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MJFF: 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.

Rebecca Gifford: Hi and welcome everybody. Thank you for joining us today. I'm Rebecca Gifford and I'm your moderator for today's webinar. I'm a writer and workshop facilitator. I also co-host podcast When Life Gives You Parkinson's with my husband, Larry Gifford, who occasionally moderates these webinars. He was diagnosed with young onset Parkinson's disease in 2017. So today we are going to discuss life with Parkinson's from a loved one's perspective. Our panelists will share their experiences and tips and answer your questions. They will also talk about what being a care partner can look like, and whether there's a more preferred description for those who care for a loved one with Parkinson's. We'll also discuss how to recognize stress and burnout and strategies to prevent it. So this is a big topic, a lot to cover, and we would really love to get started. We're excited to talk with all of you. So let me introduce our panelists. First. We have Rich Sussman from New Jersey. His wife, Pola, was diagnosed with Parkinson's in 2017. Welcome Rich.

Rich Sussman: Good morning. Good afternoon.

Rebecca Gifford: We have Dr. Jori Fleisher, who is a movement disorder specialist and associate professor at the Department of Neurological Sciences at Rush Medical College in Illinois. She has several research studies underway focused on caregivers. It's exciting.

Dr. Jori Fleisher: Hi everyone. Thanks so much for the opportunity to join you.

Rebecca Gifford: And we have Maggie Rowland Wortendyke from Tennessee. Her dad, Mike, was diagnosed with Parkinson's in 2014. Welcome Maggie.

Maggie R. Wortendyke: Yeah, thanks for having me.

Rebecca Gifford: Well, thank you everybody for being willing to share your experiences and wisdom today. Let's get started. So, Michael J. Fox has a wonderful quote that says, "When I first heard about my diagnosis, I was so angry. And Tracy just looked at me and said simply, 'In sickness and in health.'" As care partners and loved ones, we know in a way we also are diagnosed with Parkinson's. So I'd love to start with Rich. When your wife, Pola, was diagnosed with Parkinson's, what was your initial reaction, and how has your care partner experience evolved over time?

Rich Sussman: Wow. My initial reaction was, I don't know. It was a combination of being scared, being afraid, being upset. The background was that the closest experience I had to Parkinson's prior to that was from Pola's dad, my father-in-law. He was bald most late in life. So the first thing I'm thinking is, no Pola's much too young to have Parkinson's. That's not right. The second thing I'm thinking is that he quite frankly didn't do very well with his disease. It progressed very rapidly, you know, taking his body, taking his mind. So I confess, you know, one that I was thinking terrible things about what this actually meant. And the second thing was I wasn't actually sharing that with anyone. I wasn't going to actually say, "Oh my gosh. Is it going to be the same as my father-in-law?" So that was my initial reaction. Not necessarily the best reaction.

Rich Sussman: Subsequent to that, you asked about kind of the journey. So, I discovered that a, I was wrong. People with Parkinson's, they all have unique experiences and most people can do quite well and accomplish a lot for a long period of time. So, that was wrong. I learned that there's lots of resources to help me and help Pola along the journey. So that's really important. I think I learned, and I'm still learning, how to be a good care partner. And I think very importantly, I learned to focus on the positives and focus on today. So for example, while it's true that Pola has trouble with dyskinesia and there are points during the day where walking might be difficult or parts of the day where standing might be difficult, she still manages every morning to do her stretches. We still go and we take the dog, best puppy ever, for about a mile long walk every morning and afternoon. And she does between an hour and two hours of exercise each day, which has been really important. So I focus on that. I focus on all the positives. I focus on how well she's doing, as opposed to focusing on some of the other aspects of it. So I think that's been really important to me and to Pola.

Rebecca Gifford: Yeah. And kind of taking control of what you can take control of. Right? Yeah. So the exercise and the things, then the research and the things that you can do. Yeah. I like that. And our journeys are constantly evolving because the disease is always progressing. So we're kind of in that constant state of evolution.

Rich Sussman: Yes, yes. And one thing that Pola says, and truly believes, and this is another reason I'm kind of living in the moment, is that if the disease did not progress any further, she'd be perfectly happy with where she was today. Well, she's perfectly happy where she was today, then that's great. That's a good starting point. It's much better to be focusing on that.

Rebecca Gifford: Right. Thank you. Thank you for that perspective, Rich. Maggie, I want to ask you a question. We often refer to people who care for loved ones with Parkinson's as care partners. How do you feel about this? Do you feel there is a more preferred term for someone like yourself who isn't a person or isn't a partner of a person with Parkinson's, but is certainly affected by Parkinson's?

Maggie R. Wortendyke: Oh, that's such a good question. I actually was intimidated to take part in this webinar when we talked about care partners. It's not really how I see myself. I think the name of the webinar's [inaudible 00:06:56] do you love someone who

has Parkinson's. I do, like a whole lot. So I think that that, to me, it's just as simple as that. I don't need to label or anything like that. But again, I care for my dad in a different way. So a care partner isn't really applicable to me.

Rebecca Gifford: Do you have a term that you would rather use or is it just "my dad has Parkinson's?"

Maggie R. Wortendyke: Yeah. It could be that simple. I don't think you have to complicate it.

Rebecca Gifford: Right. Rich, I'd love to get your take on that. Are you comfortable with care partner? How do you respond to caregiver?

