



## Parkinson's Care Partner Training

### Session 1: What it Means to Be a Care Partner, Care Partner Roles & Care Partner Strain, and Outcomes

Davis Phinney Foundation

*Note: This is not a flawless, word-for-word transcript, but it's close.*

Polly Dawkins, MBA (Executive Director, Davis Phinney Foundation):

Hello, everybody, and welcome to the first session of our Care Partner training program. I'm Polly Dawkins, executive director of the Davis Phinney Foundation, and I am thrilled to welcome Dr. Joy Fleischer, too, the first in the seven-week series on Care Partner Training. Hi, Dr. Fleischer.

Jori Fleisher, MD, MSCE (Leslie Nan Burridge Endowed Faculty Scholar in Parkinson's Disease Research, Associate Professor of Neurological Sciences at Rush University Medical Center):

Hi Polly. It's so great to be with you and just watching the number of participants climb as people are logging in; it's so exciting to have everyone here today. Thank you all for joining.

Polly Dawkins:

Yes, thank you. Thank you. Thank you to AbbVie, who has provided a really nice grant for us to do this work and continue to do the work that we do and make it available free of charge. To all of you who are logging in today, Jori, I'd love to introduce you to folks who might not have had the benefit of watching our conversation last week. Sure. So, I want to introduce you as a friend of the Davis Phinney Foundation and a movement disorder neurologist working at Rush Medical Center, Rush University. But aside from that, maybe I could have you introduce yourself and tell folks who you are and why you've really focused a bit of your work on care partners and advanced Parkinson's as well.

Jori Fleisher:

Absolutely. So, thank you for the kind introduction. So, I'm a movement disorder specialist, which means I'm trained as a neurologist and then did extra training for another two years in Parkinson's and related movement disorders, and realized as I was going through my fellowship training that I just wasn't seeing people with more advanced Parkinson's and that there really wasn't a big focus during fellowship training or really during residency on our care partners. They're there hopefully, most of the time, you know, they're someone seated with the person with Parkinson's in the room, but what am I supposed to be asking them? What are we, and what resources are we supposed to be offering them? That was really never a big part of training, and it's such a huge need and such a huge missed opportunity. And so, I had the



privilege of being able to work in this space and go out to people's homes when I was on faculty in New York and then again here in Chicago. And unless we are treating the care partner as equal and, as, you know, having so many needs, we're really just doing a disservice to our patients and, you know, to people living with Parkinson's. So, you have to care for the whole.

Polly Dawkins:

Is there research before I actually do it? Let me make a few housekeeping notes before I dive in and ask you some more questions. Thanks for that introduction, for your passion in this area, and for caring so deeply about our community and our community, our broad community of people living with Parkinson's and those who care for and love them.

Jori Fleisher:

I should mention I also have experience with this, having Parkinson's in the family side as well. So, I know this wearing my white coat; I know this on the flip side as well.

Polly Dawkins:

As a family member, thank you, everybody, for saying hello, and telling us where you're from. And I'm going to jump into a little bit of an overview of what our goals of the training over the next seven weeks are. And then I'm going to get into asking Dr. Fleischer, also known as Jori. I'm going to ask her a bunch of questions as she's the expert and turn it really over to her. So, we have brought you here today and for the next seven weeks, really with a goal to improve your knowledge, your attitudes, and your skills as a care partner for a loved one living with Parkinson's. That terminology care partner can be interchanged with caregiver or career depending on where you're from and what you like. We at the Davis Spinney Foundation lean towards care partner and also know that many of you like the terminology Care partner. And oftentimes, switch to talking about caregivers if your Parkinson's or your person with Parkinson's gets quite advanced.

But for most of what we're talking about, we'll be talking about care partner and care caregiver for the role that you all are playing. You all may be spouses; you may be sons and daughters of a person with Parkinson's, neighbors, or friends. The role of care partner really can extend to a number of people who take on that title. We are also, another goal of ours is to educate you on the types of care needed to improve your person with Parkinson's quality of life. We will be aiming to teach you the skills you need to help yourself and your Parkinson's with Parkinson's to live well and how you can manage change. As we know, this is, this is a constantly changing landscape.

