. I think it's an unbelievable discussion and so important that all of us are irrespective of whether we're in kidney disease or any other field I think we're facing but aging and depression. And thank you. Thank you for your time.

**Felicia Speed**
Thank you so much. I really, really enjoyed this moment. I hope we get to have more.

**Len Usvyat**
And thank you to our listeners for joining the Reno Research Institute for this episode of Frontiers in Kidney Medicine and Biointelligence. We invite you to connect with us on our social media channels and stay tuned for future episodes as we continue sharing insights and advancements in kidney research.