Rich Sussman: Yeah. I'm not uncomfortable with care partner. It's probably not my preferred term, much to Pola's chagrin, we've been married for 40 years. And after that period of time, we're life partners, so we take care of each other. So when I hear "care partner," it sounds like it's a very one-sided relationship, and I don't think that's right. So the phrase that I like, which I can't take credit for, but you and Larry can take credit for is for partners in Parkinson's. And I view Pola and I being partners, I view our movement specialist as being with us as partners. I view the, the Fox Foundation as partners, our kids, friends, you know. It's just a whole community. So that's what I like.

Rebecca Gifford: Yeah. Well, and I have to be honest, we can't take credit for it either. Larry and I for partner in Parkinson's that came from Cheryl Hague, our friend Cheryl Hague, the wife of Tim Hague. And he coined that. And so we co-opted it and use it for the podcast all the time. But you're right. It's perfect, right, because at least most of the time, because we're all kind of partnering in this, we're all involved in this and everybody, at least the intention is for everybody to have an equal say in how it goes and in the care of this person. We're all involved in the care of this person we love.

Rich Sussman: Exactly.

Rebecca Gifford: Yeah. Great. So Dr. Fleisher, what advice do you have for people who love someone with Parkinson's but aren't sure how to support them?

Dr. Jori Fleisher: It's such a great question. And I think the best thing to do is ask the person with Parkinson's what they can do to be helpful. I'm sorry for any subway noise. So many times we jump and think, I'm going to send an article, I'm going to do this. I'm going to send something, and it's really so person dependent on what is helpful and what's helpful in that moment. You know, an article might be wanted a month after a diagnosis or, you know, two months after a hospitalization or, you know, something. But maybe right in that moment, that's not what that person needs. So I think rather than assume and rather than act from a place of here's what I think I might want in this situation where we can really never know what that's like until we walk in that person's shoes, just ask what would be most helpful.

Dr. Jori Fleisher: And coming to it, sometimes I hear from a lot of partners in Parkinson's, a lot of families that say, "My loved one doesn't want to talk about it. They don't want anything," and respecting that. And sometimes a great way to be helpful is to put it back on you and say, "I would really like to feel helpful. It would make me feel good to be able to do something for you. What might that be like,". And then it shifts the conversation a little bit.

Rebecca Gifford: Yeah. Focuses on their needs, but also allows them to acknowledge that you're just trying to help, so keeping those communication lines open.

Dr. Jori Fleisher: And I think it gets to Rich's point that this caregiver feels very one-sided. But if you can have the person with Parkinson's in the giving, see it to say, let me give you something to do as someone who wants to help, that can be helpful.

Rebecca Gifford: That's great. So we have an audience question that maybe Maggie, you'd like to take a stab at this. My mom has Parkinson's, but I live far away. How can I best support her from afar? Because you don't live in the same place as your father, correct?

Maggie R. Wortendyke: I don't. I live in Nashville, Tennessee, and I'm from Birmingham, Alabama, which is where my parents currently live. So not super far away or I'm a quick drive, but not in the same town. So this is a constant struggle. So I feel for this person who asked this question. It changes, I would say, along your journey with Parkinson's. You always talk about how it changes and grows and evolves as your loved one changes and grows involves. So at the very beginning, we talked about communication. We didn't talk about it at all. So supporting from afar was pretty difficult, or I guess you could say it was easy because we just continued about normal life.

Maggie R. Wortendyke: As we've been a couple years out from diagnosis, we are more able to talk about it. So for me, I would say just like Dr. Fleisher said, figuring out how your loved one, how does mom want to talk about it. Does she want to talk about it, does she want to ignore that it's happening? Maybe not the healthiest option, but I would say follow mom's lead. Make sure that you're asking how her doctor's appointments went. When is your next one? Do you have any things that you're worried about? Have you noticed anything changing. Sometimes just an ear for somebody to listen who's not involved in the everyday life and can have a bit of a different perspective. I found that that to me is the best way to try and support.

Rebecca Gifford: Well, and it can be tough too, because you're trying to support and help them where they need help. But you also don't want to encroach upon their independence. You want them to feel like we support them doing as much as they can do for as long as they can do. So you're always kind of walking a fine line there. And so, yeah. So the thing that like you and Dr. Fleisher have said, keeping that communication open and just kind of keep having that conversation. Yeah, I like that.

Maggie R. Wortendyke: Yeah, absolutely.

Rebecca Gifford: Great. So I just want to remind our viewers that there is a guide called You, Your Loved Ones, and Parkinson's Disease. And there's a link to that in the resource list if you want to read more about that. Okay. So let's move on to talking a bit about something that is sometimes a daunting process, managing the care of a person with Parkinson's or helping to manage the care of a person with Parkinson's. Now we know everyone is different and every relationship is different, but there are some tips that seem to come up pretty consistently as helpful tools or things to keep in mind regarding this. For example, from the list on the slide, get help, build a good care team. And part of that is if you can, consult a movement disorder specialist. Be organized, keep lists, and prepare ahead for appointments.

Rebecca Gifford: That's a big one for Larry and myself. We always have a meeting before the meeting and kind of get a list together, make sure that we're remembering all the things that happened since the last time we saw them, make sure that we're able to get addressed all the things that we need to, because sometimes that's a pretty long list. And then stay informed as much as you're comfortable. But Dr. Fleisher, care partners can be invaluable resources I believe when it comes to getting information and perspective on how the person with Parkinson's is doing. What tips do you have for care partners and how they can best manage the relationship with the care team and then participate in the care team?

Dr. Jori Fleisher: It's such a great question. And this really comes up every day. So I love your idea of the meeting before the meeting. Strategizing, we're going to have this appointment and whether the appointment is half an hour or whatever it is, having that prioritized list coming into the visit with that is so powerful and can help you get the most out of the visit. I also think a really important thing to talk about in that pre-meeting is, you know.

