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Speaker 1: Navigating Parkinson's disease can be challenging, but we are here to help. Welcome to The Michael J. Fox Foundation Podcast. Tune in as we discuss what you should know today about Parkinson's research. Living well with the disease and the foundation's mission to speed a cure. Free resources like this podcast are always available at MichaelJFox.org.

Lisa Volenec: Hello everyone and welcome to The Michael J. Fox Foundation's Parkinson's podcast. I'm thrilled. I'm honored to be your guest host today. My name is Lisa Volenec. I was diagnosed with early onset Parkinson's back in 2014. I can hardly believe that. I'm an advocate for the Parkinson's community and a Teen Fox fundraiser, and I'm the general manager for the CBS Affiliate KMTV right here in Omaha, Nebraska, my hometown. One of the things about Parkinson's is it certainly kind of tears through everybody's life at kind of rapid speed, right? It just ripples through the community, your own community, certainly starting of course with the person who's gotten the diagnosis and impacting the social network. Parkinson's can affect many kinds of relationships with care partners, children, parents, grandkids, friends, siblings, chosen family, colleagues, and rules can shift, right? That person who was there maybe in the beginning may look different later on in life.

The communication may have some challenges and changes and connections might look different than they did before. Today we're going to get into all of that and answer community questions on Parkinson's and relationships. And no big surprise. The foundation receives thousands of questions every year from community members at events and online. I was at an event back in May and bombarded with questions, and the community certainly has questions about love, relationships and the complications of staying connected with Parkinson's when that becomes part of the picture. So today I'm thrilled to be joined by a panel of experts in this topic and they're all going to answer some different questions and offer their perspective and experience. We're going to start with Becca Miller. She's a psychologist and associate professor at Yale School of Medicine and a mom. She's a member of The Michael J. Fox Foundation's patient council and was diagnosed with PD a year before I was in 2013. Thanks for being here, Becca.

Becca Miller: Thanks so much, Lisa, for having me.

Lisa Volenec: Next we have Mike Kelly, and Mike is a husband, father to three, grandfather to four. He's an avid teen Fox member. He's also been married for 46 years. He was diagnosed with PD in 2004. Hi Mike.

Mike Kelly: Hi.

Lisa Volenec: Great to have you here. And last but not least, we have Courtney Doherty, who is a registered clinical counselor in Vancouver, BC Canada. Mom of two young boys. She specializes in working with the Parkinson's community and her father lived with Parkinson's Disease. Thank you, Courtney, for joining us.

Courtney Doherty: Thank you so much for having me.

Lisa Volenec: So I'm going to start with Mike and Becca and you kind of got to probably think back a few years. Could you share one reflection on how your diagnosis changed your relationships in your life? Anything that stands out?

Mike Kelly: I don't know if it changed my life. My wife and myself went to the doctor's office the day we were told right there. As soon as we walked into, "Hey, you've got Parkinson's," this, this and this, and we just kind of looked at each other and said, "Okay, we'll take care of this." Of course, that wasn't exactly the way things have been, but from there we just took it and ran. We never slowed down. Eventually we got to the point where we were running the New York Marathon. I ran that four times and never had been a runner, and my wife was right by my side and not running it, but there, and it's been okay.

Lisa Volenec: Mike, I can barely run upstairs or run to grab the phone, and I've always joked that I'm only running if somebody's chasing me. So that is very, very impressive and you should be so proud of that. Becca, how about you?

Becca Miller: Mike, I'm so impressed with your running and your marathon achievements. That's fantastic. I think for me, I was diagnosed when my daughter was nine months old, and so I really had a crisis at that point as a mom wondering how was I going to manage this and what was I going to do kind of moving forward? And I was lucky enough to have a psychiatrist who I was working with at the time who said, referring to my daughter, he said, "She doesn't really care about your diagnosis, she just needs you to be her mom right now." So that really helped me kind of reset and refocus, I think my priorities on what I needed to do as a mom as opposed to focusing on my Parkinson's per se. And that was really helpful to me.

