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Speaker 1: Welcome to a recap of our latest third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at Michaeljfox.org.

Lauren Zelouf: Hi everyone. Welcome. I'm Lauren Zelouf. I'm a clinical social worker at the Parkinson's Disease and Movement Disorders Center at Penn Medicine, and today we're going to be talking about care partnership, the role of the Parkinson's care partner throughout the Parkinson's journey and how to maintain good communication throughout that partnership, to keep it a strong partnership for Parkinson's.

I've recently co-authored a guide with the Michael J. Fox Foundation on Care Partnership, and I'll be sharing more about how to access that guide later in the webinar. This webinar is brought to you with support from Acadia Pharmaceuticals, so thank you to them. So we have a lot to talk about, but I first want to introduce our great panelists that joined today. So first we have Ethan Henderson. He works at Michael J. Fox Foundation, and he's a member of our patient council. He was diagnosed with Parkinson's in 2016 and was a care partner to his father who also lived with Parkinson's.

He lives in Arizona where it's nice and warm. Thanks for being here today, Ethan. Christine Herzellaris is a retired CEO and care partner to her husband Jim, who lives with Parkinson's. They live in Florida, also warm, jealous. Welcome, Christine.

Peter Lenny is a nephrologist who is based in California and is a care partner to his husband, John, who has also Parkinson's. Thanks for joining today, Peter. And lastly, we have Dr. Roseanne Dobkins. She's a psychologist and a professor of psychiatry at Rutgers University, and she's also on the executive steering committee for the Foundation's Landmark PPMI study.

So we'll start today in the conversation about what makes a Parkinson's care partner, what is unique to this care partner journey. So first I want to kind of hone in on why we are using the term care partner. Everyone has a different take or a different preference on how they define themselves throughout this journey, but today we chose the term care partner and that's what we also use in the guide. So Christine, Ethan, and Peter, what word do you use to define yourselves in your relationship with your loved one? Do you use the term care partner? What do you prefer? Maybe we'll start with Christine.

Christine Hurtsellers: Yes, we do use the term care partner, that really feels right for us. My husband and I are going to celebrate our 40th anniversary in April. So we've been together a long time. We took very traditional marriage vows, going through life together through ups and downs. And so again, as you know, sometimes one person is leaning in doing more than the other, but again, it's a lifelong journey commitment, and so for us, we view it as a partnership.

Lauren Zelouf: What about Peter? What about you? How do you define your role?

Peter Lunny, MD: Yeah, amongst ourselves, John and myself, we don't overtly use a title for my role, but I think the term care partner makes sense because part of our relationship is caring for each other. We've been together for nearly 30 years and most of the things we do in life, we do this as partners. So when it comes to dealing with a major health concern and chronic illness, the term fits.

Lauren Zelouf: That makes the most sense to you. Absolutely. And Ethan, what about you?

Ethan Henderson: Yeah, I would definitely say, I was a care partner for my father, partnering with my siblings and as well as the professional staff at the home where he lived his final years, but also for me, a care partner because it's kind of a reciprocal equality of care for me and people who also are a part of my journey.

Lauren Zelouf: Definitely. And that's the reason we actually use care partner in the guide because it is meant to show that you're working together in managing Parkinson's, it's a give and take. And what I'd say is also unique about the guide is that it highlights the different roles and relationships that we see with care partners, whether it's an adult child caring for a parent or a spousal relationship, or even a friend who's involved in caring for their loved ones.

So it goes to show that there are so many unique relationships that can act as care partners. And Roseanne, what are some ways that you would say that care partners provide support to their loved one?

Roseanne Dobkin, PhD: So many different ways. Definitely too many to count, but just to name a few, knowing that I'm not doing it justice, certainly in my work, I hear examples all the time of care partners helping to support with all the practical, tactical things, day in and day out, fixing meals with their loved one, making coffee, running to the grocery store, helping to sort of spearhead the social plans, figuring out, okay, which friends, which family are we going to get together with today or this week or later this month, planning for doctors appointments. So not even maybe helping to arrange transportation, but speaking with their loved one with Parkinson's before the doctor's appointment to kind of come up with a list of questions. And then being a second set of eyes and ears in the room when we go and attend the appointment.

Maybe also healthcare and day-to-day related, helping to organize the medications, and I think maybe most importantly, being present, being that true friend, that true companion.

