

Dave Iverson:

Hello everyone, and welcome. I'm Dave Iverson, contributing editor at The Michael J. Fox Foundation and an emeritus member of the Fox Foundation's patient council. Our topic today, as you all know, is caregiving, and it's a subject that I think affects everyone whose lives are affected by Parkinson's disease. And that's whether that involves care for ourselves, for our spouses or partners, our parents, or our siblings.

In my own life I first experienced caregiving witnessing my mom taking care of my dad during the late stages of his Parkinson's disease. And then decades later, I experienced it more directly when I became the principal caregiver for my mom during the last 10 years of her life. And while I happened to be doing really well 15 years since of my own diagnosis with Parkinson's, my wife still keeps a sharp eye on me as I have tried to do for her during her own journey with breast cancer a few years ago. I guess I'm saying all this because I really believe that caregiving is universal. We all experience it, and we all experience it each in our own way. We are challenged by it, I think, and also changed by it, and that's what we want to talk about today.

One other housekeeping note before I introduce our panelists, we've already received lots of wonderful questions from all of our webinar participants today. We will do our best to answer as many of those as we can. And you'll see a little Q&A box on your screen. If you want to add a question now or throughout the hour, do that, and we'll get to those questions as our webinar progresses.

Let me introduce who's joining us today. We have Christie and Prentis Brooks joining us. They join us from Tempe, Arizona where they both work as human resources professionals. Christie was diagnosed with Parkinson's back in 2013, and Prentis is her husband and care partner. So Prentis and Christie Brooks, thanks so much for being part of our discussion today. Taryn Fixel also joins us. She's managing director of Liminal Ventures in Santa Monica, California. Liminal invests in health and wellness technology companies. Her father has lived with Parkinson's for more than 20 years. Taryn is also a member of the Fox Foundation's leadership council. Taryn, welcome, and thanks for being part of our discussion as well. And last is Amy Chesire. Amy is a licensed clinical social worker at the Parkinson's Foundation Center for Excellence at the University of Rochester in New York where she joins us today. She provides counseling, guidance and support to families living well with Parkinson's disease, and to assist in that process. So thank you all for being part of this discussion.

And Prentis and Christie, I'd like to start with you and ask you to sort of go back in time a little bit to your diagnosis, Christie, back in 2013. After you spent some time, I'm sure getting used to the reality of that diagnosis, I'm interested to hear what your first thoughts were about Prentis, really, and about how he would be able to provide the kind of care and support that you thought you might need over time. What did you think at that time? What, if any, were your concerns about how that might unfold over time?

Christie Brooks: Okay, Dave. When I was first diagnosed, Prentis was out of town on a business trip, and I was home by myself. I went to the neurologist, got my diagnosis and went home. Of course, he came home that night from on his flight, and one of the first things I said to him after I said I got the results from the neurology appointment, I said, "You're going to have to take care of me one day." And he said, "Okay." And I said, "I don't want you to take care of me. I don't want anyone to take care of me." I wanted to be very independent, so it was very hard. And he just stepped into that role and said, "I'm going to do what I need to do. I'm here for you." And so that became a very good thing as we saw, eventually I would need... When you say that your wife keeps a sharp eye on you, that's what Prentis does. He keeps a sharp eye on me right now. But the first thing was, I didn't want him to take care of me. I had always taken care of my family and I didn't think that I wanted to be taken care of.

Dave Iverson: Yeah. And Prentis, how did you negotiate that knowing that Christie very much wanted to be independent, but sort of maintaining kind of perhaps a vigilant eye all the same?

Prentis Brooks: Well, Christie has always been very independent, and that's one of the reasons why I married her over 33 years ago. And from my experience, caregiving, my first introduction to that was also watching my mom take care of my stepdad during his last year as a dementia patient. And so I got to see that evolution, and there were challenges and frustrations. My mom did a wonderful job under the circumstances. And so coming back from that business trip and knowing that she had gone to the neurologist, you know something is going on. And so it's just a matter of taking that evolution and say, "Okay, there are times when I need to step in and times when I not need to step in." And so far I haven't when it comes to her Parkinson's. We negotiate some things as a result of some surgeries that she had shortly after she was diagnosed, and so you learn how to work through that. But as circumstances happen, then you have to figure out, "Do I lean in a little bit more or do I kind of allow that independence?"

Dave Iverson: Would you say then, Prentis, that the key quality that you need most is to be attentive? To just really pay attention.

Prentis Brooks: Yes. Pay attention, be observant, be willing to ask questions about how she's feeling and what's going on with her. That is something that we had an experience with a hike this past weekend that Christie wasn't feeling well, but she still wanted to do that. And so I was just asking questions. How are you feeling? Do you want to continue, go on? And she did. So it's just something that you have to experience in a moment.