Lisa Volenec: For sure. And Mike and Becca, I'm sure you can relate. I know when I received my diagnosis, the whole world felt different, least of all the relationships, and I chose the most unhealthy route of not telling people because I was single and I was climbing the professional ladder and I was afraid that I would be denied promotions or growth in my career if I would have shared Parkinson's. I don't know that. It was not the wisest choice because what has come from sharing my diagnosis since then has just been amazing and its connections with the Parkinson's community and others and just such a healthier existence of living my life with Parkinson's. It doesn't define me, it's just part of me. Courtney, how about you with your father? How did that maybe shape your relationship, change your relationship with him?

Courtney Doherty: I'm so fortunate to have had and still have such a close relationship with my dad, really very close, and I'm the youngest of three girls, and so I remember him telling us, and at first it's like, "Well, what is Parkinson's?" Oh, it's that thing Michael J. Fox has. Not a lot of people know. And so educating yourself on it, learning how it's impacting him, that was my response. And fast-forward to now, I've been working with that population for 15 plus years, and so really dedicated my whole life in a way to trying to help everyone. So I know he's proud of me and we just, I learn and grow along with him and teach my family. And so yeah, I think it's bonded us in different ways and it's taught us a lot.

Lisa Volenec: For sure. Courtney, this seems like a silly question, but why does Parkinson's impact relationships in general?

Courtney Doherty: Oh, well, yeah, it's a big question. I mean, it changes so many things. First of all, what is Parkinson's I was just talking about, right? How does this impact our life? What does this look like? There are so many questions, so many unknowns, a lot of anxiety that comes with the diagnosis. Communication can change not only because of different things like apathy and some other non-motor symptoms, but also speech can be impacted and cognition can sometimes be impacted. And so there are so many different reasons that relationships can shift and change. And so it's super important to communicate.

Lisa Volenec: It's important to communicate, and it's like, I'm just going to go... For 10 years I'm just going to be silent and not tell anybody, which is, again, do not do that because we can talk about that later, how wonderful it is to share that information with people who love you. But obviously a lot of the questions receive are about that parent-child relationship regardless of the age. And there's certainly a big difference between having young children and older children and adult kids. So Becca, you said your daughter's 12. How did you decide approach and have that conversation with her?

Becca Miller: Yeah, I mean it's interesting because she has never known me without Parkinson's, so that's an interesting phenomenon. I really tried to start introducing it in ways that were kind of developmentally appropriate, I hope at least. But if she saw my dyskinesias or she saw my being slow or I had to... Just, I couldn't do something with her, I would blame the Parkinson's. So I tried to make the Parkinson's the enemy in a way that we could both kind of say, "We hate Parkinson's." Because I was frustrated too at not being able to do things or having to stay home, for example, when she wanted to go to the park, if I were too tired or had symptoms. I think that was helpful for me and kind of externalizing it and having it be not... I mean, she could be mad at me if she wanted to, but then we could both be mad at the Parkinson's.

I also got a little disco ball for us to do the dyskinesias with, Disconesias. And so trying to make it a funny thing in a way, that's a... It's not my invention, it's Tom Isaacs who came up with that term, but trying to make it something that we could laugh about also as well as be frustrated with. So as she's gotten older, she's gotten involved in the Parkinson's community, and that's become, in a way, her community. She knows a lot of my Parkie friends and she kind of is known to them. And so she has friends too who are people with Parkinson's. And I think my proudest mom moment was recently she spoke at a World Parkinson's Congress on a panel for them about kids whose parents had Parkinson's. And that was really like... Yeah, I'll tear up if I start talking about that too much.

Lisa Volenec: It's amazing too, 12 years old and probably has more knowledge about the illness than the average individual. Right? And I love that you had her try to take her emotions and turn them towards Parkinson's and not at Mom. "Let's be mad at Parkinson's together." And I love that. Mike, your kids were certainly older, so how did you prepare or navigate that conversation and was it anything that you were nervous about and maybe even their reaction?

Mike Kelly: Well, I didn't really think there would be any problem with the reaction or whatever. My kids have been very good all along. We handled it and we're still handling it the same way through those foundations, the fundraising, but also we do a lot of exercise. I've always felt exercise was best for any illness you have. The more exercise you get, the better you're going to feel, and then hopefully that'll come along and help you with your illness.