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Dr. Jori Fleisher: Important thing to talk about in that pre-meeting is because Parkinson's can be so insidious, it can be so sneaky and some symptoms might not be noticeable to the person with Parkinson's, but care partners and family members might notice things. It's a good time in that pre-meeting to maybe say, "Would it be okay, I noticed that your leg is dragging when you're walking, or I've noticed that your handwriting is changing a little bit. Have you noticed that? Would it be okay for me to bring that up at the visit?" Because sometimes it can be really difficult if care partner is bringing something up for the very first time in the doctor's visit. I can sense that tension of why did you say that? What's going on?

Dr. Jori Fleisher: So I think if you can, if there are symptoms that you're concerned about and you're worried broaching that with the loved one first is great. If not, many, many healthcare systems are on an electronic health portal, whether it's a My Chart or something else. And you can always send a message, if you have access to your loved ones chart, if you're a proxy. You could send a message, you could

call and leave a message with the nurse, just to say, here's something I'm concerned about, I wanted to give you a heads up, if you don't feel comfortable and you'd like the provider to bring that up first, that's something that I have a lot of family members who do.

Rebecca Gifford: Yeah. So you've got, so you're kind of helping to keep the communication open when the person with Parkinson's may not be inclined to, or maybe having an off day or something like that. You're kind of assisting in that process.

Dr. Jori Fleisher: Exactly.

Rebecca Gifford: Okay, great. Maggie, you are an adult child of a person with Parkinson's. How do you participate in your father's care?

Maggie R. Wortendyke: Well, Dr. Fleisher actually sent a message that said many MDs are thrilled to have family members join visits by phone, which- [crosstalk 00:16:56] So I might start to, start demanding some phone calls. I would say an adult child specifically who lives in a different city, being a part of the care is, and I hate the word care because my father requires no care, being a part of the care is, is a little more difficult. So for me, what that means is after each appointment or before, or a couple of days later, I always try to get on the phone with that and just get a full download of what did you guys talk about?

Maggie R. Wortendyke: Did you have to do this? Did you have to do the walk test? Did you have to do this? How did it go? Anything new? What are they talking about in the future? Did you ask them about that thing that we talked about? And then also talking to my mom and getting the same download from her. And then sometimes with half of the pictures from both of them, I can get a full picture of what went on at the doctor's appointment. So it's just trying to be involved as much as you can and just understanding what everyone, what page everyone is on.

Rebecca Gifford: Right. Do you have conversations with your parents about how you might be helpful in that process?

Maggie R. Wortendyke: I think rather than having conversations with them about how I can be helpful, I typically just butt my way in, and force my way into being helpful. I think that communication is important in every family, or every friendship of someone who has Parkinson's and you kind of have to learn what works for you.

Maggie R. Wortendyke: So, it works for me and dad to catch up every Friday. And sometimes we talk about Parkinson's and sometimes we don't mention it at all. So understanding kind of by body language and whether or not anyone's willing to talk about it, and not to push too hard if I don't have to.

Rebecca Gifford: Yeah. Has communication changed over time with your father? And I'd love to ask Rich about that as well. Has communication shifted at all over time with, as your father or your wife's Parkinson's progresses?

Maggie R. Wortendyke: Yeah, sure. I can take that one. It has definitely changed. So I kind of alluded to in the beginning, right when dad was diagnosed, we didn't talk about it at all. It's a really strange elephant in the room. Kind of pretended that no one had Parkinson's and now it's kind of a part of our daily life and I'm kind of a jokester. So I tried to make some jokes in the beginning that did not land. And I think we've finally gotten to the point where we can all kind of laugh and joke a little bit when appropriate. So it's definitely a spectrum from not talking about it at all to it's here and we're going to talk about it, and kind of name it.

Rebecca Gifford: Right. We have an audience question and I'm going to pose this to Rich. How do you separate spouse and caregiver if one has Parkinson's and the other has a medical condition, or maybe that's a better question for Dr. Fleisher or if anybody wants to chime in.

Dr. Jori Fleisher: I'm not totally sure if I under-

Rebecca Gifford: The question is how do you separate spouse and caregiver? And I guess, I guess that's the crux of the question. It looks like they asker has with the one of the spouses has Parkinson's and the other has a medical condition. So they're kind of in the process of trying to negotiate caregiver versus care partner. And how does that work? And maybe this is a question for Rich, for how do you negotiate, how you work together in managing the Parkinson's, but then like how your relationship perhaps has shifted since the Parkinson's joined the family.

Rich Sussman: Yeah. I'm not the perfect example here because I don't have a medical condition that can compare with Parkinson's. So that makes it difficult for me to put myself in their shoes. But I would say that Dr. Fleisher said something earlier that I think was really important, which is that you ask the person what can you do to be helpful. And in Pola's case, what she finds helpful is something kind of comparable to what Maggie said, which is not to dwell on the Parkinson's. She doesn't want to be reminded about the Parkinson's all the time. She doesn't want to have to think about all the what ifs and what might happen in the future. So she asked me to be incredibly supportive, to be with her with, at all the doctor's appointments, to be as knowledgeable as I can that I can help out in that way, and to, in general, try to, to encourage her.

Rich Sussman: I point out reasons for optimism. For instance, her exercise that she does, there's no question whatsoever in her mind, that it's helped to slow the progression, she's been doing really well with it. So I'm going to emphasize that, for example. So that's kind of our strategy.