We also aim to increase your confidence as a care partner and confidence in your own ability to care for your person with Parkinson's and to make appropriate healthcare decisions and really help you find joy and meaning in your everyday lives. We also hope to increase your connection

to other care partners, build a care partner community, and increase your efficacy and your own resiliency. And then, finally, we hope that you'll learn a variety of strategies that you can employ both physically to reduce the physical and emotional toll of being a care partner. As that strain creases on you each week, we expect that you'll log into the training hub that we just showed you and look at the materials. If you missed the session, you could go in and watch the recording and go in and use that hub as your place to find all of the materials that we think would be helpful to you all. You can also jot down answers to questions that we've posed to you and look at all of the additional resources we've compiled for you. And then, if you're comfortable, we expect you to participate in the chat. And we, our expectation, or our commitment to you all, is that we will show up, we'll answer your questions, we will provide you with really important content, and we will respond to you when you have queries for us.

Got anything, Jori, you think I've missed?

Jori Fleisher:

No, I think it's a great summary. Hopefully, people will get a lot out of this, and we're so interested to see what you'll do with this, and, you know, how this will translate to your own caregiving, how this will translate to the communities you are a part of already. So, keep us posted.

Polly Dawkins:

Yes. So, to start off, let's participate in the chat. Let, would you tell us before we dive into the content today. Hello, Dublin, Ireland. Wonderful. When you showed up today, and when you're showing up for these next seven weeks, do you have initially any questions for us before we get started? So, feel free to use that chat feature if you have questions for us. Again, we can't see your raised hand, so if you have questions, please jot them down. All right,

Melani Dizon:

Just want to chime in real quick. The password for the hub is Care Partner, one word. So, if you're having trouble getting in there, it's just Care Partner one word, and it'll be the same password.

Polly Dawkins:

Thank you. For the next seven weeks, you will hear the voice of our dear Mel Dianne in the background. Sometimes, you'll see her face pop on, and please know that she's right here alongside us, even though you might not see her on screen. That's who that voice from above is. All right. We have a question about preventing burnout. We are going to definitely address that. We have a question. Ah, Winthrop Williams mentioned. If we have questions, we should reach out to [blog@dpf.org](mailto:blog@dpf.org). That's, thank you for highlighting that. We'd really like you to reach



out to [carepartners@dpf.org](mailto:carepartners@dpf.org). Both will work. It reaches us at the Davis City Foundation. It just helps us sort those emails. So, we'll update that. Thank you, Winthrop, for telling us. Allie, no, there is no expectation that you'll become ambassadors after this training.

There's an expectation that you will take a survey after the training, before the training, and after the training. Tell us what you've learned through the process, and then we hope that you'll stay involved and that you'll feel more resilient, and better at doing this role. But we don't have any other expectations now. Certainly, you can become ambassadors. All right. Managing medications while traveling, increased freezing rigidity, locks at night. What's a conservative approach to adding care? Adding meds, stiff stiffness, lowness, drooling. Okay. Well, there are high levels of stress, depression, and irritation constantly. Physical limitations are becoming a part of the process. Okay. We've got lots of good questions. How do you, how do we keep from being overwhelmed with potential deterioration in the future? Yeah. Yes. These are great, great questions. We're capturing them. And interesting. Somebody says that they were shocked at how poorly they did on the self-knowledge test. We also, Jerry, do you have any comments on the survey ahead of time?

Jori Fleisher:

Yeah, so that's, it's actually a survey that my team and I developed when we were creating an education program for home healthcare professionals. So, in my research hat, I am working on home visits and seeing folks with advanced Parkinson's. So, yes, we'll totally talk about stages. We can talk about advanced; we can talk about dementia for sure. I feel like I could have planted so many of the questions that people are putting in here. So, like, binging, Bing, Bing binging. We will try and cover all these things. But we heard from our care partners that, you know, home health nurses or home health physical therapists might come in, might not really understand Parkinson's. And so, we took some of the content that's been woven into this program. But we took some of that content and actually did just a one-day symposium, and we taught home health professionals, and we developed that survey that you took to test their knowledge at the beginning, and at the end of the day, it was just the one day.