Dave Iverson: Yeah. And Taryn, so let me bring you into this conversation and speak to it from the point of view of a daughter, because it's obviously a different kind of relationship, but I'm sure in some ways the same qualities apply to be observant and to pay attention. How has that evolved for you over your dad's long journey with Parkinson's disease?

Taryn Fixel: We've really worked to, as a family, design alliances, so we try to be very articulate because, as you know, one day is different from the next. Some days are better than others. And so you might want help on a Monday and not want help on a Tuesday. And so really making sure to be articulate and say things like how would you like me to ask you when I think you might need help? So that before we're in the moment, we have some understanding of what would make him feel supported rather than nagged.

Dave Iverson: I think what you're saying is so useful that someone might want help on Monday, but not on Tuesday. And Amy Chesire, let me ask your perspective on that, because I think one of the challenges in caregiving is to be accepting of that and not immediately say, "But yesterday you said this." So help us kind of put that into perspective from what you see as in your social work experience.

Amy Chesire: Yeah, thanks. I often tell just because you have Parkinson's doesn't mean that you're immune from everything that happens to people that don't have Parkinson's. So we all have our good and bad days, right? And sometimes for a variety of reasons, you're just maybe having a really bad day. So whether you didn't sleep too well last night, or you're kind of just low on energy, or didn't eat well, but to really recognize that it's pretty common that people will be having off days, and to not overly read a lot into it, probably, if you can, which is easy to say, and sometimes hard to keep in perspective. Sometimes our neurons are firing basically quite nicely, as I often say, and other times they see a little sluggish. So I think just kind of being aware of that, and always trying to fall a little bit more on some self-compassion can make daily life go a little smoother.

Dave Iverson: Let's take a look at our next slide if we might, because within that is a quote from Michael J. Fox about his own care partner relationship with his wife, Tracy. So if we're able to take a look at that, that will give us a sense of where we want to go next, because as we've been discussing already, it is about, I think, adjustment and change, and how we manage those things. So coming back to you, Prentis and Christie, what's surprised you about those changes? What's taken you back a bit perhaps, and thought, "Well, gosh. I didn't think I'd need to do that." I remember you were telling me a story when we talked on the phone, and perhaps you'd be willing to share that Christie, about the importance of looking good, and something that you wound up having to ask Prentis to assist you with.

Christie Brooks: Yeah. So after I was diagnosed, unrelated to Parkinson's I had a shoulder surgery, and I had, in fact, four shoulder surgeries. And that was pretty brutal. And I had to be immobile the whole time. I mean, three months of total immobilization on my shoulder. And it was really hard to do some things, and one of those things is to take care of my hair. And so Prentis actually learned how to use a blow dryer and flat iron my hair, because that was really important to me. And I think that I needed to look together... I needed to not be frumpy. I wanted to look together. And so he learned how to get up, do my hair in the morning, put lipstick on me, put my shirt on just for me to sit on the couch and

watch TV another day while I was immobilized. But I just feel like if I felt better, if I looked better, I was going to start feeling better.

Dave Iverson: I hope that's on your bio now. You've added that, Prentis, to your resume.

Prentis Brooks: Yeah. I can say that was a big challenge for me. I didn't even think about that ahead of time. Just from the aspect that I'm the youngest of three children, and we have a daughter, and Christie usually handled her hair. There were a couple times when I did have to do that, and that's when Christie was out of town when she was younger, and our daughter would say it was a big disaster.

Christie Brooks: Yeah.

Prentis Brooks: So coming to work through that, I had to be very patient and learn, and Christie would guide me through that. I had been frustrated, and so now I have a little bit better understanding. But the good thing about it is where we live now, Christie's cousin lives here and is a hair designer, and so she would be willing to come over and do anything if I could not do it at this point in time.

Christie Brooks: But that whole part, Dave, about looking good, I guess in a moment of vanity, I get a monthly massage. Before COVID I got a monthly massage. I also got a monthly facial, and I told friends, "I get the massage for Parkinson's and the facial just because life is hard." And so just treating myself to that component of... I don't know. It makes me feel a little better about myself.

Dave Iverson: And Amy Chesire, is there a lesson in that about the importance of just kind of asking for what you need? It seems obvious in a certain way, but I think often we're not always great about that with our care partners or with our parents for just saying, "Hey, this is what I need." Being willing to say that. Amy?