Rebecca Gifford: Yeah. Have you and Pola had conversations about important decisions for the future? You're talking about being in the present, but have you had kind of those tough conversations about the future as well?

Rich Sussman: We very briefly had those kinds of discussions. Again, it's not something that we were going to be discussing a lot. Pola's dad that I mentioned had Parkinson's and for the last three years of his life, he was essentially bedridden and on hospice care. He stayed in his house. My dad had vascular dementia and for the last 18 months of his life, he was in a memory care unit and Pola very quickly said, okay, let's get this settled right now. And let's not even talking about it after this. I'm going to stay in the home. Maybe am to see you, you can stay in the home and we're going to stay in our home. You know, I don't want to go into one of those facilities, that's just the way it is. So we did have a discussion and it's done now, it's decided, and that's what we're going to do. And we don't, we don't bring it up anymore.

Rebecca Gifford: Right? Yeah. You, you got the tough conversation out of the way. And so now you know what the plan is and you can focus on the present.

Rich Sussman: Exactly.

Rebecca Gifford: Yeah. Yeah. Great. I think that's wonderful. Okay. So now we'd like to take a short station break. And so I want to tell you about the Foundation's landmark study. PPMI right now it is recruiting. The Parkinson's Progression Markers Initiative, also known as PPMI, is the study that could change everything about how Parkinson's is diagnosed, managed, and treated. And right now the study needs parents, siblings, and adult children of people with Parkinson's. You can take a short survey and get started by clicking get started, and the take action box on your screen. The study is also recruiting people diagnosed with Parkinson's in the last two years who are not yet taking PD medications. You can learn more about PPMI by clicking on the link in the resource list. Rich, I believe you are a PPMI participant, am I right?

Rich Sussman: Well, I have volunteered to be a control person. I've not been onboarded yet, but I've been promised that I'll be control subject number one at the hospital where Pola's movement specialist is.

Rebecca Gifford: Right. And so why did you sign up?

Rich Sussman: Just a little bit of background, which is that Pola has a mutation that is linked to Parkinson's, one of the mutations that the PPMI study is looking to study more. When Pola's mutation was found, I did sign up for genetic screening. I was, and it sounds a little weird, but I was kind of hoping to be found with a mutation that I could participate in her research because as a care partner, as a partner and participants of a partner in Parkinson's. You might have to fix that one, I had trouble getting that one out. It's one thing just to kind of be on the sidelines and a cheerleader and helping, but now I want to try and see if there's something that I can do to actually be involved and help. And we have participated in research studies. Pola's the active participant and I am kind of a control. We do Fox Insight and I signed up for PPMI for the same reason, because if I can somehow contribute to it helps Pola, it helps everyone else. It helps out kids who might have the same mutation, so why not do it?

Rebecca Gifford: Great. I know it's this what can we do, right? There's no cure, but we can do so much to try to move things along and organizations like the Foundation rely upon people to participate.

Rich Sussman: [crosstalk 00:26:23] podcast, but it's probably not my thing.

Rebecca Gifford: All right. Thanks for telling us about that. So let's move on to talk a little about stress and burnout. Exciting. The world right now is dealing with an increased level of stress. My goodness, not to mention raised levels of physical, emotional, and mental exhaustion, and for anyone caring for a loved one with Parkinson's or any disease for that matter, the potential burnout is very real. Dr. Fleisher, what are some of the symptoms of burnout that we can be looking for to recognize in ourselves and our loved ones?

Dr. Jori Fleisher: I'm so glad we're talking about this topic. So, anger frustration with the loved one, increased anger, frustration, just in general feeling like you're detaching more from your caring from just the relationship with that person. These can all be signs of burnout, and as well as physical exhaustion, emotional exhaustion, feeling like your fuse is so much shorter. And I think we are, we're in a burnout pandemic that is not unrelated to the main pandemic that's going on. So I think it's so critical to recognize and to know that there are things that we can do about it.

Rebecca Gifford: Well, what are some of those things that people can if they start to recognize the sign, what's a way to get started and taking care of yourself and, and moving through that?

Dr. Jori Fleisher: So, I mean, I think number one is recognizing that you might be going through burnout and knowing that that is normal, that that is okay, and that this work, dealing with this disease, is hard. When I tell someone, when I give someone a diagnosis of Parkinson's, I tell them this doesn't define you, but this doesn't just affect you, this affects your family. This affects your circle, right? So, recognizing that this is hard and it's okay to ask for help. It's okay, and it is critical to take a break. Someone posted earlier, you can't pour from an empty cup, right? There are all these analogies the flight attendants on flights, it's when we all used to fly said put the oxygen mask on yourself first before helping someone else.

Dr. Jori Fleisher: You have to find ways if you're feeling burnout to recharge in some way. And that may be as simple as being in the moment and just taking a breath and going, that's not how I wanted to respond to that request. Or that's not the way that I would have phrased this if I had some more sleep. Let me take a breath. Let me just go take a lap around the dining room. Let me go pet the dog or call a friend, even if it's for two seconds. Let me look at some stupid memes. Let me do something. And then trying to find ways. I mean, I'm not knocking stupid memes, they get me through Sunday nights. But finding ways to really recognize the burnout in yourself, normalize that, and then take some kind of action.

Dr. Jori Fleisher: And it's not like you're going to say, man I feel burnt out today. Well, I'm just going to meditate and do some yoga and then it's all going to go away. No one thinks that, and that's not realistic. But recognizing and starting to take steps of what is self care for you as the partner, in Parkinson's or as the person with Parkinson's, who's feeling that burnout. What is meaningful to you? If that's yoga, if that's having a piece of chocolate, if that's going for a walk or petting the dog, whatever that is, being able to try to, to work that in on a daily basis, on a regular basis.