And we thought they would probably score pretty well. And we were pretty shocked at how poorly home healthcare professionals did. Nurses, physical therapists, occupational therapists, and speech therapists who we presume have some knowledge of Parkinson's. But the good news is, by the end of the day, they had actually improved really significantly. So, those are some questions that of them may seem obvious, and actually, the answers may be the opposite. And so, hopefully, we can poke some holes in some of the many myths and misconceptions that are out there about Parkinson's. All to the end of helping you be an empowered care partner and recognize, wait a minute, I'm seeing this thing. This might actually mean the following, or I know what to do with this situation. So, that's the goal of that survey. Do not feel bad if you don't know the answer. If, you know, the answers, feel fantastic, but we hope to get everyone doing better by the end.



Polly Dawkins:

Great. Super. Wow, so many, so many questions and areas that, as you said, we are going to touch on over the next seven weeks. I see that there's a comment that Bruce made that's resonating with so many people. And I think that was the comment about, let me, so many comments here. I think that was about, wow, I can't keep up with all of these comments. Well, there was a comment: I'll go, we'll find it. That Bruce made that was really just; everybody seems to be resonating with it, and I read it out loud earlier, but I can't find it quite yet. Anyway, we'll come back to that.

Jori Fleisher:

I see Bruce wrote, I don't know if it's the same one, how to keep from being overwhelmed with potential deterioration in the future.

Polly Dawkins:

Yes.

Jori Fleisher:

I don't know if that was the one. Yes, that was.

Polly Dawkins:

Thank you. Thank you, Beth, and thank you, Jori. Yeah. Is there something we could start off with or refer to one of the sessions that we're going to be diving deep into that topic?

Jori Fleisher:

I think maybe two things. I think one is sort of kind of a mindfulness component of just recognizing, you know, I've had someone tell me, like, stress doesn't exist in the present moment. Stress is either worrying about things that happened in the past that you can't control or worrying about things in the future that you can't control, right? If you're actually in the moment, it's harder to be stressed, right? You're just sort of grappling with, like, what is right there in the moment. So, some sense of being able, sort of cultivating the ability to kind of be present with your loved one in whatever moment that is. And then something else, which is one of the care partners who I've worked with really closely. And she was part of our mentoring programs. And she said that her mentor told her, listen, this is a progressive disease, and things are going to get worse.

What are you doing to prepare? And the first time I heard her say that, I was like, why would anyone say that to you? That feels really difficult. And it also acknowledges the reality, right? No one, we want to be both optimistic and realistic that Parkinson's is a progressive condition.



We can't say what's the timeframe that any one person is going to change, but if we are talking about years, right? Things are going to change. And if we know things are going to change, then we can prepare. And that should alleviate some of the stress on care partners and the person with Parkinson's rather than adding to it. And I think if we think about it as, like, we've got time, and we should think about how we use that time the best, right? Whatever that looks like. If Covid taught us nothing else, right? Do the things on your bucket list, not because there's some finite amount of time; we don't know what's going to happen, right? But if there's a trip that you've been wanting to take, start planning it, right? So, how do we plan what we can and be in the moment so we can actually enjoy those things? I think those were two sorts of helpful things for me.

Polly Dawkins:

Yeah. In the session on Monday that we're going to have, and we're going to talk about change and managing change, and then the week after that, we will talk about care, care partner strain, depression, anxiety, loneliness, isolation. So, those will be deep-dive topics to look forward to. Oh, I'd like to ask folks in the chat, and please know we're capturing your questions, and we're going to use answer the questions in the session that might be most appropriate. I and some, but somebody did ask about the survey, and the survey you would've gotten in an email and from us when you registered. So, there was a survey to take when you registered. And if you didn't get that and you'd like to take the survey, we can send it out to you again. Oh. And there's the quiz in the survey, in the link in the chat. So, for you and the audience, could you tell us, put a few words in the chat, what you think of when I ask you what does it mean to be a Parkinson's care partner?