Amy Chesire: Yeah. Yeah. It's one of the things we talk about with care partners frequently is one of the hardest things for many of us, myself included, is asking for help, right? Because that causes us to feel kind of vulnerable, kind of dependent. And so it really is a fine art. If you can work on it and practice it, it really can help, especially through this pretty long journey related to caregiving. And you're not always going to get the answer you want, which is what I tell people to be prepared for. But it's amazing how many people can often be surprised when they really reach out and ask for help, whether it's with a spouse, or a neighbor, or the mailman, or your rabbi, or whoever it is, that people more often than not want to help. I also tell people, the more specific you can be with your requests, the better they tend to land as well.

Dave Iverson: I think that's a great point about specificity is really helpful rather than just saying, "Well, tell me what I can do." If you can be specific, that matters. Taryn, I'm interested in your perspective on this, too, and about perhaps how you've tried to be a support to your mom, and helping her ask perhaps for what she may need as a care partner.

Taryn Fixel: It's a great question. I think the number one thing we've tried to do is to give my mom breaks. So on occasion, my mother will go visit another one of my siblings and I'll go and stay with my father, or one of my siblings will go and stay with my father and she'll come visit me or go away with girlfriends. And those breaks have been incredibly important for her and actually a really nice bonding experience for us as well with my dad.

Dave Iverson: And that's something you've had to manage from some distance. You now live in California, your folks live on the East coast, I'm not sure where all of your siblings are, but this roster requires a lot of coordination and scheduling, doesn't it? As far as kind of making those alliances functional.

Taryn Fixel: It does, but we try to be communicative sometimes it's better than others, but we've learned how each other liked to communicate about things too and we're very lucky. So we have a very cohesive family, all of us are very involved and I would say that's an important thing too, is to make sure that the caregiving among the children is shared, even if you might find that different people have different specialties and let them lean into the thing that they are good at doing.

Dave Iverson: I think that's really a great point. We're not all oriented in the same way, we don't all have the same talents and skills and to take advantage and be accepting also of that and maybe we can talk about this some more, well, let's just talk about it now because resentments can build up if you feel like you're doing more than your sibs are or whatever, that's something that can... Has that been an issue for you, Taryn? And then how have you worked through that if it has?

Taryn Fixel: We're all very involved, so I don't think that's been as much of a challenge for our family, but we've definitely had moments where somebody has need to say, I need to pause and we've been working with Parkinson's for over 20 years, so that process of how we've developed that way of communicating with each other has changed, it needed to get a lot, I think the point about specificity is really great because you don't want to say, "I need to pause." Five minutes after you need to pause.

Dave Iverson: Right.

Taryn Fixel: You want to say "I need to pause." Five minutes before you need to pause, because I've found that that at least for me can lead to, if I wait too long, I've already crossed a certain mental threshold and that's not useful for my dad.

Dave Iverson: Let's deal with some of the really questions that are coming in this morning and let me throw a couple of those out and then we'll get back to other parts of our conversation. This individual writes in, my husband is very private and a very private individual person and he rejects most help, what can I do? Amy, could you take that one on, if someone is very private, doesn't want help, how do you go about negotiating that?

Amy Chesire:

Yeah, that's a good question and a common one. There's usually a couple of things behind that, sometimes when people use that term private, they may mean more introverted perhaps as well. And sometimes, folks that are sort of wired that way, kind of get more stressed by having new people in the situation or strangers kind of coming to them, so, I think instead of trying to kind of change, someone's sort of natural wiring and trying to get into all the resistance about that, if you can find a different way to go about it, sometimes sharing how it would help you and to really make it like your problem instead of the person with Parkinson's problem, in other words, this is something that I'm really starting to get kind of stressed and I know I need to take care of myself or this is what my doctor's telling me.

If you might consider something and start off very tiny and small because you want to build for success, right? To see if it really, if you can make it more about you and not so much about the other person, because sometimes folks with PD will think, Oh my God, I must be getting really bad, now we need to bring in help, right? So I think again, kind of trying to not really try to change the person, but to really kind of put it more back on yourself, sometimes that may help

Dave Iverson:

Prentis, I'm interested in your perspective on this as a spouse, has it been hard for you, easy for you to go about asking for what you need? We were talking a bit before about tournaments, making the point about if you need a break to sort of be sure to say that before you need the break, rather than five minutes after you need it, how have you, have you faced that Prentis? And what would you advise others about being able to speak up for your own needs as a care partner?

Prentis Brooks:

So, currently I haven't had to face that yet because I knew Christie where she's at in her journey with Parkinson's, she still is very capable of doing a lot of things herself and I mean, she's still currently working right now, I go back to the example of my mom and there were times where I felt that she needed to take a break and she didn't and it was very grueling on her.

And so from that model, I feel that the best thing for me to do is to keep our children engaged in what's happening and they are, sometimes too much, at this point time, we were just talking and Christie and saying that now we have a two helicopter children who sometimes overreact in situations as we communicate with them about, the latest as far as what we're experiencing.