Lisa Volenec: That is awesome. Becca, your daughter's a little bit older. Do you find that your conversations have changed or evolved? Obviously she's gotten a little bit older and more aware of all aspects of this illness.

Becca Miller: Yeah, I mean, I think one of the more challenging conversations was about the DBS when I had DBS surgery. So that was about four years ago. She was a little bit younger, but that was I think more actually anxiety on my part about bringing it up to her. She instead had some very funny questions, which was, "Are you going to become a robot and if so, can I control you?" So I was like, "Okay." All my anxieties about... Oh, and then she had concerns about what shaving my head was going to look like and kind of working through that.

So it's such an important thing to bring up to them and then hear I think from my daughter what her concerns are. I can make all kinds of assumptions about what she's going to think and what I'm afraid she's thinking, and then it turns out to be something totally different. So I think that that's been helpful for me to... I can have my own imagined concerns for her, but then really I need to hear from her. And sometimes really she's just more concerned about her own life and her homework and her school and her friends. And Parkinson's, she's like, "I got that." I try and leave the door open and the conversation open, but sometimes I'm the one who wants to talk about this stuff much more than she does.

Lisa Volenec: Mike, has your conversation changed with your kids since your illness has progressed or evolved at all?

Mike Kelly: I'll tell you within the last couple of years it's been a little bit more, "Well, let's watch out for dad." And that continues on, and my wife's the same way, and they do take care of me, and I'm accepting that fact.

Lisa Volenec: They love you, Mike. They love you.

Mike Kelly: Yeah, it's changed, but it's changed for the better.

Lisa Volenec: And I'm so grateful for the people that I have in my life that want to support me. And there's recently been a situation where I fell and I had to get some help. It wasn't all that fun, but they were the first ones who wanted to grab each side of me and pick me up and get me up and moving, and I'm so grateful for that. We've also had so many questions about those adult-parent relationships, and Courtney, how do you support aspects of that role reversal where you're now caring for your parent while still honoring kind of, "That's dad," right?

Courtney Doherty: That's a tricky thing I think is going from sort of the child and having a parent and then there is a bit of that role of reversal. I think again, communication is key. Saying things like, "I don't really know how to support you, but I want to, can you tell me? Is this too much?" Because you also want to let them stay as independent for as long as they possibly can. So really just offering support the way you know how and then saying, "Hey, am I getting this right?" Checking in and say, "Hey, is me helping you do X, Y and Z helping or is that something on me?" Right? Similar to what Becca was saying, she is sort of assuming her daughter's going to think certain things or communicate in certain ways, and it's often not what the story we tell ourself is. And so checking in, getting help, and I actually am caring from afar as well.

So my father's actually in Toronto where I'm in Vancouver, and so calling a lot, having a certain routine when we do speak, making sure there's no other distractions, being kind of concise when you're speaking and having a plan to speak again. And so there's different strategies. I also think it's really important if you do have siblings, let's say, that you all kind of communicate with one another and get on the same page of, "Okay, so how can we help dad? Can you guys go visit this time of the year and all go that time?" And there is a lot of different navigating, but again, it is so dependent on what stage of the disease they're at and everybody's circumstances.

Lisa Volenec: I think that's a really important point though, is because a lot of times you do live away from your parent and you can't get on a plane every single time that you want to. And there's times that you're on the phone and you're like, your gut's telling you, "I need to book a flight." So maybe can you give some advice about what can you do when you don't live where your loved one is?

Courtney Doherty: Yeah, I think again, it depends, but it would be communicating with if they do have a care partner, if you do have a mother or in my case, a step-mom in the picture, communicate with them and say, "What would be helpful for you?" And can we make it work if, "Okay, well I can't come that often, but I can come at this time of the year, what would be most helpful?" And trying to get your siblings on board as well, but that's a whole other podcast itself is that can communication piece with siblings, getting everyone to agree. And it's really vital, I think though, to the ongoing care of your loved ones really.