You put two or two or three words. What does it mean to be a Parkinson's care partner? Uncertainty, team player. Support. Support, structure, supporting, ever-changing. Rewarding but stressful. Doing it all to walk with. That's beautiful. 24 7. Love,

Jori Fleisher:

Flexible,

Polly Dawkins:

Challenging, committed to being my best friend to my partner. That just gave me goosebumps. Support planning for the future. Responsibility surprises, being present, and loving unconditionally. Quite a few people say unconditional love support. I mean, the words, I keep seeing joy. I don't know if you're saying the same things. Oh, I,

Jori Fleisher:

It's beautiful. Yeah.



Polly Dawkins:

And hard, as somebody said, sometimes, heartbroken.

Jori Fleisher:

I also see Larry wrote, fill your own cup first. And I think we'll talk a lot about that, whatever analogy we use for that. And that's part of why I hope people signed up for this, right? Is this being to help you fill your cup, are you can't pour from an empty cup, or, you know, put your own oxygen mask on yourself first before helping someone else?

Polly Dawkins:

Yeah. I see some fear fluctuating emotions. Somebody said, Eileen said, fluctuating emotions, which is what I'm seeing in the chat, right? From fear to bravery, teamwork, patience, stress.

Jori Fleisher:

I saw some sensitive

Polly Dawkins:

Yeah.

Jori Fleisher:

Anne said, we've learned that we can be happy and sad simultaneously. The holding of multiple emotions is so huge.

Polly Dawkins:

Yeah. Sadness, uncertainty, fear. Boy, you all have really captured what it's like to be a care partner with a few words. Words.

Jori Fleisher:

Yeah. Make a word bubble and just be able to, you know, present.

Polly Dawkins:

Yeah. Honor, privilege, grief, unpredictability, exhaustion. I bet a lot of people understand that. Thank you all. Yeah. Keep humor. Yes.

Polly Dawkins:



Yeah. A quick question that came in. Can someone sign up for this program within the next week if they have missed a session? Absolutely. The session. They can sign up; the session will be recorded. They can watch this session.

And as you know, some of the sessions you might want to miss because you don't think the topic is important to you right now, and you can go back and watch it in the future. We'd love for you to be a part of every single one. But we understand you're also managing a lot in your lives.

Jori Fleisher:

So, I see someone posted that all the changes in the way we live now are so outside of my life expectations or different, you know, dreams that have changed and adapted. And I just want to sort of say we will touch on that in one of the future sessions; this idea of ambiguous loss this is not how I thought things were going to go. This is not how I thought things were going to look. And that that is common and shared. And there's a word, you know, there's a term for that. There's a whole field all about that. So, we'll touch on that.

Polly Dawkins:

Yeah. Ambiguous loss, that's what you.

Jori Fleisher:

Yeah.

Polly Dawkins:

And then, and also the topic of this sort of grief and anticipatory grief. Yeah. Grief is what you've lost, and grief is what's

Jori Fleisher:

Exactly. And sort of grieving for, you know, grieve, truly grieving for, you know, in my mind I had this, you know, I had this dream retirement was going to look like this, you know, we were going to interact with so and so in this way, and now we can't. Or grieving the loss of the relationship that you used to have with your loved one, even as you still have an important critical and maybe different relationship with them now. And those, I think, are things that often I hear from my care partners that they feel alone in that, or that it's not okay to say, I miss the person he or she or they used to be. Hmm. And that's not, you know, that's normal.

Polly Dawkins:

Yeah. Somebody, somebody mentions missing conversations. Yeah. With this person. Yeah.





Jori Fleisher:

Yeah.

Polly Dawkins:

Jori, you've done so much work in this area based on your experience. Yeah. What, to you, what does it mean to be a care partner?