Lauren Zelouf: Great. I think you explained that care partners wear many hats, and so those roles might also shift throughout the journey. So as symptoms change and progress, we might see those roles change as well. So Ethan, maybe you could touch on what surprised you as your care partnership changed over time? How did you navigate that role reversal with your parent, your dad?

Ethan Henderson: What surprised me was, I mean, I knew he was a quiet New Englander who didn't really share much. So getting him to share what was happening, what was troubling so that I could be able to go out and help more get the resources that he needed. While I was diagnosed, it was like I was, at least for a moment, thrown back to my childhood where he was taking care of me, asking me questions and providing advice about what things were like for him early on during his role and just being a voice of support. So that was a change for me, but actually a welcomed one, now that I think back on it.

Lauren Zelouf: Yeah, that's a really good point that you might feel like the parent, even though this is the parent that raised you, so it's entering this weird new space that you haven't maybe been in before. So a lot of unknown territory. So Christine and Peter, maybe you could share how your responsibilities in the household changed over time as a care partner to your loved ones and how that shifted.

Peter Lunny, MD: After John's diagnosis and going through our stages of grasping with that reality and that future, I've given him space to have autonomy with regards to how much he needs help and support from me, and he's a pretty independent person to begin with. However, over time too, I've taken on a few more responsibilities in the house, maybe a little more driving, more of the cooking, but in general, like the term care partner, we are a partnership and try to divide things more or less evenly.

Lauren Zelouf: That's great. You're a team, so you divide and conquer. What about you, Christine?

Christine Hurtsellers: I would say earlier in our marriage, I used to work full-time and traveled quite a bit. So my husband, we have five kids, grown now, five sons, and he did a lot with the relationship with the children when I was traveling, as well as managing all of the things that go on with the house. Now with his Parkinson's, he has some challenges with executive function, and so scheduling repairs, doing paperwork, things like that have become more anxiety producing or overwhelming for him. So I would say the biggest change for us is really, I've stepped in and taken over just a lot of the organization that's needed.

Lauren Zelouf: That's great. And sometimes it's hard to decide when to step in and it involves good communication to be able to say, "It's time. Christine, I need your help with this." Or for you to be able to say, "I think it would be helpful if I got involved just so that it wasn't so stressful for you to do all the scheduling." Right? And Roseanne, can you speak to how Parkinson's changes people's relationships from your professional experience?

Roseanne Dobkin, PhD: Yeah, no, absolutely. I mean, it can change and impact relationships in so many ways. And I think we've already heard from my co-panelists this afternoon, that roles and responsibilities in the relationship change. People start wearing different hats and maybe taking some hats off and putting them on the back shelf in the closet.

There can also be some additional communication changes and challenges that are associated with many of the symptoms of Parkinson's disease, right? Voice can be lower, it can be difficult to always speak with intent, which can make some of that day-to-day exchange a little bit more challenging.

And I think there's also emotional change, an emotional impact. I know everybody on this panel knows the Parkinson's is not just about physical symptoms, but the overwhelming majority of people living with PD also experience a lot of emotional changes and challenges. We see higher rates of depression and anxiety and insomnia and fatigue, and all of those symptoms can also impact quality of life day to day for both the person living with PD as well as the care partner.

And those emotional symptoms can impact not only what couples and care partners and loved ones with PD are able to kind of plan and do throughout the day, but maybe also the timing of those activities, are we planning around medication schedule? Are we planning around on time? Are we problem solving around some of those physical challenges, limitations, so we can be as involved in our day-to-day in a meaningful way as we possibly can.

Lauren Zelouf: I think Roseanne, you're pointing out that it's both professionals that maybe can help with that problem solving, but it's also within the partnership, right? You know your loved ones best. So you can see whether they're withdrawing or not engaging as much in conversation. And it's important as a care partner to really be curious and ask what that's about. Are they having trouble because of the slow processing like you're mentioning? Or is it that it's hard to read the conversation?

So there can be a lot of different reasons that someone could be pulling away. So we've talked about, it's important to maintain good communication, but what does that look like? How do we do that? So maybe, Ethan, you could share, what is one technique that you used or have been using to help you both feel heard and understood with your dad that you've used?

Ethan Henderson: I think consistency, just making sure the message was the same, when I would talk to him or talk to the people that were around him, to make sure that his needs were met and/or things that I wanted to make sure that he was doing... Making sure that he was doing that, was a suggestion or a requirement from his movement disorder specialist. And that seemed to work a lot. As a former professor, he liked the repetitive aspect of it, so I think I turned and used that to him. And then for me, I think it depends on who I'm talking to, but I think an honest, no-nonsense type of conversation or approach to things I need to do or things that need to be addressed in my care, both from my doctor but also my care team.

