



Mental Wellness for Parkinson's Care Partners with Elaine Book  
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Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello and welcome everybody. My name is Melani Dizon. I'm the Director of Education at the Davis Phinney Foundation. And I'm really happy to be here today with you and Elaine Book. Hi, Elaine, how are you?

Elaine Book (Social Worker and Center Coordinator, NPF Center of Excellence, the Pacific Parkinson's Research Centre, University of British Columbia):

Great, thanks.

Melani Dizon: Great. We're going to be talking about mental health and care partners, and it's very fitting—this month is Care Partner Awareness Month. I'm really excited to talk about this super important topic.

We started doing a care partner monthly meetup on the first Tuesday of every month. And I'm hosting it with Connie Carpenter Phinney, Davis Phinney's wife and care partner. And we're going to be having some other care partners on as well. It's a fun call. Leigh is going to put the link to that, to register for that in the chat box. So you don't have to do it now, but you can take that link, and if you want to sign up for those, you can do that. We're not recording them due to this sort of intimate nature of it. But you can show up on those days when you're available.

Okay. I'm going to get started and tell you a little bit about Elaine, and then she's going to tell you more about herself. So Elaine has worked in the field of social work for over 30 years in a variety of community and hospital settings with an interest in the geriatric population. She has worked with individuals, families, and as a leader of support groups. She's a leader in the Parkinson's community, serving as a speaker at support groups or presenter at neurology meetings and a faculty member of the Allied Team Training Program of the National Parkinson Foundation. She's the center coordinator for the NPS center of excellence, the Pacific Parkinson's Research Centre at the University of British Columbia. She also coordinates a blog designed for neurological social workers who specialize in Parkinson's. She earned her BSW from the University of Manitoba and her MSW from the University of British Columbia, where her thesis focuses on caregiver stress. And she's joining us today from her home in Vancouver.

So I'm going to get started. I have a bunch of questions for Elaine. You can listen in and maybe your question will be answered. If not, feel free to throw your question in the chat and if it's

appropriate at the time, I'll ask it during our conversation; if not, I'll hold them till the end. First, I just want to know, how did you get started in this work, especially specifically with people with Parkinson's?

Elaine Book:

So, you know, I would love to have a story that talks about a relative or a dear friend that had Parkinson's and that's why I was driven in that way. But in actual fact, I was a mother with two young children and I was looking for a job that was close to home and was part-time, and this job fit the bill and I was hired for this job. And unbeknownst to me would it really become such a rewarding career personally for me, that as I got involved in the community and involved with working with organizations, finding that this really has become my passion. And that's how I've gotten to where I am.

You know, there's kind of a funny little story that we have—very early on when I started, I had the good fortune of going to an international conference with my co-workers, and it was in Miami and we had to catch a 6:00 AM flight in order to get there. And so we were all at the airport at four in the morning and, you know, people are not too happy usually when they're at four in the morning. And I get into the airport and I am bouncing off the walls. I'm just so excited to be going to this Parkinson's conference. And, you know, people are looking at me. Now, maybe I was a little bit excited because I was going to be going on a trip without my children, maybe that had something to do with it. But yeah, you know, I kind of bounded up to the boarding gate and just went, "I love my job." And it's kind of been this funny little saying that everybody on my team has held for all of these years. It's, "Oh, there's Elaine with her exuberance because she loves her job," but she does.

Melani Dizon:

Well, you got lucky then, that day, and you took the job when who would have thought. So you've done a lot of work with support groups, people with Parkinson's, and care partners of people with Parkinson's. What do you think are the biggest challenges that people, your clients talk to you about being a care partner?

Elaine Book:

I think that there are many different challenges, but as you all know, Parkinson's is a very individual condition. It's like this boutique condition, right? Because symptoms present differently in different people at different stages. And so there's a lot of individual uniqueness to the condition. But then there's definitely some core challenges, those motor symptoms, the non-motor symptoms — depression and fatigue and apathy and anxiety. So, you know, depending on who it is and how it's impacting them, I think there are different kinds of challenges.

For many people who I work with, many caregivers, the non-motor symptoms are often much

more challenging to deal with than the motor symptoms. So many times I hear that dealing with anxiety or depression or hallucinations are much more difficult than managing rigidity and slowness of movement and that sort of thing.

So I would say that certainly the non-motor symptoms tend to be more challenging. And I think the other thing is that we have to look at how those symptoms impact that person. So if you know, if somebody has tremor and used to be an artist, or has a passion of being an artist, or I worked with somebody who was a dentist, well, that tremor is pretty impactful. But if you've got tremor and you know, your work or your hobbies are not requiring fine motor skills, then it's not so much of a challenge. So we always kind of have to look at those symptoms and how do those symptoms impact that person, right?