Lisa Volenec: And I would suspect you want your loved ones, as you have said, to have a voice in this. Sometimes there's hard kind of conversations as the progression can evolve.

Courtney Doherty: Yes. And oftentimes with my dad, he's very much like, "No, I'm okay. Everything's great. Everything's fine, don't worry." And so you have to kind of between the lines and say, "Hey." Or you get creative, right? Not necessarily saying, "I'm coming there to check on you," so to speak, even though maybe we are. It's more like, "I miss you, I want to come visit," which is also a part of it, but it's the way you're communicating with them and letting them know that it's not just all about Parkinson's either, right? I just miss him often. Parkinson's is one piece of the pie, but there's a whole other pie there. It's multifaceted and they're not only Parkinson's. There's so much more to them.

Lisa Volenec: Mike, can you tell us, and you don't have to elaborate if you told your grandchildren or if you plan to tell them?

Mike Kelly: I don't have any problem telling them. I mean, that's a wide open issue for me. Just like the one Marco, he was laying on the couch next to me and he said to me, "What's wrong, Papa? You're shaking." And I said that, "I get that from the medicine I take," and basically it's somewhat true, but I wasn't going to go into a long spiel about Parkinson's with a five-year-old. But they do recognize difference.

Lisa Volenec: We might not give them enough credit for how much they understand and they're okay with it. Just kind of like what Becca was saying, it's kind of like they have their lives and they don't focus on it because this is just Pop-Pop and he just shakes a little bit here and there and we all kind of try to find some humor and some tough situations. And I certainly laugh at myself and try to make a joke and make light of it too. And I don't know if that helps or if you do that with your grandchildren, Mike?

Mike Kelly: Anything they ask me, I would tell them, but I didn't want to go and bring it up just out of the blue.

Lisa Volenec: It might be a little bit of information overload in between some of the things that may be more their speed at this point. Right?

Mike Kelly: And you think that they don't want to know, or how come they're not asking me problems or why aren't there parents telling them? But I know why. There's no reason to keep on saying, "This is what's wrong with Pop-Pop. This is what's wrong with Pop-Pop." If you're near them, they need the same protection I guess as any child in any family with or without Parkinson's.

Lisa Volenec: They just want your time and love and attention, right? And just get to spend time with you. So Courtney, one community member, they wanted to know if someone needs to fully understand and accept their diagnosis before telling their grandkids. And how would you advise someone who came into your office and kind of posed that question, if you will? Because look, I don't know if I even fully understand my diagnosis and I'm 11 years into it. So how do you answer somebody that can pose that kind of question to you?

Courtney Doherty: It's not that black and white. I think no is my first answer because I agree it may be a life-long acceptance process. It shifts, it changes. It's not linear. And so I don't think we should wait ever for that. I do understand, you were saying that you didn't really tell anybody for a while. My dad was the same. He had a big job and this and that, and he was young and didn't want anyone to know. But I'm kind of the opposite. So I have my own two little kids and I do share, I think it's... A little bit though, right? To the appropriate age group. "This is why mommy has to go by herself this time to visit because he has something called Parkinson's and it's when your brain doesn't work as smoothly as it used to. And sometimes it's bumpier," and I can give them analogies comparing it to cars and things like that, that are, it's age appropriate for them and they're kind of like, "Okay, that's all. That's cool. That's all," right.

And that's kind of why his voice is quiet on FaceTime and it's not as loud as it used to be, and I always tell them funny stories about before. But yeah, no, I think it's important to say what you want to say and you don't have to over explain. I think that's the thing. We are so nervous and we often over explain and over share things, but you don't have to. You can say, "Listen, I was diagnosed with something called Parkinson's and I don't know that much about it myself. I'm going to learn. We can learn together. Tell me how much you want to know." I think obviously knowledge is power, so educating oneself is very important. I think it also can be a bit scary. I'm so for saying things like, "Listen, I don't know how to talk about this and," dot, dot, dot, "we need to talk about it," right? "I'm scared to bring this up and," blah, blah, blah. Whatever it might be. So prefacing it with, "Something's going on here, we don't need to talk about a whole lot," but it's better than the power it holds over you when we keep it quiet.