But for me, it really goes back to myself. I had a situation three years ago where I had two surgeries within three months of each other, where I was literally on my back for three days and Christie had to take care of me. And so thinking back to that experience, that when she provided caregiving for me, I literally had to ask her to do a lot of things that I would not have asked anyone to do.

And so from that example, it kind of reminds you that, okay, now I can put myself in her situation and understand what she's feeling and experiencing and that's the important thing I need to check in with her, how is she feeling? What

is she experiencing? And then from that can get a gauge of how much do I need to be involved.

Dave Iverson: Yeah, that's a really good point to remember what that's like from a kind of first person point of view. Let me ask another audience question, which has come in, which is, I think a tricky area to negotiate as well, which is how can I remind my loved one to use his walker or to stand up straight without sounding like a nag? Amy, let me turn to you, maybe you have some thoughts on that as well, but Amy session.

Amy Chesire: Yes, this is, I can't tell you how many times this dialogue goes on in my office here and there's never a perfect or great response. I think sometimes if you can, as a care partner, shift gears and put yourself in the other person's shoes. So would you want someone to be telling you those same things, if it was you? And that will give you a good barometer, I think about sort of what's the temperature here that's going on between the two of you. All this tends to come from a very well hearted place, no doubt and I think it's where caregivers get caught too, because I think the people will call that nagging or friendly reminders, or I think it's a way to try to feel like you're trying to get some control over the situation, right? And Parkinson's is such a tough one because there's so many things that you feel like you don't have as much control over. So again, I try to remind the person with Parkinson's that most of this is coming from a well hearted place, it's often hard for caregivers, what I noticed to stop doing it, once it kind of gets started and what happens is many people then just kind of start to tune it out quite honestly, that I notice. So there's not a easy solution, I guess, to it.

Dave Iverson: Yeah. Taryn interested in your point of view as a daughter in this, how you perhaps notice this with your folks or how you've tried to encourage in that direction, because there's also real, it's not just being good hearted as Amy is saying, there's also real safety concerns, you can worry about, my dad used to fall all the time and so you may feel like you're being a nag about standing up straight or being careful how you stand up or using a walker, but there's real consequence sometimes to someone not following those, those activities, how have you wrestled with that turned in, in with your folks?

Taryn Fixel: I would just say, I feel like a nag. How would you like for me to [inaudible 00:26:36], where I don't feel like a nag or where you don't feel like I'm nagging, again just kind of calling it, naming what's going on. And then the other thing that I often find myself doing is saying, I don't feel like I'm able to help you if we do it this way, so if we do it this way and you fall, I'm not in a position to support you, so how could we do it differently so that I can actually help you?

Dave Iverson: Yeah, no, really useful, I think. And there are no simple land, a caregiving truism, I think is that there are no simple answers and when you've answered them, the answer will change tomorrow, so it's sort of on-going in that way that I think builds in its own challenges. We should reference the current circumstance though, that's on one of the slides and the pandemic is a reality for all of us and

it changes, it makes it more challenging, I think all of these questions. So another question from the audience, how do you go about during a pandemic to ask for help? There's more, it's trickier to bring caregivers additional help perhaps into your home, if you're able to do that because of the pandemic, things change more readily because of the pandemic, Amy Cheshire, again, any thoughts on how to cope with these very questions during a time when everything is harder because of COVID?

Amy Cheshire:

Yeah, absolutely. This idea of social connection and social engagement is so huge for all of us and we've all been called to task during the pandemic about how do you keep any of that going and then I think you add Parkinson's into the picture and you just add another layer. We're always concerned about caregivers feeling isolated and we know those starts to go on when we kind of stop hearing from people, they used to check in on a semi-regular basis for whatever reason, and then we stopped getting the calls and so we know once caregivers start to find like they are pulling back and getting isolated, they're often maybe starting to feel more hopeless about the situation and starting to really spiral and I think the pandemic has often just added to that, I know we've tried to really encourage people to think of kind of more creative ways to keep engaged and to keep asking for help.

I think the biggest thing is to find ways to keep asking, for help, it's probably not going to be as much in person. I know for example, our home health agencies have been really over-run, I'm having to spend many hours trying to find a home health agency that will even have available physical therapist to come out home, for example, and that as a professional, trying to deal with it that I can only imagine that it's doubly hard for our families. So I think it is, one being your best friend can be very helpful here, okay? And I think I've always told people to, especially during COVID to manage your expectations, is super important and to try to not put so much pressure on yourself during this pandemic, but the important thing is to keep reaching out in whatever way you can, whether that's through the phone, through Zoom, writing letters, whatever kind of creative ways, but don't lose engagement, just really important.