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Dr. Jori Fleisher: ... and on a daily basis, on a regular basis, to know that you have that break is really critical.

Rebecca Gifford: I love that you acknowledging the fact that no one is perfect and that we can't expect ourselves to be superwoman, superman and do everything. Take care of ourselves, take care of the person with Parkinson's, take care of the world, and still be able to be super with-it and balanced all of the time. And that something as simple as stopping to take a breath, or go to a different room, or walk around the block can really help to break that stress cycle.

Dr. Jori Fleisher: And I would push back on that a little bit, just to say, "If you're here today, if you're listening to this, if you're identifying as a Partner in Parkinson's, you're already a superman, superwoman, super non-binary. You're there already. You've already taken those steps to get connected, and to learn, and to learn, and to be empowered. You're already doing it. Give yourself the credit that you deserve."

Rebecca Gifford: Right, yeah. Well said, well said, thank you. Rich, what advice or tips do you have for people on how to move through the challenges and sometimes the surprises that arise related to [Pola 00:31:13]? So we know that with the unpredictability of Parkinson's, sometimes our days can change really quickly. Do you have any tips or strategies for how you move through that?

Rich Sussman: Well, first of all, I have to say that Pola's doing pretty well. She makes a concerted effort to take care of herself, whether it's through exercise, diet, maintaining social relationships, and keeping a positive outlook. So all that is important. But in terms of how to cope with things, I think Dr. Fleisher mentioned the dog, we do have a great puppy, that's always something that's important. But I think it's really important to A, be knowledgeable of what Parkinson's is. So some people who have not been exposed will just think about the tremors, but as an example, and I don't think Pola would mind my saying this, one of her major issues is anxiety. And Parkinson's related anxiety is one of those things where you can't do a lot with it. Now, sometimes, there's some drugs that may or may not help, but just recognizing that the anxiety is from the Parkinson's and recognizing that there's not a lot you can do about it helps, because you don't have a discussion like, "Well, what are you anxious? There's

no reason to be anxious." "No, I know why you're anxious, it's because you have Parkinson's." And the fact that we both can recognize that I think helps.

Rich Sussman: The other thing that I find very helpful is if you get to one of those periods where it's like, "Ah, this Parkinson's, this is a really bad thing." I go and I take a look to see what I can find that is positive that's going on. What new research is out there, if there was a previous webinar that was given that was really optimistic and positive, I might even re-watch that. So I just look for ways for recharging the batteries to make myself more positive and give Pola more reasons for optimism. So that's my go-to strategy.

Dr. Jori Fleisher: [crosstalk 00:33:17].

Rebecca Gifford: So there's so much information out there, right? And so many reasons to be optimistic. Yeah. Maggie, we have a question from the audience. This person asks, "How can I help my father go through his experience with Parkinson's and also help my mom cope?" You're doing this from afar, so how do you participate in that?

Maggie R. Wortendyke: Yeah. I've already talked a lot about an open line of communication, specifically with mom, we talk every day. So again, we don't always talk about Parkinson's, but it's nice to have a check in and figure out how she's doing, how she's feeling. But one of the ways that my family and I and our friends [inaudible 00:33:58] ourselves into this is to find something tangible that we can do to help, which for us, that manifests in fundraising for The Michael J. Fox Foundation. We are part of Team Fox, the grassroots effort to raise money for the Foundation. So we host events and it's a tangible way that we can feel like we are doing something. So you can see the dollars tick up, so you can see exactly how much impact you've had.

Maggie R. Wortendyke: So it's been really great for us to have an outlet and something we can do where we're feeling like we're helping, we're not sitting back and letting it happen to us. We are moving forward and making change. But as that relates to burnout, I'm not a physical care partner, so burnout for me is a little different. Every year, we host a big event and we try to raise a lot of money, and it's fun and we shake pom-poms and we wear fox masks, and everything is orange and everything is blue. And it's a really good time and it's a really great way for our community to rally around us, but sometimes, usually about once a year, I get into a bit of a funk and say, "I don't want to shake the pom-poms and talk about how exciting Parkinson's is." It's not exciting, it really stinks. So I get into a spot where I'm really not interested in being joyful about Parkinson's. So I just have to let myself feel that.

Maggie R. Wortendyke: It's not one of those things that you can push through, because then it gets worse. I think every once in a while, if you're in a situation like I am where you're not a physical care partner, but you're trying to support in other ways, sometimes it's fine to just step back and say, "Okay, for a week, or a day, or however long, I'm going to not think about it. I'm not going to send out

fundraising emails, I'm not going to secure water for the water stations. I'm just going to live my life and put it to the back of my brain." That might not be the healthiest option, but for me, it is. And then you're more refreshed and able to jump back in full force once you've breathed through it.

Rebecca Gifford: Right. You're allowing yourself to feel feeling that come up, right?

Maggie R. Wortendyke: Yeah, [crosstalk 00:36:01].

Rebecca Gifford: So that you can move through them and get back to that place of enthusiasm and support, right? Yeah.

Maggie R. Wortendyke: Just give yourself some grace.

Rebecca Gifford: Right. Oh, I like that. Give yourself some grace, I'm going to use that. So it's important to note that many care partners and caregivers also are experiencing financial challenges. And I bring this up because congress is considering a bill that would provide financial relief to caregivers. The Foundation's policy team is advocating for this, and you can learn more about it by clicking on the resource list link. Dr. Fleisher, the Foundation often gets questions about the challenges of supporting a loved one with cognitive and memory changes, which certainly can add to a care partner, a loved one's stress level. What advice can you offer regarding that?