Lisa Volenec: I would suspect that the individual, the Parkinson's patient, just like the disease, the illness and symptoms are so different for everyone, so is whatever the relationship might be with young children, whether it's grandchildren or your own children. And you know what they can and cannot handle probably and what you should and shouldn't tell them because you know that better than anyone.

Courtney Doherty: You said it. Everyone is so different. We always say you walk in a room with a hundred people with Parkinson's and you'll see a hundred different cases of Parkinson's, but talk about relationships, especially family dynamics. There's so many variations and so on and so forth. And communication is often the struggle and the challenge. So yeah, I think it's everyone's discretion, but maybe you do, you get someone like me involved that can kind of help navigate conversations and whatnot when it is really tricky.

Lisa Volenec: A lot of folks wrote to us about relationships with their loved one. Mike, we got to talk to you about this one because you've been married for 46 years and it sounds like such an amazing marriage. You've had Parkinson's for nearly half of your marriage. How have you and your wife adapted and have dealt with the changing circumstances in navigating a bit of that?

Mike Kelly: Well, she's a registered nurse, retired, so she's in that field, not Parkinson's, but having to deal with that type of stuff. And she has just... She's taken care of me, let's put it that way. Even when I was totally healthy, she was always there to take care of me.

Lisa Volenec: She's a retired nurse, so I'm assuming she's keeping you in charge and keeping, making sure that your care is number one, if I had to guess.

Mike Kelly: And I was not in exactly a great profession that anybody would want to get into. If you know anything about asphalt, it's hot. And then since we've sold and I've gotten older, it's more of her taking care of me rather than me taking care of her at all.

Lisa Volenec: That's why it's love, Mike. And that's what's so incredible about the relationship that you have and the testimony to the 46 that you've had, 46 years with your wife. Courtney, I'm going to go back to you because romantic relationships can be impacted so much with just time and then life, and then you throw Parkinson's in there. And so how do they change with Parkinson's?

Courtney Doherty: Well, it can change in various ways from physiological changes, like shifts in libido and energy and just motor symptoms, so physical symptoms sometimes getting in the way to some of the non-motor stuff, like when someone is feeling anxious or maybe depressed or has apathy. Often things like intimacy and maintaining different elements of a romantic relationship can be not as high up on the priority list. And so it really is. And when you're in a romantic intimate relationship, it's about renegotiating roles possibly. Oftentimes things can maintain quite the same for a very long time. So I think at the beginning, fear can kind of take over and wondering, "What's going to happen?" And, "Everything's going to change." And then you can kind of come to realize, "Well, actually, no, this is,"... In essence if it's through Parkinson's, it is slow progressing. And as Mike mentioned at one point, exercise is key to slowing the progression.

And so notice when it's fear, when fear is taking over versus facts and really zooming it into factual information we have and working with that. So if things have not actually changed, then you keep going as you are and you remind each other you're on each other's team. And then if and when things maybe are a little progressed and do change, renegotiating roles like saying, "Hey, would it be helpful if I start to learn to do a little more of the cooking and some of the preparing, or should we be ordering in more?" It's about getting on the same page with one another and maybe creating new structure and new routines and systems in place that will help one another because at the end of the day, you're still together, you're choosing to be together and you are on the same team. And so it's a partnership and sometimes things shift in roles.

Lisa Volenec: I got to bring my girl Becca back into this because, Becca, you and I are single. And so it's a whole different world out there for some of us single folks living with Parkinson's. How do you ask for help and who do you ask for help from? Obviously you have your daughter, but I'm talking from a relationship standpoint because you don't have the live-in care partner. I don't either. And so I have a 12 pound Shih Tzu who I ask for help, but so tell me how you kind of navigate some of that.

Becca Miller: Yeah, I mean, I try and keep my circle of friends close to me and kind of distribute or titrate how much I depend on each person so that no one gets overwhelmed. And I still have my parents in my life, which is an interesting thing because they're much older, so they actually need some care too. So they want to care for me, they want to help me out, but meanwhile, they're in their eighties now and they need certain level of care too. So that's sort of a negotiation.