Lauren Zelouf: And again, it's very individual and you have to know the person you care for and you also have to know yourself. So that's a good point. What about you, Peter?

Peter Lunny, MD: Yeah, as I mentioned earlier, John kind of runs his own narrative and is very autonomous, but I'm there as a sounding board and if it's been a while or I noticed a few things that seem to be off or some struggles, he's having all do a check-in, but I try not to micromanage and sort of allow him to kind of take the lead on it.

Lauren Zelouf: I know you emphasized before him asserting his autonomy is really important, that he still feels like he has a voice. So I think that's really great you do that. And Christine, is there a technique that you've used to help you with good communication with Jim?

Christine Hurtsellers: I would say it's similar to Peter, and Jim and I really didn't necessarily have it right when we entered the Parkinson's journey, so we actually went to marriage counseling for a little while to help us improve our communication skills because the dynamics have changed and I don't want to fall into the position of being a nag, yet. Also wanting to make sure that as he struggles with apathy, how can I be encouraging? So we're continuing to work on it and I think what we're finding is just being as direct as possible with people. How are you really feeling? Do you really not feel well enough to go to the grocery store with me, as an example? And so again, trying our best to just be straightforward and to check in with one another.

Lauren Zelouf: That's great. And good communication is a practice, so it's going to take many conversations to get a sense, like what works for you guys. Going back to Roseanne, how do emotions kind of factor in here? So obviously we have lots of emotions that come up throughout the care partnership journey, what's your take on how they factor in?

Roseanne Dobkin, PhD: So emotions factor in in many different ways, and I want to just say upfront that emotions are not the enemy, right? Emotions are really helpful. They are adaptive. They really kind of clue us in to what's happening around us and to what's important and to what we want to sort of react or respond to, maybe in a more proactive or in a different way.

But when emotions have more of a negative flavor, when we start to feel, when those negative emotions, like guilt, or start feeling overwhelmed, frustration, when those emotions set in, and this could be for the care partner, this could also be for the person living with PD. Those negative feelings can impact our communication, can impact how we interact with our loved one day in and day out, what we're willing to do, what we're not willing to do. It can also really influence not only the words that we choose and the messages that we're trying to express, but the packaging related to that messaging and that communication.

If we're experiencing negative emotions, there's a pretty good chance that maybe the words that we're using when we speak to our loved one are not as kind and as compassionate as they could be.

Lauren Zelouf: That's great. And I will say that we're all human and it's important to have self-compassion because we all get overwhelmed. So I would say it's normal, and to kind of forgive yourself for those moments.

But it is true that when we're overwhelmed, it impacts how we communicate or what we say to our loved ones. We might regret that. Again, having self-compassion is key, but I don't know, Christine, would you be able to share how, when you feel a strong emotion like overwhelm, how that impacts you as a care partner or how you communicate with Jim? I don't know if you'd want to be vulnerable and share what that's like for you.

Christine Hurtsellers: Certainly. And I would say sometimes with the overwhelmed nature comes a sense of guilt for how I show up in the relationship. Again, it can feel really overwhelming because so much of what he did as far as helping in managing life, he's not able to do and also he doesn't feel good sometimes. And then also for him, you said earlier, so much of PD really can be the things that you can't see. And he was always the most optimistic person in the world and very brave. He's a veteran and now he has anxiety and sometimes depression. So all of those things can lead to me feeling overwhelmed and not showing up and maybe being snappy or saying... This is the worst thing that I ever said, like, "Don't you remember, you asked me that five times." Which is a horrible thing to say.

And so within that then becomes a little bit of guilt, trying to forgive myself at times and to be better. And then to the point of what do you do when you're overwhelmed? It's a personal decision, but I just try and get away and just have some me time and some space, and that really helps me recharge my batteries and then helps me show up with Jim and just to be a better care partner overall.

Lauren Zelouf: That involves being honest with yourself, being able to check in with yourself about what you need and then knowing how to ask for it. Also, knowing your loved one, what he might need and giving him that space. So I'm going to ask Peter, I don't know if you have thoughts on this or what's running through your mind about this?