I think that the challenge has changed throughout the progression of the disease. So somebody who is providing care to somebody at the new, or you know, a new diagnosis or in the early stages versus somebody at advanced stages—again, the challenges are different. So in the earliest stages or a new diagnosis, you might not be providing so much hands-on help, but you might be providing a lot of emotional support as people are trying to come to terms with this diagnosis and how it's going to impact them, or might be making some decisions about work and about family life and that kind of thing. So at the early stages, those might be kind of more of the challenges that you as a care partner might be seeing.

Certainly in the middle stages, as there's perhaps more unpredictability with the symptoms, there may be more depression or more anxiety on behalf of the person with Parkinson's. Then your role as a care partner is now starting to look a little different. You might be having to provide, to start providing more hands-on help. More time in your day is being spent. Your life is looking different because of the unpredictability. So as a caregiver, your role might start to shift.

And then certainly towards the advanced stages—again, you know, looking at less predictability, more possible cognitive changes, psychiatric changes. And again, then your role as the care partner is going to look a little bit different, and the challenges might be a bit different. As I talked about, again, those non-motor symptoms might be more challenging than the motor symptoms at the later stages. You might have to be making advanced care plan decisions. You're now more responsible from everything from homework to housework. So I guess the idea being is that the challenges really depend on symptoms, but it also depends on the stage of the disease that you might be in.

Melani Dizon:

Right. So if we go back a little bit to sort of those beginning diagnosis phases—we talked a little bit about what does that mean for the care partner, in relation to the person with Parkinson's, but what is it that you see care partners coming to you with in those early stages? You know, they are also dealing with that sense of loss and, “Oh, my life's not going to be what I thought it was going

to be.” What or when do you typically see people, care partners? At what stage? And then also, how do you work with them at your center? How does that work?

Elaine Book:

So, I mean, you mentioned the word loss, and actually that was something that I was going to bring in because regardless of what stage you're at, that experience of loss and grief is pretty present for most people with Parkinson's and of course for their caregivers. And again, very individual, depending on what your experience is, but I think it's important that that's always acknowledged, that that's a part of that response.

So in terms of how I work in my clinic, it's really referral based. So it's not as though every new diagnosis gets referred to me, and it's not a certain stage that a person gets referred to me. People can be referred at any stage of them coming to our clinic and at any stage throughout the progression of the condition. And I think that's one of the things that I really do love about my job is that I have grown with people and have come to know them along their you know, their journey throughout. Did I answer everything there? I may have missed something.

Melani Dizon:

Yes. So what are things that you suggest people do if that feeling of loss, and also another big one is uncertainty. I think in the beginning there is that, “What's going to happen?” And, you know, they have all these models for people that are maybe further along in the disease process, and they see that and they anticipate, “Oh, that's going to be us.” And that uncertainty lasts for quite a while until maybe there gets to be sort of this stability around the disease—the medication start to work—and there starts to be a little bit more predictability. To an extent that it can be with Parkinson's, what can people do with that uncertainty and that feeling of not what I planned?

Elaine Book:

I think there's a lot that can be done. And I think one of the things is certainly acknowledging what's happening—that, you know, Parkinson's disease is a family affair. Yes, that person has the condition, but it absolutely impacts you as their spouse or partner or adult daughter or son or whomever, you know, whatever your relationship is, it impacts you. And so I think acknowledging that and keeping those lines of communication open as much as possible is really important. I think the other thing that's important to remember is that it's okay to not be okay. You know, that when you're, when—and that goes across the whole progression, you know, at any point in time—and know that with being a care partner, you're going to experience these waves where things are going to be okay. And then something is going to change and it's not going to be okay. And then it's going to get okay.

And so what are some of the things that you can do? Well, I believe knowledge is key. So, you know, really attending webinars, reading from reliable sources on the internet, because it's really important not to—you know, there's a lot of in port information out there and misinformation. So going to the big organizations for your information. So reading is key.

You know, I remember speaking to a caregiver who was talking about, it was a cognitive change. And when I kind of explained to her that this isn't him being manipulative, this is, you know, this is part of the condition, it was a light bulb effect. And it was like, "Oh my gosh. Oh, okay. Now I get it. And now I can respond to it in a different way." So really knowing and reading and learning about it to the point that you're comfortable.

But I think that's really also important when you talk about the uncertainty and how do you deal with that? There was a caregiver who said to me, "Oh, now I've got to just get it right. I'm just going to look it up because I don't want to say it incorrectly because it's so important." Oh, I know she said that what your experience as caregiver is going to be, so I'm kind of talking, you know, you were referring to people who say, "Oh my gosh, all the uncertainty."