Dr. Jori Fleisher: So I think Rich said it really well, is to get information, to be empowered, to get the knowledge to know what might come up and what you're dealing with, so that you can understand it. Because some of the symptoms, like anxiety, the anxiety might seem like it's a response to something else going on, but it's actually part of the Parkinson's. One of the things that I think becomes an elephant in the room and a real source of frustration is apathy. So a person living with Parkinson's just kind of loses their motivation. I think of motivation as a gas tank, and it's like someone poked a hole. And they know they should exercise and their family is telling them they've got to exercise, they've got to do the things, and they just, "Not today, but maybe tomorrow." And it can become this source of frustration and not recognizing that that's the disease talking, rather than that person.

Dr. Jori Fleisher: So I think understanding things like apathy, understanding the ways in which memory and thinking can change in Parkinson's, not in everyone, but the things that can be affected and the things that don't tend to change. One thing that often comes up... and my bias is that my clinical focus is more in advanced stage PD, and so this does not apply to everyone. But sometimes, people can have hallucinations or they can have delusions. They might be paranoid that someone is plotting against them, or family is doing something behind their back, and no matter what, as tempting as it is to try to prove them wrong, you can't fight it. You can't argue with the brain firing on a faulty pattern.

Dr. Jori Fleisher: So what I tell my care partners and family members who are so frustrated by this is, "You have to let them be in their reality and either you can join them..." so if someone is saying, "Here's what's going on, and whatever that is, tell me more about that." Instead of saying, "No, no one's here. That didn't happen." Yeah, what was that like? What do you think they're thinking about, what do you think they're doing? Be with them in that reality and then they see you as a partner. Or distract, redirect. So if someone is really fixated on something, recognizing you're not going to convince them out of it.

Dr. Jori Fleisher: But for example, I have patients sometimes where they might see a dog in the room. They're not upset by it, but they keep asking about the dog. And I have great care partners who will say, "Oh, that dog is leaving in about five minutes. You want to go in the kitchen? And then when we come back, I know the dog will be gone." And things like that really show the partnership, and it seems like they help that person... in these experiences with patients, patients feel heard. It does not make them feel like they have a disease. They feel like they have a family member who is listening to them, respecting their reality, and helping them get past it. So understand those symptoms and work with them, rather than trying to fight against them.

Rebecca Gifford: Great, thank you so much for that. We should note that there is a new guide on thinking and memory in the resource list that should be on your screen there. Also, a great online resource is the Parkinson's Buddy Network. There is a group for caregivers and care partners in that. You can also find that linked on the resource list. So there are lots of resources and help available for you, should you feel confused by any of the things that we're talking about here.

Larry Gifford: A landmark study that could change the way Parkinson's disease is diagnosed, managed, and treated is recruiting participants now. PPMI, or the Parkinson's Progression Markers Initiative, needs people with and without Parkinson's, especially people age 60 and up who have close relatives living with the disease. Take a short survey today at michaeljfox.org/ppmi to see if you're eligible. That's michaeljfox.org/ppmi.

Rebecca Gifford: Well, it is time for Q&A. We have been receiving a lot of great questions. Let's start, let's see what we have here. Okay, here's an audience question. "I've just started dating someone with Young Onset PD, diagnosed four years ago. He spends a lot of time checking in to be sure I know what I'm in for in the future. How can I best support him and help him understand that he may have PD, but he is not PD?" Dr. Fleisher, did you want to take a stab at that?

Dr. Jori Fleisher: Sure. So when I hear that question, I hear that that person with PD is anxiety, just ringing out so loud in that. The needing to keep checking in and say, "Do you know about this? Do you know about this? Do you know what's going to happen?" To me, that sounds like someone whose anxiety about the future really needs to be addressed. And so there are all kinds... and I'm not a therapist, but ways to deal with that anxiety. So helping connect the person that she's dating, saying, "Maybe it would be helpful to talk with someone about

this, because it sounds like you're really concerned about what the future might bring, but I want to be with you in the present. Maybe it would be helpful to connect with someone who can help talk about that, but I really want to be with you in the present." And sometimes setting limits... so as a mom of a kid with anxiety, what I've been taught is the couple question rule. Which is, "We're only going to talk about this... All right, you've asked that question two times today. We're not going to talk about that question anymore today. We can talk about it tomorrow. What do we want to talk about instead?" And using that to reframe, "I'm here with you in this moment. I'm here for you. Let's focus on now."

Rebecca Gifford: Great. Great, I know we're all dealing with a level of anxiety right now, and I also have a child who has some anxiety. And so there are so many tools available, and people are so much more aware about it, and there are so many great ways to address that. And I love that you picked up on that right away, that that's probably what's going on. Wonderful. Okay, another audience question, I'm going to pose this one to Rich. "How do you encourage without being a nag?" That's that fine line all of us are trying to walk, of, "I want to be positive and supportive, but I also don't want to become irritating. And I want to encourage them to do things, especially when they're feeling apathetic, encourage them to keep exercising and move through that. But how do you do that without becoming annoying?"