Peter Lunny, MD: The emotions associated with our PD journey have sort of evolved over time from the initial diagnosis when John was 49 years old and kind of hit us out of nowhere, and went through the Elisabeth Kübler-Ross stages of grief. And then finally after going through those emotions, kind of being practical about what the next steps would be, and again, focusing on John's autonomy, I didn't go to all of his appointments with him, but I went to key ones when he wanted me to go or when there were major decisions to be made, such as when he embarked on proceeding with DBS, which is deep brain stimulation surgery, which required a lot of care partnering before and after that experience.

And then I guess internally, I do have a little bit of guilt, kind of why John, why not me in just thinking about the future and what a neurodegenerative disease entails in terms of what our futures will look like.

Lauren Zelouf: So emotions can definitely shift and change as you go through this journey. From the beginning, middle, and as you look into the future, could bring up a lot of fear, I think is what I'm also hearing, is not knowing what to expect and not knowing what's ahead. In my work with care partners and people with Parkinson's, I'm constantly encouraging people if they're both feeling fearful about what's going to come, and trying to come together and being able to talk together about those fears so you don't feel so alone in thinking about the future.

So I want to touch on an exercise that's pointed out in the guide, which can help you both, care partners and people with Parkinson's and your loved ones, being able to kind of reflect and connect and kind of check in with yourself on how your day is going, how your week is going. It helps to kind of improve communication. And that's the rose, thorn and bud exercise. It can help to kind check in with each other. I don't know if, Roseanne, if you wanted to share what that is?

Roseanne Dobkin, PhD: Sure. And you can kind of jump in if I leave out any important details. But I think the big picture takeaway related to the technique is to kind of set aside some time and really talk about a couple of different things. So what's going well? What are we really pleased about? What are we really happy about? What are some challenges that we're currently feeling and experiencing, and maybe problem solving around those challenges as well as sort of sharing perspectives about those challenges with your loved one.

And then with challenge comes opportunity. So while there may be various challenges, is there an opportunity to maybe do something in a different way, to kind of share together, to grow and develop, to become closer in some way as a result of the challenge that we're going through together in this moment.

And I think just related to this idea of sitting and talking, I think just in general, what I usually recommend to the people that I am working with is to try to set aside some time every day.

It doesn't have to be an hour, but could it be five minutes over your morning coffee or a cup of tea in the afternoon, to talk about the best part of your day, what you're really grateful for, what your loved one did that really made you smile.

And to really focus on the small things that matter because so much of the time we get so caught up in the minutia and the stress of the day to day, that we don't necessarily stop to, number one, acknowledge, but then also verbalize and point out what our loved one is doing that really made us feel special or important or cared for.

So being very intentional about setting aside that time, again, two minutes, five minutes, but let's talk what was really good about today. We know what the problems were, but what was really good? What am I really grateful for? What did you do that warmed my heart today?

Lauren Zelouf: Roseanne, you took the words out of my mouth. I was going to say, you have to be intentional with your communication, which is so true, setting aside that time, but also I think it allows for quality time together because you're sharing, you're being open, and like you said, you're cutting out time to have these conversations which you might not normally in a day to day.

So maybe to ask the panel, how do you guys approach difficult conversations? So sometimes it's just figuring out what someone wants at the market or picking things up at the pharmacy and just having conversations about mundane day-to-day things. But how do we approach more difficult topics? I'll start with you, Ethan.

Ethan Henderson: It's, one way you're trying not to be the parent, but being just a care partner in this and making sure that I am well-prepared for every type of response that I was going to get or that we were going to get and ways that we could try to work around it or work with his limitations in either ability or wanting to do something.

I'll admit it was not always easy and there was always something that you have to shift or pivot or lean a little more, or back off. There were times when you just need to do that just as much. So that was, over-preparedness on my part is probably my short answer to that really important question.

Lauren Zelouf: It's a difficult thing because it's hard to know how to approach these things and it's hard to also know when to step in. What are the areas that you step in, when do you kind of hold back? So maybe we can get into that too. What about you, Christine? How do you approach a difficult topic with Jim?

Christine Hurtsellers: Well, we've learned, number one, not to avoid them through therapy and things because then you can get frustrated. And so what we try and do is prepare in advance. So just say one to the other, well, we set aside a very specific time to talk about something. And then for us to, particularly I think for Jim, it's important for us to remember that a lot of this is Parkinson's, right? It's a neurodegenerative disease. It can affect your reactions or things. So to not judge me or him to say, "This is who you are now," because you're still the same person, but to recognize that things are going on that somewhat cannot be helped and therefore grace and forgiveness and understanding is needed. And again, to avoid that feeling of judgment and guilt.