What it's going to be is likely better than what you're envisioning it to be. It might be a little bit worse than what those optimistic healthcare professionals are telling you. It's going to be somewhere in between, between what you're envisioning and what they're telling you it's going to be. It's going to be somewhere in between. And I just thought that that was a really valuable tip. All my tips come from care partners. They're not coming from me. I'm just the conduit to you.

Melani Dizon:

Somebody said, "I talk to our patients and families about the concept of ambiguous loss." Yeah.

Elaine Book:

And that's a big one, and there are some great resources out there. I don't know if anybody knows about the author Pauline Boss, that is B-O-S-S, and she is kind of a guru on ambiguous loss, but it's really that idea of where, you know, you can, somebody can lose some of their physical abilities, but mentally still be there. And vice versa. You can have somebody who's cognitively challenged, but physically really well. So it's very difficult to manage these losses that are changing every day.

Melani Dizon:

Right. We talk a lot about burnout and it's everywhere. People talk about caregiver burnout and compassion fatigue and those kinds of things. What are some of the signs of burnout for a care partner, and what are some things that people can do?

Elaine Book:

Sure. We talk about it a lot. That's what I probably get referred to the most for when working with care partners. But I think one of the things that I want to just start by answering would be really what are the reasons why people end up feeling burnt out in the first place? And I think that there are a few different reasons. And certainly one of them is those multiple roles that I kind of alluded to it at the beginning. You know, I'm now doing everything from paying bills and working and making meals and providing hands-on care. And so there's multiple roles, and there may even be some role confusion. So perhaps paying the bills was my spouse's job. And now it's my job. And,

and I wasn't doing the cooking before, but now I am, or, you know, so it's just those multiple roles. So that can lead to burnout. There's also some of these unrealistic expectations that you might have for yourself, that you can actually do it all and do it all really well. And that might be unrealistic. And those expectations that we put on ourselves can really contribute to burnout as well. I think you also hit when you talked about uncertainty—so that lack of control that can contribute to feeling burnt out and any kinds of excessive demands. Again, if you're juggling lots of balls, perhaps as the condition presents itself, that might be creating some excessive demands that can lead to burnout.

So what does burnout look like? Well, it looks different for everybody, but it's about feeling overwhelmed. It might be looking like not sleeping at night or sleeping too much through the day. It might be not eating well, or it might be overeating.

What I hear most from people is that they say to me, “I don't know what's going on, but I am so irritable. I am getting so angry so quick. This is not me. This is not who I've ever been.” And, and that is often to me the biggest sign of burnout in people. I mean, there's other things, like losing interest in your activities or feeling depressed or sad. Those are certainly signs of burnout as well. And it can manifest itself physically as well. So you might have a few more aches and pains, or you might be getting the common cold a little more often than you normally do. So those are some signs.

So then now you know why you might feel burnt out. You know what it looks like. What can you do about it?

And I kind of go back to those issues of loss and grief. I think it's really important to address any emotional reactions that you might be having to your care partner role. And whether or not you do that through self-help—and there are some great resources out there—or whether or not you decide to go and see a counselor, just kind of dealing with those strong emotions that you might be feeling. I think one of the other things is really know yourself. Know what you can do and what you can't do. I have one caregiver that I work with; she came to me and she said, “You know what? I am not a nurse. I cannot do this. This is, this is not in my DNA. And, you know, we need to find other ways to get his needs met because I can't do it. I can be his wife, but I cannot be his nurse.” And so it's really about knowing what you can do and what you can't do, and living there and figuring out what you need to do around that.

One of the other things, and I alluded to that with knowledge is key, but I kind of want to reframe it in terms of kind of caregiver preparedness or kind of a self-management model of being a caregiver, where you really do your due diligence and you find out, “What is it that I need to know in order to do this job well? Do I need connect with an OT, a PT, a speech therapist? Who do I need to connect with in order to help me with falls, or who do I need to connect with in order to manage the communication? That's not going so well.” So really looking at what's challenging.

What knowledge do you need to gain in order to manage those challenges? So really getting prepared to be a caregiver. And I think what's important to take home from that is that when you're able to better provide care and maintain the person with Parkinson's wellness, that's going to contribute to your own wellness. So there's nothing selfish about this. This is it's going to be a win-win for everybody.

So that's another strategy that can really help combat or mediate some burnout feelings. Of course, getting the help that you need and getting creative in doing that, whatever that might look like—whether it's through a support group or whether it's hands-on help from a neighbor. I have caregivers who shared the most creative resources for support, you know, where one caregiver I know prepared an evening meal for the neighbor, and he did the lawn because that was something that she couldn't do. So just really thinking outside the box about getting the support that you need in whatever way that looks like. I think the other things that, again, cause burnout and ways to mitigate them is a lot of caregivers I speak to really are anxious or worried about having some difficult conversations that might need to come up.