Jori Fleisher:

I don't think I could have summarized it, you know, better than everyone else. I think it's slowing down and living at the speed that your loved one with Parkinson's is at, but also trying to be the researcher, the communicator, the forecaster, the anticipatory of what if, what happens when, but what will we do? You know, all of that. I think it's being an advocate and recognizing, you know, my loved one may not be able to state their needs in the following way, or they might not have as much insight into where they're struggling. So, who can I reach out to try to get that need met or to try to get the resources that they need? And that's not just, I have a phone number, and I'm going to call them that's trying to figure out like, what is there a name for, you know, for this that we need is there a resource that matches this? And then, who do I call? So, it's so complex. You know, and it's just love, right? I mean, it's all, whether it's a spouse, whether it's a, you know, significant other, whether it's a parent or a neighbor or another family member, it's all love just showing up in different forms. Yeah. So, yeah.

Polly Dawkins:

You, in your work and being in the field, if you were in a clinic and out in people's homes, what were some of the roles you saw care partners take on at various stages of living with Parkinson's?

Jori Fleisher:

I mean, I think people are nurses, right? I think, I mean, from every, you know, physical lifting and moving and adjusting and repositioning and turning and cleaning and toileting. You know, sometimes, all of the basic activities of daily living, feeding right. To therapists for their loved one, being that shoulder that the person, you know, can cry on being the open ear, right? Being the person to talk them down or to distract or redirect them if the loved one is having hallucinations or is having a delusion where they think something else is going on, right? Being a social worker, trying to figure out, you know, okay, where what resources are out there? How do I solve this problem? Do you think we might need a lift of some kind? Or maybe we need a commode, and where do I find that? You know, I am on a daily basis astonished and so impressed and humbled by care partners who come to me and go. Did you know about this?



Whatever, it's right. So, there's something called a lending closet, and no one taught me about a lending closet before I went into medicine. Right? This could be at your local, you know, village town hall. This could be associated with a YMCA, this could be associated with a house of worship, but it's literally often a closet or, you know, an old beat-up classroom that is filled with donated walkers, wheelchairs, lifts, urinals. Right? And if you don't know that, it's out there, right? You don't know what you don't know. And so many things, little tips, and tricks that I have learned from Care Partners and, hopefully, been able to pass them on, right? And it's just people find ways; I think care partners become occupational therapists without maybe recognizing what that means. But to me, an occupational therapist is the troubleshooter. This person is struggling to do this task. How do we get them easily in and out of the car? How do I get them up this step? This step is the one that they're tripping on. How do I, you know, reconfigure the house? How do I change the texture of their favorite food so they can still eat the thing that they want? Eat? Right. It's just that daily troubleshooting and wearing all of the hats. So, what role do they play? I think they play all of them.

Polly Dawkins:

Yeah. Those of you in the chat, what are some of the roles you've taken on that have surprised you, frustrated you, or inspired you as a care partner? Feel free to pop a message in the chat. Paying the bills. Yes. Paying a nurse personal care attendant is hard. Financial advisor motivator without nagging. Boy, we should dive into that one. Yeah. Driver

Jori Fleisher:

Complex medication management, a hundred percent.

Polly Dawkins:

Organizing all the family events. Yeah. Another MEA medication manager, cooking physical fitness expert. Yes.

Jori Fleisher:

I think the question, someone wanted the question repeated.

Polly Dawkins:

Yeah, so-

Jori Fleisher:

What role do you play as a care partner?

Polly Dawkins:



Thank you.

Jori Fleisher:

Personal trainer. Yes.

Polly Dawkins:

Sharon mentions helping family members understand what's happening. You know, doing the translation for the family, managing social interactions, being his rock. He was always mine. Helping with showers, personal hygiene, incontinence, and physical therapy.

Jori Fleisher:

I see everything from a pharmacist to managing a chainsaw to cut down a fallen tree to clear the driveway.

Polly Dawkins:

It's a lot. Yeah. Incontinence. There is a session. We're going to talk more deeply about incontinence, aren't we? Jory?