Rich Sussman: Yeah. I can't help being annoying, it's just who I am. I just have to accept that for what it is. So my approach to that, which works for us, hopefully works for everyone else... on the subject of exercise for instance, we saw... Pola has been an exerciser, have always exercised, so that was not something she needed convincing to do. But a few weeks ago, we watched a webinar about this current state of research on exercise and Parkinson's. She watched it with me, it was just incredibly positive, incredibly optimistic, that exercise really can slow down progression. So my approach is to bring that into the conversation, "Take a look at this. Look at what this can do for us." There's something about what diet can potentially do. As opposed to it just coming from me saying, "Gee, you should try to eat this," or, "You should try to do this kind of exercise." Bring in someone that's actually an expert, as opposed to me. So that's my approach.

Rebecca Gifford: Yeah, I found... and this is something that I learned pretty quickly in our marriage, that [Larry 00:44:50] won't do anything unless it's his own idea. So me encouraging him to do something, he'll file it away and he'll note it, and he won't discourage from encouraging, but he won't necessarily do it until-

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Rebecca Gifford: ... and he won't discourage me from encouraging, but he won't necessarily do it until he's absolutely ready to do it, and so I like the bringing in the third party and just kind of, "Hey, if you watch this documentary, have you read this article?" And just kind of giving him the information he needs, so he can make his own decision rather than trying to steer him a certain direction, right?

Rich Sussman: And exactly. Ultimately, it's their decision, they have to buy into it.

Rebecca Gifford: Right. Yeah, they have to want to be well, right? Yeah. Yeah. Maggie or Dr. Fleisher. Do you have anything to add to that?

Maggie R. Wortendyke: My dad would tell you I know nothing about that. Nothing about not being able to [inaudible 00:45:40] , so, nope!

Rebecca Gifford: Oh, I'm sorry. Go ahead, Dr. Fleisher. I'm sorry.

Dr. Jori Fleisher: Oh no, I wouldn't say I've certainly been accused of nagging family members who have different health issues, but one thing that we've found helpful is humor. And also sometimes having like a shorthand. So, during a heated time, when I was trying to convince someone to do something that they knew they should do, I said, it's coming from a place of love. And I got back this like, "place of love, place of love". If I suggest something, I literally just go "place of love". And it's almost a shorthand for "this is going to annoy you, but I [inaudible 00:46:20] ", and so, having that.

Dr. Jori Fleisher: I have a partner, a care partner who her husband was getting really frustrated with constantly being reminded to fix his posture. And so they came up with this shorthand where she tells him to "boing it" and just kind of thrust his pelvis forward. And so it's hilarious and it just makes both of them laugh. It makes me laugh, but you know, they're walking along and he might get more stooped and she just goes "boing it!" And it works and it's not nagging, it's become this thing for them. So, not that that works in every situation, but I think if you can find the little bit of humor, it goes such a long way.

Rebecca Gifford: Well, laughter is a great healer and a great equalizer, right? And it's a great way to communicate even some of those dark or regarding some of those dark things or worrisome things. Like, I really want you to take care of yourself, but you know, sometimes people can hear it better when it comes through from a place of amusement and humor.

Rebecca Gifford: Okay. Another audience Q, "as a person with Parkinson's, I am feeling more and more guilty about having to rely on others. So how does one deal with this?" Just raise your, if anybody who wants to answer, you can raise your hand. Maggie, do you have any perspective on that?

Maggie R. Wortendyke: I mean, I feel this a lot in my normal life, I don't like to ask people for things so I could see how you would feel this way if you're somebody who is dealing with Parkinson's diagnosis. I would say that for me personally, I like to feel needed. And I'm sure that if you are a Parkinson's patient, there are people in your life who feel the same way. So although it may seem to you like you're a burden to them, they probably like to have tangible ways to help you and it makes them feel involved, it makes them feel like they're part of it, and they're actually doing something to help. Oftentimes, as people in the circle of someone who has

Parkinson's, we feel like we can't really do anything. We just kind of have to sit there and not really take an active part. So... for me when anything that I can do to help always makes me feel better. So I would say hopefully that would assuage some guilt, but I'm sure that is a constant battle.

Rebecca Gifford: It's hard to ask for help, right? So I, I identify with what this person is asking. Especially if you're feeling vulnerable or you have a new issue that's come up, that you don't really want to talk about but that you need some help with, and asking for that help can be a really, really hard stuff. So I get it. Richard, Dr. Fleisher, do you have any, anything to add?

Dr. Jori Fleisher: I think flipping a script and imagining if someone else needed that help and asked you, or if you thought that they needed that help, most people would say, "oh my God, I would jump to do that," and recognizing that's how others may feel, so having a little bit of that sort of self compassion to say, I would do this for someone else, someone else probably wants to do this for me, while simultaneously reframing and recognizing how many things you can do. Great, so it might be that you need help for A or B, but there's so much else that you can do. So I think holding those two things together is important.

Rebecca Gifford: Yeah. Rich, I think you wanted to chime in?

Rich Sussman: Yeah, I was just going to add that I know that Pola doesn't like to ask for help, so even little things like if I'm going to the grocery store, which is not exactly something that I actually like look forward to do, I'm not very good at it to be honest with you. I want to come along, but you know, there might be some times a day that walking might make it difficult, so we just pick a time that works and that way she doesn't feel like she's imposing upon me that I have to be the one doing shopping. So it's just the little things like that.

Rebecca Gifford: Well, I think like several of you have said, I think they might be really surprised at how much people want to help and maybe they don't know how to, and they're waiting for you to ask. And so, just posing that question and having that conversation, like you said Rich about negotiating, what is helpful and what can she do?

Maggie R. Wortendyke: I have learned that a lot of times there's stuff that's happening that me or my mom and my sister, we just don't really know what's happening because obviously we can't get inside of dad's brain. It's really helped me to read things that are written by people who are living with Parkinson's, specifically, Michael J. Fox books are great, also cause he's really funny, but there are other things that you can read and resources and understanding symptoms that other people are having, helps you know what to ask for.