And so really getting some skills under your belt in order to manage and approach those conversations. Because the longer they stay, the more your stress builds because you know that you need to have this conversation about this taboo topic, whether it's about stopping driving, or accepting help, or about stopping work, or whatever it might be. And so it's really important to actually take the plunge and have the conversation. And again, there's places where you, you know, there's some resources available online, or I can talk to you a little bit about how do you have some of those things, start having those difficult conversations? But, you know, it's kind of that anticipation that I think can be so draining as caregiver. And so the strategy, the antidote to that, is have the conversation.

One of the other things that I talk a lot about with caregivers to help reduce that feeling of burnout is coming up with some tangible—like, again, it's about those unknowns, the uncertainties, the things that are out of your control. So come up with a “What if?” plan. “What if something happens to me— do we have in place?” “How, who is going to help Dad, if I'm not here to do X, Y, etc.?” So really come up with—that might be reaching out to family and friends and seeing who could fill in. Where it might be reaching out to actual formal agencies that provide home support, really connecting with them, finding the ones that you like, making sure that they can jump in at a moment's notice if something happens to you. It's about keeping on your fridge a list—who are the doctors, who are the medications, who's the neighbor, phone numbers, all of that information. And just kind of having that on the fridge or by the telephone so that if emergency personnel needed to come in, they would have all of that.

And putting in some of these “What If?” plans in place can really decrease some anxiety about what—oops, just lost my picture; there we go—about what might happen. I even talk about having a go-bag ready. So, you know, a bag that has three days of medication in there, or even just a few

things and a list on the top of what needs to go into the bag in case of an emergency. And one of the other things, which I got actually from a care partner as well, with that: you as the care partner, in your wallet, in your purse, on, in your jacket, on your cell phone should have something in there that says, so, so if you're out driving and something happens to you that then emergency personnel knows that you've got somebody at home who's compromised and might need help. So again, having those things in place can sometimes just give you a little bit of a breath.

Melani Dizon:

Yeah, absolutely. I love that. Actually, I was, you know, when my daughter was young, I was like, "Oh, well, she's, she's gonna be fine. You know, she can handle herself at the home by herself." But then the question is, "But what happens if something happens to me?" And that's not something we always think about. So I think that's a really important thing to have. And it's such a good idea to have that go-bag and have those in your car, you know, in your wallet, those kinds of things, if something happens to you.

I want to speak a little bit, back to what you said about the person saying, "I'm not a nurse." And I, when you said that, even I just felt lighter. It's just that feeling of like, "I don't have to be; you don't have to be everything."

And if you can just be honest with your person with Parkinson's and say, "I love him and will do anything I can, but is it, I can't do this piece. Is that okay?" You know, like, "Is it okay if we fill this in? And what would you like to see in that person?" You know, have it be an ongoing dialogue instead of you just getting so frustrated that you don't want to take on that role.

One of the exercises that I often had people do was sort of like that "What if," but you're—when you're feeling—most of the time, I don't recommend writing these things down when you're in a really sort of frustrated and agitated state because it's just a little bit too charged—but in this instance, if you're feeling overwhelmed and overburdened and tired, give yourself a second and say, "If I only had blank, what is that?" Write it down. Write those down every time you get a chance. And then when things calm down, then you can go back to that and read it and be like, "Oh, I said that. That felt like a huge hit. What can I then do to plan forward and to have those things in place?" But I do think the backup is so important. The "plan B," the backups, all of those things. You may never use them, but just getting them all down is very sort of freeing.

Elaine Book:

And even to what you were saying, that, you know, you're kind of talking a little bit about journaling. And journaling is an excellent strategy for dealing with some of those strong emotions. And so if going to see somebody or talking about them in a support group is kind of not your thing, journaling is a really excellent way to. It provides a release. We talk about how the written word, you know, once it, once you've let it out, it lessens its hold on you. But it can also provide you with some perspectives. So, you know, "I'm so angry about X, Y, and Z dah, dah, dah, dah, dah, dah, dah." And then you go back and you read that at a calmer time and you go, "Well, actually, you



know, I was really tired that day and I flew off the handle,” or “That really actually wasn't as big of a big deal” or it can be. “Yeah, that was really huge. And what do I need to do?” So it can provide a bit of clarity to know what are the things that are really bothering you and what needs attention. So I think that's a really good suggestion that you've made.

Melani Dizon:

We wrote a post a while ago about the value of expressive writing. James Pennebaker is amazing, and he talks about how expressive writing truly is, can help you physically. So Leigh just put that up in the chat, if people want to check that out. And that's just a step-by-step thing that you can do. And also you can make it, you know, whatever you want to make it, but that's something to definitely check out.