Jori Fleisher:

I think so, yeah, getting through to the family about the issues. I think that's so huge. I think so many times there is the primary care partner, and often there may be really helpful family and friends around who say, you know, how can I help? Right? And it's really hard to try to put into words, you know, what one thing can you ask of someone, and how do you explain what the day-to-day looks like? And that's if you have family.

Polly Dawkins:

Yeah. Arlene mentioned when their person is in the hospital or rehab, they constantly reach out and ask for care on behalf of the person. When nurses and aides are in short supply, we hear that so often. Yeah. And ensuring that meds are given on time. And,

Jori Fleisher:

And I would say most people, people to crate on that question on the survey, which also makes me sad because, you know, how big of a problem this is, but there's, there's really ample research saying that for our people with Parkinson's, there are medication errors, which are usually missed doses of levodopa and other Parkinson's medicines, and at least 75% of people. Right. And it's not because the healthcare system doesn't care, I promise you, being inside the system, even as, you know, not the hospital nurse or anything, it's not that people don't care,



it's that they're so unfamiliar with this condition and they're so unfamiliar with medications that are as times sensitive as our Parkinson's Medica medications can often be. Yeah. You know, if someone gets their blood pressure pill at eight o'clock versus 10 o'clock, it's not usually a big deal. Right. If they take their baby aspirin each day at 4:00 PM or 4:00 AM, it doesn't really matter.

That's not the case with Parkinson's. Right. And that's a really hard thing to try to communicate, especially in this post-COVID time when, you know, healthcare is really still stretched so thin. There are still staffing shortages pretty much anywhere you go in any setting; you know, they're often nurses scrambling with the very best of intentions to try to get all of the meds to all the people they're taking care of. And they may just have that wiggle room and think, well, an hour or so here or there is not going to make a difference. It is okay to be the squeaky wheel.

Polly Dawkins:

Have you had experience watching people be the squeaky wheel and getting what they wanted?

Jori Fleisher:

I have. And I think sometimes, it's the only way. It can feel really hard for some people that may come, you know, second nature to them; they're really great advocates just naturally. Right. And for other people, they don't want to be a bother. Right. It's okay, I'm telling you, be a bother. If someone gets annoyed by that, you just tell them I told you, and you get someone to blame; you can throw me under the bus. Okay. But a movement disorders neurologist said, no, you know, I have to advocate for my loved one to get them as close to on time as possible. And what I'll say is there is a caveat that, you know, in case of emergency, right? If someone is having a heart attack in the bed next door, right? Something may, you know, trump getting that bed on time if a nurse calls off, correct?

You know, there's, there's always going to be something. So, do you want to be an advocate 24/7, every single moment? Maybe not. Maybe we'll want to let, you know, some of the smaller things go. But if you're seeing a pattern, please advocate if your loved one is in a facility for some reason. There are laws that say, even if I send in medication orders and it says, I need you to get these pills at eight, noon, four, and eight, whatever the time is, right? They have an hour on either side of whatever time I said legally. We can ask nicely. You can cajole and beg and befriend and all of those things. Sometimes, those are better strategies. But know that, you know, if they come back to you and say, no, no, you know, we've, we've got wiggle room. Legally, technically, they do.

But if you can help make a case for, listen, if my loved one has his or her meds on time, they don't have to press the call bell to ask you for help getting up because they're able to move, right? If they have their meds on time, they can eat their meal fully independently, and they

don't need your help, but I need your help to make sure that they get their meds when they need them. Sometimes, those can be helpful strategies. Yeah. Yes. And I see that a nurse said that you can ask for a patient advocate to help if no one is getting meds on time in the hospital. Yep.