Lauren Zelouf: What about you, Peter? How do you approach things with John?

Peter Lunny, MD: Yeah, I think somewhat similar to Christine, I like to be open-minded and present and a sounding board. And I try not to be prescriptive about issues that I may recognize, but let John bring them up first and then I'm more the sounding board or the responder to the situations. But in general, we have a pretty open line of communication with each other and have experienced some difficulties related to the Parkinson's, but nothing that we were not able to handle.

Lauren Zelouf: That's great. I'm glad that you've figured out how to maintain open lines of communication that maybe you always feel comfortable being able to come to each other and talk pretty openly. And Roseanne, maybe you could share, I know you've already alluded to some of this before, but how Parkinson's impacts communication, what are the other things to look out for? Christine was mentioning that these are things that are not her husband's fault. It's a part of the disease that might come up in communication, how it might be impacted.

Roseanne Dobkin, PhD: Yeah, no, I think that's so important to remember that all of these changes and challenges that are unfolding are part of the disease process, are part of the disease journey, it's nobody's fault. These changes are not intentional. And I think related to that, and I think this ties back to a point that Christine made a few moments ago, a lot of the emotional changes and challenges are also not intentional and they're nobody's fault.

So if your loved one is sad or depressed, it's not because you've done something wrong as a care partner or you didn't meet their needs. People feel lots of different things and sometimes there may be an identifiable trigger for a negative feeling and sometimes there might not be, but people can again, experience the whole spectrum of emotions. And it doesn't necessarily mean that anybody did anything wrong. In terms of communication, certainly we know with Parkinson's, not only does movement slow down, but thought processes can slow down.

And so if it's going to take a person living with PD a little bit longer possibly to put their thoughts together, it's also going to take longer to maybe express those thoughts. And it does not mean that your loved one doesn't want to speak with you or isn't fully paying attention. It's just going to take a little bit longer to first process and then respond. So I think that's part of it.

And I also think that Parkinson's can provide us all with an opportunity to maybe change some of our habits that were never good for communication from the beginning. So if we're talking to each other, when it's possible, let's make eye contact. Let's at least be in the same room. Let's speak with intent. Let's try to focus on what we are trying to express versus multitasking while we're trying to engage in conversation. Let's try to break the communication down, there may be five points that we really want to get across, but can we focus on one thing at a time, talk that first point through and then kind of layer in the second point, the third point, the fourth, and so on.

Lauren Zelouf: I think some of this involves unlearning some of our habits, not screaming across rooms or behind closed doors, the things that we're kind of used to doing that we don't really think about. But now we do have to be, like we said before, really intentional about how we show up and how we communicate with one another. So we're actually going to highlight, there's five keys for good communication that we talk about in the guide, and I just want to point them out on how we can approach this. So the first one, Christine, if you can kind of walk us through what setting the stage means, how can we make sure that we're kind of ready to have a conversation, whether it's a difficult one or just kind of a day-to-day check-in.

Christine Hurtsellers: Yeah, I really think setting the stage is key on the emotional front, to be as present as you possibly can, to be prepared, for both of us to go in knowing that. Another thing too that we're trying to work on more, if this resonates in setting the stage, is sometimes it feels like we're talking about Parkinson's or symptoms eight to 10 times a day. And so my husband... Then it's becoming so integral to who we are, relationship, that I don't think it's healthy. And so in setting the stage, we're also trying to acknowledge bad days and things, but also trying to come up with specific times and specific days, even to go into more things related to care beyond the actual relationship or emotional side of things.

Lauren Zelouf: Sometimes you need, what we call Parkinson's-free zones where you can just kind of be yourselves, Parkinson's aside, because you had a whole life together before Parkinson's entered the picture, but so setting the stage, we want to make sure that there's not distractions where we know what we're about to sit down and talk about. And again, I feel like we've used this term so much, but it's true, being intentional.

So then Ethan, how do we get on the same page? How can you make sure that you stay on track and communicate what you hope to accomplish in the conversation?

Ethan Henderson: We'll use my current situation to answer that one. And it's one where getting on the same page where because of cognitive issues, I don't always remember what we're going to be talking about. I don't always remember what I'm supposed to be doing or I don't remember things that I may have or may not have done. So trying to get there where we're communicating and also being patient with each other, or spouse, siblings, what have you, making sure that we're on even ground when we're starting the conversation.