So this is a question that I'm often curious about because I will get emails from people that will, you know, the deep dark secrets about the care partner experience. And it's always interesting to me what they're willing to share with the sort of outside person. What is it that you find a lot with your clients that care partners are very often hiding? Too afraid to talk about? Maybe ashamed to talk about, feel guilty about? What are some of those things that you see with your clients?

Elaine Book:

So I think the most common that kind of falls into that category would be this idea: that he—I tend to refer to “he” because we tend to help more female care partners that come to me, but, you know, please interject “he” and “she” interchangeably—but that “I just don't love that person in the same way that I did before.” That “this person is not the person who I married. Parkinson's has changed their personality, has changed how we relate to one another. And, and I love that person, but I am not in love anymore.” And people, you know, caregivers I work with really have a hard time with that. And certainly when it comes to intimacy, that becomes an even bigger problem. So they're not saying, “I don't want to provide care” or that they want out of the relationship. They're just acknowledging that I'm just not happy in this relationship anymore for what the relationship used to be.

So I think that's one of the big things that I hear. And then the other one is just feeling resentful, so resentful against the disease and how it's changed their lives. “This wasn't part of the plan. It wasn't part of our plan if we were a young onset and it certainly wasn't part of our retirement plan. I'm so resentful of the disease.” And oftentimes that spills over into resentment towards the person with Parkinson's, especially if the care partner feels that they could be doing more to get better. You know, if only they would exercise more, I know he would feel better. Or if he would just use the pill timer, then the medications would work better because they would be taken on time. So then some resentment starts to build up because how the Parkinson's is impacting—it's not just impacting the person with Parkinson's; it's impacting the care partner too, and “they're not doing it right.” So I wouldn't say those are probably what I hear most often.

Speaker 1 (32:15):

Melani Dizon:

Yeah. So what does somebody do in that situation? I mean either one of those situations. Those are big pig topics, but what does a—I think that the exercise one, the medication, those sorts of daily activities that the person with Parkinson's could technically do that they don't do is very frustrating for care partners. What do you recommend they do? How do you start a conversation? How do you deal with it?

Elaine Book:

Glad you brought that up. So, you know, I think there's a variety of different ways. And it kind of does go back to one of the things that I always talk to people when I meet them for the first time, regardless of what stage they're at, is that communication is key. For you guys to get through this, to get through this well, to live life well with Parkinson's, you've got to communicate. And, you know, we have to remember that sometimes people are coming into this condition in a bad—of not such great relationship or not great communication patterns to begin with. If everybody came in, you know, really great communicators, well, we can keep that up. And I talk about how important it is to keep that up. But, you know, we have to be mindful that not as everybody's relationship is ideal to start with, and then you get this thing called Parkinson's on top of that.

One of the things I often talk about is that there can be this disparity or this discrepancy between what the person with Parkinson's thinks is a problem, or how Parkinson's should be dealt with, and what the care partner thinks is an issue and how it should be dealt with. And a lot of work that I do is kind of navigating that gap. How can you find a common ground in there? So I think it's important to go into those conversations with not wanting to win the war, but that you're just trying to live in the bunk together. And how are you going to approach this together? And so there's going to have to be give and take on both sides, and compromises.

I think the other thing too, you know, as long as cognitive change isn't impairing the person with Parkinson's judgment, then I think a lot of work has to be done on the care partners side of letting go. And that there are some things that you cannot change, that you have to accept. And identify the ones that aren't putting anybody at risk and that you can allow the person with Parkinson's to continue to live and make those choices. But then there's obviously other ones where there is a line in the sand—if it's around driving or other kinds of medications. Obviously, you know, if you don't take your Parkinson's medication it can be life-threatening if you've got a good fall coming down your way. So I think it's just about opening up the conversation, picking and choosing what is most important. Staying focused on what is most important. Come into that conversation with some observations, like "I've noticed that" so that you've got some good examples to bring to the conversation.

Be mindful of time of day whenever you're going to open up a conversation like this. You know, not at the end of the day when you're both tired, not when meds are not working, but really mindful of when is a good time? Remember to keep things time limited. We don't want to have these

conversations going on for two hours. It's not productive for anybody at that point in time. So time limited. Know that you might need to revisit this conversation, that you might not resolve at all in the first time. You might do some brainstorming initially, and then both of you go your separate ways to think about it and reconvene again. So there's a few different strategies out there, depending on what the topic is.

Melani Dizon:

Yeah. And I think that one really helpful thing, if you're open to seeing a counselor, a therapist, a social worker, is you know, you go with them, you with your specific problem and you say, "Can you role play?" And you kind of give a little bit of information about what you think that your person with Parkinson's might say, and you guys can play that out with each other. Sometimes just having those initial—I mean, we'd do it now if we had time and everybody on—but sometimes those initial role-plays can just be like, "Oh, okay." Because it's getting into that conversation is like, "What do I say first?" Well, we're gonna test it out. And if you don't have a therapist or you don't know one, and you don't really want to see one, the other thing you can do is pair up with somebody who is usually in your care partner support group. And you can say, "Hey, can we do some role-plays together? I need to work this out." Or a neighbor or a family member or something like that. Those would be super helpful.