Dave Iverson:

Christie and Prentis, what would you add to that? Because the world does get smaller when you have a condition like Parkinson's, it gets smaller still with the pandemic and our ability to reach out. You're both still working, you're both still active, you both were just out on a hike, you have those helicopter children, you've got a lot of engagement, but what suggestions do you have along those lines to maintain connections during this really challenging time?

Christie Brooks:

Yeah, so one thing Amy said about trying to find those agents it looks different, right? It looks very different. When we have people in our home, I used to go to boxing class and when I was in the office, so I had a lot of interaction with my co-workers and now I don't have any of that. So we don't go boxing, so a group of our Parkinson's people, we meet once a week and we hike, so we're socially distanced and we're outside, so we've kept that connection and you just have to, I think we have to find the connections differently. We have to be

comfortable with that Zoom is going to be our connection instead of in person and how can we make that as real and as intimate with the person we're sitting with as possible and be satisfied with that, but you have to really work hard to make the connections and it might be different, but still trying to figure out how to do them.

Dave Iverson: Sorry, Prentis, go ahead.

Prentis Brooks: And I would add to that for me it's been that I have a circle of friends that even before COVID, we would do meetings over Zoom because they're not located here. And these are people that through the years I've worked with and we all had left an organization and doing different things and so continued to meet with them every month or every other month and that has continued even through COVID, and then most importantly take care of yourself. I make sure that I exercise, I try and get enough sleep when possible. And make sure you eat properly. So those are the important things too that have really helped me and I would encourage others to put a focus on that still in the process of dealing with COVID right now.

Dave Iverson: Great point and let's dig into that question a little bit that Prentis brings up about self-care, taking care of yourself. One of the cliches you often hear when you're a caregiver is someone will say to you, or you'll read somewhere that you can't take care of others unless you take care of yourself. Which is true, but actually doesn't happen all the time. In fact, it can't happen all the time. Caregivers wind up taking care of other people a lot without taking care of themselves. One person wrote in a question that's saying how do I meet my needs when my husband's needs must come first? I think that's true, I can remember times when I wanted to go out for a jog, but my mom needed help in the bathroom. Well, what are you going to do? You know? There are times when it's hard to take care of yourself. So thoughts on that from everyone. Amy, why don't you start us out and then Taryn and Prentis and Christie, you can add in too, but how do you take care of yourself when needs are so demanding sometimes as a caregiver?

Amy Chesire: Yeah, I think some of that, quite honestly, is learning to sit with those feelings. I know people hate to hear me say that, but because it's something that we're... live in a world where we're trying to distract and push away hard feelings and things like that. But quite honestly, sometimes I remember having a pretty intimate experience.

My father suffered with Parkinson's for many years in his past and a number of years I was back home in Southern California with him as to give my mom a break, and so... I got a call from a cherished friend while I was out there saying, Oh, we're all getting together in Los Angeles tonight, we want you to come out and I looked at my dad and I just knew there was just no way I could leave him that night, even for a few hours. I remember having to turn down the invitation and hanging up the phone and I just kind of started crying a little bit because I just had to sit with... things are different now and it's hard, but that's okay. I

have this moment with my dad. So sometimes your perception of how you view a situation can really go a long way in how you kind of deal with it.

Dave Iverson: Thank you. Taryn any thoughts you want to add in your experience, both as a daughter and as you've observed your folks?

Taryn Fixel: Yeah, I think having an understanding of what your minimum required necessities are, is really important. So, if for you, that's connecting with the grandchild once a week or going outside once a day, really making sure that you're hitting that minimum and it shouldn't always be at the minimum, right. We want it to be above the minimum, but making sure that yes it's okay and it's important to be flexible within that. So if your ideal is to go out first thing in the morning for a jog and somebody else needs help in the morning, that's okay. You can go for a jog later, but have an understanding that it's important to... that you have these things that are important to you.

The other thing that I do that I found very useful over the years is I write a gratitude list every day. I make a list of 10 things that I'm grateful for and what that does is it doesn't just change my perspective. It doesn't just make me feel positive. It also reminds me of what my priorities are. So I can really be living my priorities throughout the day, the next day.

Dave Iverson: Yeah, I like that. Thank you for offering that Taryn. That leads to another audience question that's just come in about how you avoid burnout Amy Chesire would you say that's taking off from what Taryn just said about reminding yourself of what makes you grateful, reminding yourself of kind of the minimum that you need? Are those, would you say Amy, keys to avoiding burnout?