But I have to also be careful that I'm not playing the Parkinson's card, where I then also will say something along the lines of, "Well, I can't do that, or I don't want to do that because of PD." That's a cop out for me. And that's just something that I want to make sure that I'm stepping up to the plate equally as much as my care partners do.

Lauren Zelouf: That does involve being kind of very reflective and in tune and insightful, that you're recognizing when Parkinson's might be interfering, right? You have to know yourself-

Ethan Henderson: Yeah, vulnerable.

Lauren Zelouf: And you have to be... Yeah, very true. This does require a lot of vulnerability. And then the next part of it is listen actively. So that really involves trying not to jump in or interrupt, knowing that someone might be processing things a little more slowly and trying to keep up in the conversation, that they don't want to lose their train of thought.

So trying not to kind of jump in or interrupt. And unless you've agreed that that's something that you should do, maybe your loved one wants you to join in, and again, every partnership is different, but listening actively involves really hearing what the other person is saying, maybe repeating back what you heard at the end, to show that you were listening and you want to make sure that they feel heard, that you heard them correctly.

And then in terms of addressing the emotional part of this, maybe Roseanne, you can share how to be supportive of your loved ones' emotions in a conversation, even if you don't agree with maybe what they're saying.

Roseanne Dobkin, PhD: Yeah, no, and this is something that comes up very frequently. We may not agree with our loved one's point of view about a particular topic, but at the same time, I think it can be really helpful to acknowledge that we recognize you're feeling really sad right now, you're feeling really anxious. What can we do together to try to get some of those negative feelings under better control, so we can acknowledge the emotional reaction that we are observing in our loved one and work together to help our loved one to self-soothe.

Can we maybe step away from the conversation about this emotionally charged topic and can we take a walk or can we do some breathing together, or can we listen to some music and just do something to reduce that overall level of arousal so that we can self-soothe, we can comfort one another.

And then maybe at a later point in time when we're both calm, we can come back and we can more squarely tackle the issue at hand. But I think it's okay to say to our loved one, "I recognize this is really hard for you, and you're really upset by what's happening, and you're feeling really worried and you're feeling really anxious." Acknowledge the emotion. We don't have to necessarily agree with the opinion that's maybe driving that negative emotional response.

Lauren Zelouf: And that can be really validating. It could also help make the other person feel really understood and help to connect you both. And if you both acknowledge that this thing worries you or you're also fearful for the future, or this is also making you anxious, being able to just say it can kind of connect you both, that you're both feeling it and it's okay. And then Peter, how do you handle disagreement? What do you think is the best way? Patience is a part of it, but do you want to speak more to how to handle disagreement?

Peter Lunny, MD: Yeah, I mean definitely patience and active listening are very important. And with Parkinson's too, when there are difficult times, it's hard to know whether it's the Parkinson's itself, if it's the medications, it's the insomnia or what the deep brain stimulator settings are at the moment that may be contributing to some of the difficulty.

But I always try to take a step back and pause and reflect and gather all the data, and then as a care partner, work on some sort of compromise, figure out what's going to be the best way forward for both of us.

Lauren Zelouf: Well, let's move into now how you all ask for support when you need it. I'm just going to open it up to see if anyone wants to address this first.

Peter Lunny, MD: For me, it's important to have, kind of like Christine was saying, a little bit of me time and one of my strategies for mind clearing is just exercise, which is important for John too and anyone with Parkinson's, is to keep active and exercise. But sometimes we do things together exercise-wise, but we also have things that we do separately. And that's sort of my me time or my escape or mind clearing activity.

Lauren Zelouf: That's great. Anyone else?

Christine Hurtsellers: I would say, I have adult children or people in your life, is ask for some help. And for me that might look like, "Hey, why don't you come visit us and watch British Mysteries with your dad or take him out for brunch?" And I find Jim, my husband, what we call masking or showing up and acting around our family that he feels a lot better than he really is. So sometimes it's hard for the kids to realize that they need to be leaning in a little bit more. And so that's why I just overtly will say, "Hey, this is what I'm seeing, and this would really mean a lot to your dad if you would do this."