Elaine Book:

Really you could even do that by yourself, if you wanted to that role play. You know, you think, "Okay, I anticipate she's going to say this, and I'm going to say this, and then I anticipate she's gonna say this." And so you could, I think it's a great suggestion.

Melani Dizon:

Let's see. So we have a couple of questions here that were sort of relevant to what we're talking about. How do you resolve the emotional dichotomy of being a carer versus being a partner? Do you know of any peer forums for Parkinson's partners care partners? Yeah. Well, let's address the first one. I think we talked a little bit about that difficult piece, but what are some of the strategies that your care partners have used when they kind of are, you know, crossing that line a lot? In the morning, I'm the care partner, and then later in the day I'm supposed to be the partner-partner. How does that work?

Elaine Book:

Yeah. So, you know, again, it's challenging, and it's a little bit about knowing yourself as well and what, you know, because you have to allow yourself to take a break from that role. You know, I can tell you until I'm blue in the face that you need to have designated time for yourself and self-care is important and that sort of thing, but there has to come a point in time where you embrace that it is okay to go for a walk with a friend or go up for lunch or go to an exercise class. You know, many care partners say, "I just feel so terrible leaving them behind and leaving them at home. So I want to have them come with me or I just won't go. Then I'll just stay home." But I think there

comes this point where you have to embrace that concept, that philosophy of self care.

And, and I think once you do that, then I think have carving out those separate times and the separate roles can make, it makes it a little bit easier. We remain, sadly, guilt ridden, oftentimes unnecessarily. But you know, really knowing that you need to take care of yourself—we say this all the time so it feels very trite, but you need to take care of yourself before you can take care of somebody else. And that concept of putting the mask on your face first before you help somebody else. We know all about that, we say it all, but putting in practice is not easy. And I certainly recognize that. But if you could try and reframe that, such that by taking care of yourself, you are going to be in a better position to take care of your loved one. Maybe that will make it a little bit easier as well.

Melani Dizon:

Let's see. Suggestions for dealing with communication problems when voice or speech is affected and the person with Parkinson's has those issues? What are some suggestions for that?

Elaine Book:

I think my very first suggestion would be to connect with a speech language pathologist because I think they have a lot of technological devices that can be very helpful, to just help with the actual communication. So that would be my first and foremost. You know, sometimes we think, “Oh, well, what are they going to have? He, you know, he can't speak, he can't speak well.” You know what? We don't know what we don't know. And all of these different healthcare professionals have such a wealth of information, and skillsets in this area, that there are so many little tricks. It could be a little thing that can have a huge impact. So I think I would just say, start there.

Melani Dizon:

What about—so we talked a little bit about these, but I think this is a great question. What's your advice when the caregiver is not in love with the spouse in the same way, yet the person with Parkinson's becomes *more* dependent on that person. She said, “My husband is YOPD and we've had a really long road with much ahead.”

Elaine Book:

I mean, that sounds like a lot of history to this relationship and, that Parkinson's diseases landed on top of it as well. So in all likelihood spending some time with a counselor to kind of peel back the layers of the onion and see what it, you know, what it is that was going on beforehand? What can be worked on in that area and how can you move forward? You know, there are some people who really then, just really look at what parts of that role can they do, as I said before, and what can they not do? And then look at how can you make, how can you help to meet those needs in the areas that you cannot do anymore.

Melani Dizon:

What can people with Parkinson's do to support their care partners? Ah, that's a great question. I think more importantly since we're talking to care partners here on this call, what can they do to get that from their people with Parkinson's?

Elaine Book:

So we, and I talk about this a lot actually, because I think when we have the support from the person with Parkinson's to go out for lunch or to go and get exercise, that makes it way easier to do it. So it's about that communication again, where you sit down and you say, "You know what? I was at this webinar and I learned that I need to take care of myself a lot more. And so I'm telling you that I was told this was my prescription. This is my medication that I have to take every day. And that's what they said. And I need you to be supportive of that."

And you actually do need to kind of ask for it. You need to ask for that support from them, because what I have learned from working with people with Parkinson's and from their care partners is oftentimes they become very self-absorbed. You know, they're consumed with their symptoms on a minute-to-minute and hour-to-hour basis. They're taking medications with frequency. It's not like it's a condition that you can take a pill in the morning and forget about it all day. They're consumed with it all day long. And that kind of translates into forgetting that you, the care partner who's, feverishly working behind the scenes, is not getting a break or is not getting any kind of attention that that might be needed as well. And so I think oftentimes we need to enlighten the person with Parkinson's about how this disease is impacting you and what you need from them.