Maggie R. Wortendyke: So I think I read MJF's most recent book and he was describing some sort of symptom that he usually has that I had never even heard of, and I asked my dad about it and he said, "oh yeah, that happens to me sometimes." So we never

would have known to ask for that. We never, would've known how to help him with that, if I wasn't kind of understanding what other people go through. So it gives you a really interesting perspective and, to kind of know what to ask for.

Rebecca Gifford: One that speaks to the power of us, sharing our stories. And when we're willing to kind of talk about our experiences as people with Parkinson's and care partners, things like that, you would've never known unless somebody had been willing to be vulnerable and share that. Right? And that's just even one very small example of all the power that you can have when we're all willing to share our stories. So great. Thank you for bringing that up. That's fantastic.

Rebecca Gifford: Okay. Another question. "How can I make visits more enjoyable for me and my husband, who is in a memory care facility?" Dr. Fleisher, do you want to take that one?

Dr. Jori Fleisher: Sure. I mean, I think this is such a challenge right now, especially with COVID because I don't know what restrictions might be in place. So if you're able to meet, but just meet outside, is it possible to go for a walk? Is it possible to find a bench to sit outside and enjoy the scenery and enjoy the weather, or play a game, talk about something, reminisce about a trip, something else that that setting reminds you of. If you're able to be indoors together, I think coming with a loose list, it doesn't have to be followed, but maybe some ideas of activities. So can you bring a puzzle? Can you bring a book of jokes? Can you bring an audio book to listen to together?

Dr. Jori Fleisher: It can be so isolating to be in a memory care facility. Bringing something so that it doesn't just have to be, I show up and what do we talk about? Maybe we talk about what did you eat for lunch? That answer's probably not going to be super positive, coming with some simple ideas, bringing a photo album, looking through those kinds of things. I think all of those are really helpful and talk to the people at the facility. Sometimes there are activity planners and classes and things like that, and your loved one may or may not want to go to those things, but knowing what's available, sometimes there might be apathy. So kind of saying, "Hey, I heard that there's a movie night that's coming up tomorrow, what do you think about going to that?" I think often there are a lot of resources at memory care facilities that we might not be aware of.

Rebecca Gifford: Okay, great. Rich, I want to give you an opportunity to chime in, I believe you had a parent in a memory unit, both you and Pola?

Rich Sussman: Yeah I did. My dad was in a memory care unit and I'm not going to sugar coat, it's tough because he wasn't actually sure who I was. I could have been a brother, I could have been a nephew, but I was familiar face. I will tell you that I did... I would bring our dog along who is a therapy dog. The other residents, loved seeing the dog, and my dad loved seeing the dog, that'd help.

Rich Sussman: But it's tough because you bring a photo album, I found an old photo album of my dad in the army, and this was from Italy in 1945, and he thought it was me. So it's really challenging. [inaudible 00:54:37] kind of got me through it to some extent, whether it was this thought that my dad's soul, what he was as a person, as a dad, as a husband, that had kind of slowly slipped away. And it was kind of just this shell that was remaining. So I used that as a way of trying not to be as upset that he couldn't remember the things that I wanted him to remember that he... he couldn't remember my mom who had passed away a couple of years before, that you couldn't have those kinds of conversations. So I would go there, I'd feel good about going there because he was happy to see me. From that perspective, I thought that I was doing good, but it's not easy in any way, shape or form.

Rebecca Gifford: Yeah. Thank you for sharing that. We have another question, that perhaps us care partners can answer, "what about feeling isolated or lonely as a care partner, especially if a person needs a lot of assistance?" Well, Dr. Fleisher I'm sure you have some perspective on that as well, that sense of isolation and it's only gotten worse with COVID, right? They're just asking the general question, what would you say to them? So maybe you have some advice or wisdom to offer. I'll start with Dr. Fleisher.

Dr. Jori Fleisher: Oh sure, I mean I would say as strange as it sounds, you're not alone in your loneliness, right? This is so common and rampant and even pre-COVID. The United Kingdom has a minister of loneliness recognizing that this is such a huge and growing issue. Strategies that can be helpful, finding a support group, tapping into the Parkinson's buddy network, my research team, for example, we're working on studies to build caregiver or care partner, peer mentors, connecting someone who's experienced with someone who maybe is newer on their journey as a partner in Parkinson's. Tapping into those things, if you don't know how to access those things, the Fox Foundation is a great source, reaching out to your movement disorder specialist, your neurologist saying, "I need a team, I need more strategies, I need more connection, what's out there?" Because there's a tremendous amount out there, but it can be really overwhelming to navigate. So I'd be really interested in [inaudible 00:12:06] Rich's perspective.

Rebecca Gifford: Yeah, quickly for about 30 seconds, cause we're going to need to wrap up here. If either of you has any perspective on that?

Maggie R. Wortendyke: I would just say, to ask for help as a care partner. That was another question that somebody had asked about, "how do you widen your circle?" Just ask people don't know that you need help, if you don't ask them.

Rebecca Gifford: Great. On that note, we're going to wrap up. We are out of time. This was a great conversation. Thank you so much to our panelists for being here and thank you for everybody in the viewing audience for being here, it was such a pleasure. Thank you again for being part of our community and for joining us today and thanks to our panelists for sharing your time and expertise. We'll be

sending a link to the webinar on demand to listen again, or share as you'd like. And we hope you found it helpful. It was such a pleasure to do it with you. Have a great day.

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