Amy Chesire: Yeah, definitely. I think as many tools as you have in that tool kit are going to be helpful and another big one is we often kind of prescribe around here to the caregivers you need time off from Parkinson's. Okay, sometimes we literally write prescriptions to caregivers to whatever activity they used to enjoy that they have stopped doing. For example, whether it's golfing or hiking, or to really sort of mandate in a way or strongly recommend getting back to that. Because the thing that you realize is it's just like with parents, right? When mom's super unhappy boy it has a huge trickle down effect on kids often. So as a caregiver, if you are really finding yourself getting more short-tempered with somebody, which as you alluded to early on Dave, is very common in caregiving finding yourself... the littlest of thing is getting you more irritable.

These are all big red flags, right? That you're headed into this burnout state. So yeah, whatever you can do and have a lot of things available to get time off from Parkinson's, things that will fill your cup, and it's totally different for each person. A lot of caregivers will say, well, I don't have time, right, to do that. There just aren't... that sounds really lovely, Amy, but the reality, if you come over to my house is that's not available to me. So sometimes a lot of our

research around resilience... in other words, what are the things that help caregivers to be successful?

It doesn't have to be a lot or extensive, even finding... I will often say, do you have one to five minutes a day where you can really, whatever it might be, sit down, just do a couple of really deep breaths to kind of get your central nervous system a little bit more calmed down. You can do that every hour if needed. So we just want caregivers to recognize when they really are headed towards that burnout. The sooner that we can try to help you figure out ways to avoid that, the better off everybody's going to be.

Dave Iverson:

We're going to take a look at our advanced, our next slides that that can be on the screen with us during this webinar to talk a little bit more about the resource question where you turn for help, because I do think people have experience you're describing Amy where it's like well, that sounds good, but that's not the way it works at my house.

Maybe one thing... and I'd be curious to hear others comment on this. It's to accept the fact that those short little moments that you've each described. They don't so much... at least in my experience when I was caring for my mom, it's not that they fully recharge your batteries, and so not to really even have that expectation. That's not like if you get away for a night that you're going to come back and think, okay, I'm good to go now. That may not necessarily happen, but what can happen is you had that one night, right? You had that and to fully appreciate that time, that moment, and to just live that. It sounds like a cliché, but to take that in, rather than necessarily thinking that now everything's going to be good from, from this point forward.

Anyway, that's my two cents, but I'd love to hear more from others, Christie and Prentis back to you for a moment and then Taryn chime into on ways that you've found restorative, I guess.

Christie Brooks:

Yeah, I like what you said on living in the moment, be in the moment of that you get the break and then don't keep trying to live in that moment and to get back into the routine. Okay, Oh no, here I am again. And what I was going to say from the patient perspective is that sometimes we have to realize that they need a break and that they need time away, and the whole thing becomes very focused on us and on what we're doing. It's hard sometimes to let them go do what they need to do or to let else come and take their place. We don't want anyone else to take care of us. That's what happened with my mother-in-law is that she couldn't get out of the house because our step grandfather, he was like, no, I won't have anyone else than you take care of me.

And so we have to realize that our caregivers need those moments and give them those moments and see who else... be accepting of what that may mean to us then. The impact that may have.

Prentis Brooks: I would decide too that to check in periodically throughout the day and we do that. We ask what do you have going on at this time? Then that gives me an idea, okay, how can I fit exercise in that's important for me to be able to do it. Sometimes I do it in the morning, sometimes I do it in the evening, but I do make sure that I try and get it in. But if I don't for whatever reason, then I know that the next day may have the opportunity.

Dave Iverson: Yeah, I think that constant check-in really makes a lot of sense and I think you're so wise and thoughtful Christie too, to realize that it's just as we were saying, we need to see it from the point of view of the person who's receiving care. You have to see it from the point of view of the person who's your partner.

Speaks a little bit to this one question that I want to raise, which is this person asks, how do you handle a situation where the person with Parkinson's relies on the caregiver too much and doesn't do enough things for him or herself. So they want to be kind of dependent. That's obviously not your situation, Christie and Prentis that's clear, but Amy, what would you say about that? If someone, sort of like the in-law that Christie was describing, wants only care from one person and doesn't really want it from anyone else and doesn't necessarily want to do for themselves, any thoughts, Amy, on how to respond to that situation?

Amy Chesire: Yeah, boy, I keep getting the hard questions.

Dave Iverson: That's why you're here.

Amy Chesire: Yes, again, you're not alone. I guess that's one thing I would say, at least from my perspective here that this can be the flip side of this is that a lot of times what's behind that in my experience is fear. So the person with Parkinson's often has a number of fears going on, whether they're able to share these or not, but I'll tell you some common ones that tend to drive that.

Is my caregiver always going to be able to be here? Are they always going to be able to hang in there? How bad is this going to get? And these are common questions that caregivers are often wrestling with at about the same time. And the big one is am I going to be abandoned? Is this going to get so hard that everyone's going to kind of check out on me.