You know, this really comes into play a lot when the person with Parkinson's doesn't want to accept any help coming in, like for bathing or dressing. And I understand why. Or whatever that help might look like. And the conversation has to change change from "you need help" to "I need help *for you*." And sometimes that can help the person with Parkinson's get a broader perspective of how this is impacting you and what they can do to support you so that you can continue to support them.

Melani Dizon:

Yeah. Yeah. One of the ways to have that conversation is to start it by saying, you know, asking, "What is it that I do that is most helpful to you?" to the person with Parkinson's. And they say, "Oh, when you make my coffee in the morning." Whatever it is, right. They might list three or four things. And be like, "Oh, you know, that's great. I love knowing what is the most helpful to you. This is actually the most helpful thing you could do for me." And be really specific. And then it just feels like, "Okay, we're just, oh, we're doing this together. This is good. Yes. You are a person who also has Parkinson's. You aren't just a person with Parkinson's. And we're gonna be in this relationship for a while."

Elaine Book:

That's a great, great way to introduce it because you just want to create this reciprocal relationship

as opposed to it being one sided.

Melani Dizon:

Let's see. "My husband is exhibiting decline in cognition, and I have a hard time interacting him with without feeling frustrated and hopeless. How do I, how do I overcome or manage those feelings that like, I'm not getting what I need out of him." It sounds like he will like do what he needs to with his other children's kids, but not giving the attention to this person. And it's just getting frustrating. I think that's a communication issue again. It sounds like he is capable of it but he's just not doing it with you. That it's a conversation.

Elaine Book:

I think you're probably right. Yeah. And also, you know, the cognition piece again: I think gaining some information and some knowledge about how to manage cognitive change. There are a lot of tips out there on simple strategies, even around communication, you know, having conversations. So, you know, not open-ended questions, but give choices. So not "what do you want for lunch?" but "do you want a sandwich or do you want soup?" And so there's little tips in communicating that can be really helpful as you start to see cognitive change. And those tips are going to just absolutely make your day go a little bit more smoothly and take out some of the frustrations that you're having.

Melani Dizon:

Yeah, that's absolutely true. Let's see. I think we answered that one. What suggestions you have for a friend who is supporting a caregiver? I mean, how do you support a friend who is a caregiver?

Elaine Book:

What suggestions do you have for supporting a friend? Oh, so you have a friend who is a caregiver. Well, you know, what I always say with respect to, you know, kind of like my basic social work tenant is "meet the patient where they are, meet the person where they are." So, you know, talk to that friend and say, "What is it that I could do? What, you know, I can't read your mind. Tell me what could I do. I would like to do something." And ask that friend of yours, "What would be most helpful?" and start there.

Melani Dizon:

Yeah. Somebody might say, "Look at all the home aides. Research home aides for me, because I am overwhelmed. I can't do it." Look for a great grocery delivery, or make me come to you for a walk everyday.

Bear in mind, when you ask that person, "What can I do?" you have to make sure that it doesn't feel like an empty offer. Because lots of people say, "Oh, just let me know if you need anything," or, you know, "I'm happy to help." And they kind of walk away the other direction. So it's really

important that they know that this isn't an empty offer. And then for you to recognize how hard it is sometimes for people to ask for help. So you know, just be mindful of that. If the person says, "No, no, no, I'm fine." And you kind of have a sense, well, you could maybe think about a conversation that you had where you heard of a struggle. So maybe you heard her say that it gets really tiresome making dinner every night. Well, why don't you just say, "You know what? Every Thursday night I'm going to provide you with a meal." So you can also just kind of think about what struggles your friend might be having and what might be helpful and just offer that as well. Because knowing that it's really hard for people to ask for help.

Elaine Book:

So I was just gonna say the words, and you know, "what I need is." For somebody to say, "I need something" is really hard. So sometimes it's easier, and this is to the caregivers out there as well, you know, as we, you may find language quite impactful. And so you can say, "What I would find useful is..." and sometimes that is a little bit easier to do the ask.

Melani Dizon:

Yeah. One of the questions I like to ask when people are always like, "I'm fine. I got it. No, I'm fine. I'm good." I ask, "So what if you weren't? What if you weren't fine? What would you need then?" 'Cause then it doesn't feel as like "I needed to be like, well, if I, wasn't fine, I'd probably need this." "Great. I can do that."

Elaine Book:

It's kind of back door.

Melani Dizon:

Oh, this is a common question. How do I talk to my husband who has hallucinations? And let's say they're in the moment. Right. And they're having it. I think we've talked about this a fair bit, but do I say it's not real or what, you know—he sees something and often thinks that I'm somebody else. What do I do in that moment?