I think dating with Parkinson's is really a challenge too. I mean, it's always like... I don't know. It's a funny thing because it's like you think, "Oh my God, no one would ever sign up to want to be with me when I have Parkinson's." That has gone through my mind, but then as it turns out, I'm like, "Actually, that person is not for me." It doesn't matter my situation per se, but I'm still picky or discriminating or whatever, that I still want to find someone that I want to be with, not just to recruit a care partner for.

Lisa Volenec: And we also want to make sure they have less baggage than us. So I love that because you're like, "Whoa, I've got Parkinson's, but you got a whole lot of other stuff going on." I think the next big important topic is friendship. We all get by with a little help from our friends and that the friends can include your colleagues, your neighbors, or those lifelong friends. I'm going to start with you, Becca. Tell me a little bit about your community of friends and what that looks like for you.

Becca Miller: Yeah, I mean, I have a couple friends who I'm lucky enough to have known since actually nursery school, so they're more almost like siblings, and so just people that I know I can count on and call upon. They came into town for when I had my surgeries. They were a sounding board for that when I was trying to get together everything for that, for when I had my DBS surgery. And then also I consider my brother one of my best friends also. So he's family, but he's also a close, close friend. So I think that that just having friends and then just having a community of what they call loose ties, like folks who you can call up for a particular reason or to help you out with... I have a dog and three cats, which someone to help take care of them if I'm going away for something like that. Just keeping kind of a broader circle of acquaintances as well. And I think having my daughter actually helps keep me involved with different people and meeting people, which is helpful. I think as an adult it gets harder to find friends.

Lisa Volenec: And I think sometimes we just get more selective in general as we get older. Mike, how about your friends? Tell us a little bit about the friendships that are most important to you.

Mike Kelly: Well, the most important ones are the ones that we've had forever it seems like, since our kids were in grammar school. They tend to be the closest of friends. I mean, I go out to a sporting event, of course, if I'm playing in a golf outing or whatever, a few people each week, folks will come up and say to me, "You're doing something I could never do." Obviously that's not true, but it's nice to hear them say, "I's nice for you to give it your best." And I do. I'm not very good golfer.

Lisa Volenec: What's your handicap?

Mike Kelly: About in the low thirties. Terrible.

Lisa Volenec: Well, you know what? A great day of golf is better than anything. So I just love to get out there and while I still can and sometimes I get a little extra boost with the tremor and a swing. And maybe it goes a little bit further, but I want to ask for all of you, how do you keep your relationships going in an off day or when you're just maybe not feeling a hundred percent or up to the challenge of seeing people or things like that days where I'm just like, "I got to turn off the world." But I still love my friends and I'm grateful that they're there. How do you keep things going with your friends when you maybe don't feel like it? Sometimes?

Mike Kelly: I don't really have an answer for that because to be honest with you, most of them have been great ever since I've had it. But I mean, I go back to the fundraising stuff that's all through the Fox Foundation and stuff, and there's people that we've been with since the beginning, when they were first opening up their doors and they're still around doing it even with their parents not with us anymore. Those type of people are there and they're willing to give support and whatever you need. And in some cases they'll come over and sleep overnight in our extra bedroom or something and just giving of themselves. That's what a friend is.

Lisa Volenec: And I think Mike, you pretty much inspire a lot of people and they want to be around you, and you've got that personality and that heart that keeps drawing people to you. Becca, how about you? How do you navigate and keep some of your friendships strong even if you don't feel like it and you're having one of those off days or something like that?

Becca Miller: Yeah, I mean, I think one of the things about Parkinson's being progressive is that my friends have kind of seen me change little by little and adjusted to that. And then also I think sometimes I'll just tell them, "I'm having an off day and my symptoms are coming. I can't talk right now," and then just try and... And they're understanding and I'll do my best to call them back. But I think it's so important to also keep reaching out because I think as much as I think, "Oh, I'm alone, I'm feeling lonely," so are other people. And when you reach out to them, they're like, "Oh, thanks for calling." You know what I mean? So reminding myself of that that other people are oftentimes just as much kind of lonely and anxious as you are.