Sometimes instead of getting into a lot of the minutia of what I call these kinds of things is if you can tap into a little bit more of the underlying feeling that's going on, you don't have to be a social worker to do this, just be a human being. You can often get behind some of what's going on there. But to know that a lot of it is driven, it can seem very resistant to you and why don't you just do more? And I know yesterday you were able to get that shirt on, but today for the life of you, you can't seem to do anything. Again, if you can step back and try to identify a little bit more about maybe what's driving that you might have a little bit more success with it.

Dave Iverson: I think that's really, really insightful, Amy, thank you. I want to get, Taryn, your perspective on this question too, but before I come to you, we have a great question coming in, which is how do we find someone like you, Amy? So if people need social work assistance, or just assistance in general suggestions on where to turn, where to find resources.

Amy Chesire: Yeah, A couple of quick suggestions. Yeah, the more you can expand your team the better, I think. Okay, and so certainly one, there are, I'll put a plug in for the Parkinson's foundation centers of excellence, which are all around the country and actually international as well. So they're located in various large and small cities. That's a great resource to reach out. Usually they're always going to have a social worker there that is part of the team and is much more focused on movement disorders and Parkinson's in particular. If that's not available to you, I think the other big piece is a bit...

Amy Chesire: Available to you. I think the other big piece is a big push for caregivers' mental health. About 50 percent of caregivers, at some point in the caregiving experience, are going to really experience a clinical depression. So this is not just being kind of down in the dumps. This is where your mood is starting to impact your sleep, and your eating, and your energy and all those things. So these days I would put, since people are probably tuning in from all over, a couple of quick online resources for that I often utilize actually, because we service people from all parts of upstate New York. Either psychologytoday.com has a great resource for finding therapists and you can really drill it down to your insurance and your location and area of specialty, and so that's a good resource. Also, betterhelp.com is definitely all Zoom-based mental health, but another really terrific resource to reach out to take care of your mental health.

Dave Iverson: Thank you. Those are helpful. Let me mention one more that we just started at The Michael J. Fox Foundation, which is something we're calling the Buddy Network and there's a link to it on our resource page, but it's just a way of kind of matching people up. So if you want to reach out to someone in your community to talk about some of these issues, whether that's to talk with another care partner or to talk with someone else who has Parkinson's, the Buddy Network, which is something that The Michael J. Fox Foundation is just starting, is another way of providing that sort of networking and that sort of resource support. Taryn, your thoughts, since you've been listening to this about this question of how to both avoid burnout and you've worked at such a team with your siblings about providing support when it's really needed for both your mom and your dad.

Taryn Fixel: Humor goes a long way. I often ask myself two questions. How can I make this light? And how can I help my dad maintain his sense of dignity right now? And when I frame it that way, firstly, I get out of myself. So I'm not as focused on my own stress, and I'm just focused on this concept of dignity, which kind of flips the switch for me. And then when my dad has had really hard times, I've made it a point to watch something funny for five minutes at the end of every day. And

that works for me. I mean, some people might have different practices, but it really really helps.

The other thing wanted to say earlier actually that I think is important about the nagging, is also just to remember that Parkinson's is a cueing disease. So when we cue a person, it gets them unfrozen. So if you say something like "big step", it might help them to move. And so maybe what feels like nagging to you is actually really useful at times. I thought that was important to add.

Dave Iverson: Yeah, no thank you, Taryn. And, let's stay with you though for an answer to your own question, if you can provide it, about how you do help your dad maintain dignity, because I think that's an important question. What have you found it's useful in that regard?

Taryn Fixel: I... Firstly I don't do for him what he can do for himself. When we've been in situations where we're in a hospital, I try to really listen to what he wants and I make sure that all questions are addressed towards him. Oftentimes in hospitals, the doctor will address the question to the caregiver and then I'll just turn and say "Dad", and I'll repeat the question or "What do you think"? And if there's a time when maybe he can't articulate it as fully as he might want, I might say "Well, what I think is this. Is that right?"

Those are a few different strategies, but again, it's just always making sure that he feels involved. He's there.

Dave Iverson: Yeah. Exactly. I came to really appreciate those people with my mom as her dementia increased who, rather than turning to me or saying to me, "Oh, isn't she sweet", would look right at her and talk right to her. They only had eyes for her, not for me. And I think that is a quality that matters a lot. We're going to focus the rest of our remaining time, which is not much I'm afraid, on getting to as many more questions as we can. Here's one that just came in, which is advice when you don't feel appreciated, when you feel like you're giving so much. Taryn or Prentis, do you want to respond to that? How do you handle that, if you don't feel you're being appreciated? Taryn?

Taryn Fixel: I'll let Prentis start.