Elaine Book:

So, I mean, you know, to him it's real. So you can, you know, and some people do have insight into their hallucinations. And so if your husband is one of those people that does, then you can say, "You know what, that cat actually isn't on the chair." Or, "You know, but I know that it's real for you and it's going to pass." So that's the other thing is, you know, knowing kind of how hallucinations present in your person, then you can come up with some strategies.

One of the more common ones is just changing the environment. So if you're in the living room and that's where the hallucination is happening, depending on what it is, you might say, "Let's go out into the backyard." Lighting can make a difference. Time of day can make a difference. Of course, medications can make a difference as well. But in the heat of the moment, generally you know, confronting and saying, "Well, there's no cat there." And it, you know, is not going to be

obviously very helpful, but, you know, to recognize that “I know you see the cat, I don't see the cat, let's go and listen to some music.”

Melani Dizon:

Yeah. So somebody asked “Since many Parkinson's medications cause side effects that are also part of the disease, like hallucinations, fatigue, confusion, how do I distinguish between them?”

Elaine Book:

Yeah. So a really good question. You're absolutely right. And I think that that's where you reach out to your healthcare professionals—to your neurologist, nurse practitioner, even the RN at the clinic would be able to help just sort out, get a bit of a history, a little bit of a symptom diary so that they can get a better idea of what medication was taken and when the hallucination happened or when the fatigue set in or the confusion. So I think that something like that, you should go right to the medical professionals.

Melani Dizon:

Yeah. We actually have a lot of worksheets on our site and Leigh will put the link in there. You can download a lot of them. And they'll say, like, a tracking list, the tracking for the medication, where you can put in those different things and then be prepared to go to your doctor.

Does anybody else have any questions? We're getting up toward the end. I do want to ask you: what are three actions that a care partner can take every single day to improve their mental health?

Elaine Book:

As I was thinking about the title of today's talk and kind of “wellbeing for care partners,” I was really thinking about self-care can be my overarching theme. And we've talked a little bit about that, and self-care can look different for everybody. You know, it can be physical self-care, emotional self-care, intellectual self-care, spiritual self-care. It can look different to everybody, but it's just a matter of kind of carving time and making that happen. You know, that idea that you really can't pour from an empty cup. So, you know, I'm a real calendar person. If I don't diarize something, it doesn't get done. So maybe you need to diarize it and put it, you know, look at your week. Look at your day and say, “Where in this week am I going to be able to fit in some time for me?”

And it doesn't have to be two hours. It can be 10 minutes of listening to a mindfulness app or a meditation app, or maybe it's just 10 minutes of, you know, your favorite website, you know, or tabloid, or whatever it is that brings you joy. And just trying to carve in those times and really realizing that that's the time that you have and you want to make the most of it. So I think that's one thing that I would say and really remembering that carving that time is not self-indulgent. This is what you need to do in order to continue to do what's required of you.



You know, the other thing that I would say is, think about what are some of the barriers that you have to being kind to yourself. Are they financial barriers? Are they personal barriers where you just feel like you have to be all things to all people? Just sit down and think about what is preventing me from carving some time for myself. So recognizing and embracing that it's important to know what are some of the barriers to it.

And three, you know, really remember that your role as a care partner, it's similar to a job, you know. In any job we get coffee breaks, we get a lunch break, we get vacation time. We always are talking about work-life balance and all of those things. Well, try to adapt some of that language into your role as a care partner.

Melani Dizon:

Absolutely. Thank you so much. I know that this time—actually I was telling Elaine earlier that we had a care partner meetup and one of the interesting things that we learned was that during, we asked about people during COVID, and we asked, the care partners, “How has your person with Parkinson's fared during COVID?” And most people said that they are actually doing better. They are maybe exercising more regularly. They're eating better. They're just sort of thriving a little bit. And then when we asked the care partners how *they're* doing, they said “probably worse.” And so wherever you were as a care partner, I'm sure that it just sort of went up a notch because you're always there with the person, right? And that can be difficult and you can feel yourself getting very, very, very tired.

And even though we have limits with people that you can see and people who are able to come into the house, figure out what you can do in these times of COVID restrictions and get the help that you need. Get out when you can, and really think about “what am I doing to live well today?” And if you haven't done anything yet, and it's, what is it? It's one it's two or three o'clock in this afternoon for people. If you haven't done something for yourself yet today, get off this webinar and go do something great that fills you with joy and makes you feel warm and fuzzy because you have a very big job and you're doing really, really great work.

So thank you, Elaine, so much for being here with us today. It's been super helpful. Thank you, everybody who signed on. We're so glad that you came, and we'll talk to you guys soon. Thank you.

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