Lisa Volenec: 1000%. And one thing, after I started sharing my story, of course I didn't want to be in this club. I didn't want to be in the Parkie Club. But then when I started making connections and there's buddy networks and different support and social groups and meeting other Parkinson's patients has been so therapeutic for me. The one thing that I will say, and Becca and Mike, this applies to you. Everybody I meet with Parkinson's and in this community, they're the coolest people.

They are people I would want in my circle. And I sometimes get mad at myself for denying myself that opportunity to have those connections sooner because I chose silence, however, I'm absorbing it and taking as much in as I can because the Parkinson's community and these networks and connections are just so critical I think, to this disease. We're fighting and we're going to go back to communication. Courtney, we have to work on communication. And I should have worked on it 11 years ago and I didn't. But how can people work on communication and keep that important even as the disease is evolving or even just on tough days, if you will?

Courtney Doherty: Yeah, I think it starts actually with the self. So I think some self-awareness around, "Okay, what is happening for me?" So often we're just going through our day sort of mechanically. We're not even aware of what is happening for ourselves emotionally. And so if you can tune in to, "Okay, what is happening with me? Oh, I'm feeling a little nervous. Oh, I'm feeling a little scared." Oh, maybe you're a care partner or a person with Parkinson's or a child or whatnot, but first noticing the feeling within you and then expressing it to your loved one and your relationship. So I love that Becca said when she's having a hard day, she'll just say, "Hey, listen guys, I'm having a really hard day," and people want to hear it. So often I hear from clients is they don't know how to talk about it with the person with the Parkinson's, right?

So sometimes they put the ball in the person with Parkinson's court like, "Well, they don't talk about it, so I don't want to talk about it." But they also do want to talk about it. So saying, "Hey, I don't feel good right now." And then as a friend, just somebody with the Parkinson's saying, "I don't want to make it all about the Parkinson's, but how are you doing today? How can I help? Can I do this?" Making it very concise when you're speaking, depending on the stage that the person may be at with their Parkinson's. If they're more later stages, you'll want to speak clearly and slowly and give them time to respond.

So there's a variety of different communication skills and strategies, but starting with the self, noticing what you are feeling and then communicating that to the other person. So even if it's like, "I'm really nervous, I think you're progressing and I am scared and I'm sad," and allow them that time and space to respond. Sad isn't bad. I think we always apologize when we're getting upset, but sad isn't bad. It's better to communicate, get it out, and then your connection is so much stronger and both parties feel better. So instead of tiptoeing around the case and being afraid to upset someone else, I think bringing it up is better than not bringing it up, in a gentle way.

Lisa Volenec: I would agree. And I think that speaks to what Mike was also talking to, that the friends have rallied around him since the beginning. They're going to continue to rally even as things change. And Becca brought up a great point too, that's saying, you know what? Somebody else might need you to check on them just because we're just people. And I was talking with another Parkinson's patient and she said, to your point, "I don't want this disease to be the center of the discussion, but I want somebody to say, 'Hey, how you doing?'"

And I could be saying, "Gosh, I just watched my Huskers lose," which I hope I don't have to say that this whole football season, but I'm afraid that I will at some point, but it doesn't have to do with the illness. It's just that human connection, right? It is so, so important. Again, making those connections, keeping those connections, being honest and deciding what you want to say to who and when and being okay with it, I think is really, really critical. Of course, I want to thank all of the wonderful panelists who joined me today for this episode and making this such an easy thing and fun thing to do. Mike, Courtney and Becca, thank you so, so much for your time. It was great to have you.

Becca Miller: Thanks so much, Lisa, for having me.

Courtney Doherty: Thank you so much for having us.

Mike Kelly: Thank you.

Lisa Volenec: There's going to be links to the Buddy Network that we talked about, other resources in the show notes. Please rate and review the show. It helps listeners like you find our podcast. And thank you so much to the foundation for asking me to fill in. I'm Lisa Volenec, your guest host, and thanks for tuning in everybody.

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