Lauren Zelouf: That's also a way to kind of point out to your adult children how they can help as well and can say something specifically what they can do. Ethan, do you, and this could be answered by anyone, but how do you, I guess, identify what you need help with? Will you say to people in your life... You're laughing, "Hey, I need help with X." Are you specific or-

Ethan Henderson: I'm a product of my father. I am not an easy person to ask for help and I am learning how to, I'm also learning how to do it earlier on. And yes, the specific things, only because that's easier for me to ask than something general. That was one of my frustrations with my father, but that is also something I'm mirroring, and I know I also probably cause some frustration, but those specific things, I think you're absolutely right, Lauren, that are the important ways to be able to communicate and find support or find the help that I need.

Lauren Zelouf: Peter, do you have anything to add to that? How to specifically ask your support system for help or even in general, is it difficult to ask for help?

Peter Lunny, MD: I don't maybe directly ask for help, but sometimes, kind of like what Christine was saying earlier about her husband, other people, family members and friends may not realize because John sort of puts up a non-Parkinson's appearing front sometimes and people are like, "Oh, we're surprised," or they forget that he even has Parkinson's. So occasionally I will need to remind folks about that.

Lauren Zelouf: Roseanne, why do you think it's important for care partners to be able to ask for help or take care of themselves throughout this journey? Can you highlight that?

Roseanne Dobkin, PhD: So I'm going to say for everybody, mental health is health, and if we're not attending to our mental health needs, our physical health is going to suffer. So if care partner doesn't tune in to what they need and what's going to help them to manage stress and emotional overload, not only will physical health suffer, but it's going to be almost impossible to really be there for your loved one with Parkinson's and to continue to provide the support and the guidance and the love that you have been striving to provide throughout this journey. If care partner's health suffers, then unfortunately, I think the physical and the emotional health of the loved one with PD may also suffer.

And the reality is, there are so many treatments that are available that can be beneficial, that can help care partners and people living with PD to manage stress and feelings of burnout and burden. So I think it's really important to notice those changes in yourself and to know when to reach out for professional help if needed, as well as maybe leaning in a little bit more heavily to some of the friends and family that you're interacting with on a regular basis who can be wonderful naturally occurring sources of social support.

Lauren Zelouf: I think the last thing I'll say on that is it's sometimes important to check in with ourselves, but did I get what I needed today? Do I need a moment to myself? What does that look like and who can I ask to allow me to do that? If it is to run out and go to the grocery store and have that alone time, who can stay with my loved one, if they need that supervision for safety.

So I think it's hard to know how to ask for help until you know what you need first, but then also knowing what is out there, what are the resources that I can reach out to? So we're going to move into the Q&A. I know we can have this conversation for many hours, right? Because there's so much to cover, but I just want to point out, the Michael J. Fox Foundation knows that supporting care partners is essential to supporting people with Parkinson's.

So we created Facing Parkinson's Together, that's the Guide for Care Partners. That's what I've been referring to throughout. This resources was shaped by the voices and insights of Parkinson's care partners, which is what I've mentioned, is that we've highlighted many different voices of care partners throughout the guide. You're actually among the first to access the guide, which is very exciting.

So if you're interested in learning more, download your own copy. So very exciting. So we actually received a lot of great questions throughout the panel discussion. First question I'm seeing here is, how do you communicate best with your loved one with PD when it comes to safety items? And you both feel differently about this topic, perhaps sometimes where cognitive functioning is not the best. It's actually something we kind of brought up a little bit earlier, is like when do you step in, especially when it relates to safety. How about Christine?

Christine Hurtsellers: This is a hard one because my husband is, he's still very strong. He works out, but he's starting to fall and he kind of sometimes won't tell me. And so my adult son, when I was away called me, "Mom, dad fell." And so what I'm trying to do is encourage him to potentially get a service dog, because that's something that I think could really be a great thing for our family. And also I think it takes a little bit of time to get on the approval list, but the reason I'm just saying, "Oh no," I mean it's just hard when your partner is losing independence in a certain... They want to, I think oftentimes not admit that sometimes safety issues are more probable or top of mind than they really are. So again, I'd love to hear other people's answers for help.

Lauren Zelouf: And it might be kind of what Roseanne pointed out before with just validating that they might be feeling the loss of independence, that that exists and being able to name that first before addressing how to keep them safe. I don't know, Roseanne, if you want to, not to steal your thunder, but if you wanted to add to that.

Roseanne Dobkin, PhD: Yeah, no, I mean, I think the one thing I would add and something that I raise in conversation a lot with the people that I'm working with, especially when we are confronting safety challenges and the need to maybe make some changes in order to prioritize our safety and the safety of others, is that when we think about independence... There are many different ways to kind of think about it and what it means.