Prentis Brooks: I would say that Taryn, she said this at the very beginning, is to make sure that you're living your purpose and that you stay focused on that even though you may not be getting that feedback directly from your care partner. I mean, from the patient. I'm currently right now, not having that experience because of our situation, I saw that happen with my mom, unfortunately, but it's something that I think really speaks to me is to make sure you're living who you are, even though you may not be getting that direct feedback from the person you're caregiving for. Yeah.

Dave Iverson: Yeah. Thank you Prentis. Question on, which is one that comes up and I'm sure Amy you've dealt with this many times, so I'm going to turn this back to you, which is how do you go about talking with someone with Parkinson's when it's time for that person, let's say it's your partner, to stop driving? How do you have that conversation, Amy?

Amy Chesire: Yeah. Oh boy. Okay. Yeah, this can... I think some of this as the year has gone by, I'm kind of... You know, driving represents something different to a lot of people. And for folks that it definitely really has been something that's maybe been a part of their job, for example. My point, is it just that some folks have a much harder go with the idea of changing in their driving than other people. And so some families will not have a big issue with this and others it will be like their hardest thing they ever had to deal with in terms of Parkinson's. If you're in that latter camp, a couple of ideas, either if you're blessed to have a driving evaluation program in your community, which many are, if you contact kind of your office on aging, they might be able to point you in the right direction.

This gets you out of the hot seat, because quite honestly, none of us are good driving evaluators. Okay. As doctors and providers, we're not good driving evaluators, we can evaluate your Parkinson's, but we aren't really in a good place to evaluate your driving. And the same for families. So if you can turn it over to kind of a third party to basically to be able to do a driving evaluation, if it's available, that's wonderful. And then I encourage people with Parkinson's, this is your opportunity. If you think you're a great driver, this is your opportunity to shine and to demonstrate that. So that's one way. The other one, if you don't have that available, is to probably kind of fall back on your doctor. Most of them are willing to fall on the sword for you, and it becomes part of their medical record then, if they've been advised by their doctor to give up driving, but it can take some of the heat off of you. Again, and it's just a really hard situation overall.

Dave Iverson: They are. And all of these questions are hard and challenging. And... But I think coming back to this point about being willing to talk about them, being willing to ask is the starting point, and allowing yourself a lot of room for forgiveness, both of yourself and the person that you're living with when you reach some of these difficult, challenging situations. Just have a few minutes left, and I'd love to have us finish by having each of you give us some last thoughts and kind of your best takeaway advice on managing this situation during this challenging time of the pandemic and also during the holidays, which have their own challenges as well. So Amy, let me start with you and then we'll go to Taryn next after that, but just a brief, last bit of advice, please.

Amy Chesire: Yeah. I thought actually, if I can, I came across this when I was doing some research here for today's webinar, a column that I wrote a number of years ago, and I started it off by sharing a couple of lines from a poem that was called Love, that was written by May Sarton. And I thought, I know I just have a minute or so, but I'm just going to read these couple of these lines from her poem, which it's about love. And she compares it to a spider's web that is both fragile and

easily broken. And so these are the final lines of the poem. She says, "Spiders are patient weavers. They never give up. And who knows what keeps them at it. Hunger, no doubt, and hope". And so I hope that people that are dealing with Parkinson's disease will really find the ways to remember the hunger they have for the past and how things have changed, but also to kind of really try to keep sort of that hope alive. It really can help to kind of keep those batteries charged up. Yeah, they keep going, right.

Dave Iverson: And keep weaving that web.

Amy Chesire: Keep weaving, yes. Keep weaving.

Dave Iverson: Yeah. Taryn, the last thought from you, please.

Taryn Fixel: I would say really lean into your community right now. You are not alone. Everyone is having some kind of experience with the pandemic. And reach out, ask how you can be there. And if you can find someone to have a Zoom dance party with, just to get moving, or if you can go out and enjoy the sunshine for five minutes, it makes a really big difference.

Dave Iverson: Great. Thank you. And Christie and Prentis.

Christie Brooks: I would say you can keep moving forward because you can work through this journey. You've faced challenges before, you found out how to communicate and work through them and you can be patient with yourself and the other person. And just work through it, and you can do this.

Prentis Brooks: And I would close by saying be resilient. And if you don't understand, learn what that means for yourself and then also widen your network. There's so much resources and people that are willing to help and don't be afraid to ask for that help.

Dave Iverson: Exactly. Thank you all so very much Prentis and Christie Brooks, Taryn Fixel, and Amy Chesire. Thank you all for being part of this conversation, it's been really helpful, I think, for all of us. And thanks too to all of you for participating in this webinar. We'll be sending a link to it so that you'll be able to watch it again and share it with others, and all of us at The Michael J. Fox Foundation wish you a safe and happy holiday season. Thank you so much for joining us and we'll see you again next year.