And oftentimes we may need to give up a little bit of independence right now in the short term in order to really maximize the amount of independence that... So an example I can think of, was working with somebody the other day that was a little bit resistant about using the walker in the house because it felt like, "I'm giving up independence and I don't want to do that." But if we use the walker in the house and we don't fall, or we fall less often, then maybe we can prevent a fracture or an injury that would then kind of take us out of commission for a much longer period of time.

So we may need to make small trade-offs in the here and now, in the short run that are hard, but will help us to remain sort of safer and healthier, and more independent moving forward. So I don't think we can think about safety or independence in all or nothing terms. And I think it's really important to kind of think about the shades of gray and where there's opportunity for flexibility and compromise.

Lauren Zelouf: It goes to show how you frame something in a conversation is really key. So I have a question specifically for Ethan, if you want to share the experience of being an adult child care partner and how that differs from being a spousal care partner.

Ethan Henderson: I speak from the adult, taking care of my father from afar is communicate, check in frequently with... I checked in frequently with him as well as my mother, as well as friends that still lived in the area. When you go to visit, make sure that you're making appointments with the people that are the people that are taking care of needs and health issues, things like that. Keep doctors and other things like that on your speed dial. I just knew that when I went to visit my parents, it was not going to be a vacation or a downtime for me. And that's fine, that's what I wanted and that's what... I wouldn't do anything differently. Just get people involved.

You can't do it by yourself and there's just no way to do that. But I think I'll leave my answer at that, just because as a person with Parkinson's, at least I think my wife would say that she does the exact same thing for me that she did for my father as well. So being organized and making sure that you're staying communicative with the people that are there.

Lauren Zelouf: It just goes to show that care partner, especially from afar, you play many different roles. One way is you can still be in communication and be involved in their care. Quickly, Peter, I just want to make sure you have a chance to share this. How do you maintain intimacy even as Parkinson's changes things? I know that's a heated one but-

Peter Lunny, MD: To not maybe always focus on sort of the negative or the downsides of Parkinson's, but kind of celebrate the joys. And in all honesty, a lot of things that have happened since John has been diagnosed have accomplished things that are beyond things he probably would've considered prior to the diagnosis. He was kind of inspired to engage in some activities that were kind of outside his previous comfort zone as a way to kind of challenge his Parkinson's and his response to it. In a weird way that's kind of improved our intimacies.

Lauren Zelouf: So his resilience too, and also remembering the person he was before. I love that. So I just want to hear from you all, if you could share what's one thing that you wished others knew about the care partner journey?

Christine Hurtsellers: I would say certainly it's difficult, it's evolving, it changes. But I think Peter, as you were saying, there can also be some joy and personal development for you and your partner to see how are we really going to show up when life gets more challenging? Because I think as we look at people in relationships in our lives, it can become a legacy for others as far as how you're both handling it. So I would say that there are positives and hope in the partnership journey as well as the challenges.

Lauren Zelouf: I love that. Who's going to follow that?

Ethan Henderson: The person with Parkinson's will not be the most communicative about the struggles and the challenges and the needs, and nor will we always voice our thanks or our gratitude towards the people that help us, but know that we really are. And we won't always voice it but after it's all said and done, we're extraordinarily grateful for that care.

Lauren Zelouf: I appreciate your vulnerability, Ethan.

Ethan Henderson: Thanks.

Lauren Zelouf: It takes a lot of courage to be here. Peter?

Peter Lunny, MD: I guess just being flexible because things can change day to day and whether it's from symptoms or from the treatment thereof, have flexibility and being able to pivot and change directions or change plans if needed based on what's happening at the time.

Lauren Zelouf: Definitely. Pivoting is key. Roseanne, any last thoughts?

Roseanne Dobkin, PhD: I think we need to all remind ourselves about how important it is to have realistic expectations, not only of ourselves, but of our loved ones. And one of my other favorite sayings is that we're all perfectly imperfect human beings trying to have meaningful relationships with other perfectly imperfect human beings. And we're doing the best we can and we're doing way more than we all give ourselves credit for.

Lauren Zelouf: It's a great way to end. Thank you, everyone. Thanks so much for joining us and for taking part in this great conversation. And thanks to all the care partners and Roseanne for showing up and being part of the conversation.

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