Ask for patient relations; ask for a patient advocate. And that's a role in a hospital in most. Yep. In most places, they may be called something different, but if you use that language, that can usually if you're, you know, having a hard time, I wouldn't, that's sort of like, you know, there's a mistake on their seat at the grocery store, and you try to call the CEO of, you know, Safeway or something. I would, you know, you can ask to talk to a manager. You could ask to talk to, you know, is there a nursing supervisor? Is there a charge nurse to try to help explain? Sometimes, it really is just the education of making sure that all the people who are doing the direct hands-on caregiving and the people above them, right? The bedside nurse may understand that they need to give their meds on time. But if their charge nurse or supervisor is going, no, you know, you have to do all the following things, and we need to have a touch base, right? At this time, if you can explain to that supervisor, hey, you know, I get it. It's very important, you know, to have the communication, but if my loved one doesn't get their meds on time, here's what's going to happen. And that's going to be more difficult for everyone involved. Yeah.

Polly Dawkins:

Thinking about being an advocate for your person your loved one with Parkinson's. I remember the conversation that you had with Mel this spring, the webinar we did. And you talked about noticing folks who had missed appointments and why folks weren't showing up in the clinic. Why were you only seeing people with Parkinson's who are called stage three? And that was being considered advanced. And one of the things you said, Jori, was the system doesn't know that you've missed appointments or something to that effect. Like, you have to advocate if you're missing appointments; nobody's going to reach out and say hey, it's time to reschedule.

Jori Fleisher:

Right. There may, there may be some healthcare systems out there, by which I mean, you know, an individual group of hospitals or a practice that has really great information technology in place. I feel like if I miss a dentist appointment, you know, I get an immediate something, yeah. From them. Right? If you miss a hairdresser appointment, right? I get more communication from a hairstylist than I do from healthcare. Right. That's wrong. It shouldn't be like that. Right. I'll be the first to say our healthcare system is broken in many ways. And how do we sort of work within there? Right. And so, yes, when I, when we set out to try to reach people who are homebound, trying to figure out who are they, who's out there, who have we lost a follow-up is actually so difficult.

There's no, you know, in your electronic medical record, whether your dog is on a system that uses Epic or Cerner, all these different systems, number one, they don't talk to each other. So, if

you tell one doctor something, and I, this happens every day in clinic with me, someone will say, oh, yeah. You know, so-and-so said something. But you can see their notes. Guys, I hate to break it to you. Most of the time, I can't see their notes. I can't. So, some systems talk with each other a bit, but what I can see from the healthcare system, a, B, or C, even within the city of Chicago, where I am, is different for every healthcare system. And sometimes, I can't see any of that until the person checks in for their visit with me that day. So, as, you know, someone who tries to figure out what's going on with my people, and I will look ahead at the chart the night before for the people I'm going to see the next day.

I can't see what's going on at other hospitals if you have imaging. So, this happens all the time. Something happens: someone gets an X-ray or an MRI, right? And they'll say hey, you know, they'll send me a message, hey, I got an MRI, can you take a look at the picture, see what you think. If it's not within my healthcare system, I might be able to see the report from another system, but I cannot see the actual pictures myself. And most neurologists are worth their salt. We want to see the pictures. A picture is truly worth a thousand words, especially when it comes to brain imaging. So, you know, I can't see those pictures. And the system to get them is ridiculous. We might as well be like faxing or passing back, you know, stone tablets because you have to tell the one healthcare system, here's the information, and I give you permission to share this with this other healthcare system.

And sometimes, the other healthcare system has to say, hello, I have permission from the person to receive the following information from you. You have to sign both of those two different forms, and they have to reach each other before anyone will release anything that's so broken. It's so broken. So, I spent time during my residency training as a neurologist in Botswana. It is a country in Sub-Saharan Africa. At the time I was there, 2.1 million people. There was one neurologist in the public sector. That's it for 2.1 million people. We have way more than that in the US, even though sometimes, I know for movement specialists, I saw the comment; it might not feel like that, right? But the healthcare system there, at that time, the way that people kept their medical records, everyone had a folder, you had your own folder, and if you came into the hospital, your folder sat on your table, and I wrote notes as I was seeing you.

And then that folder went home with you, and it lives with the patient. So, anything that had happened, whoever was seeing you at that moment had access to, and it's very analog and very paper, but actually, that was a little bit more straightforward than the system that we have here. So, all of that is to say, you know, please don't get frustrated with your healthcare providers who want that information and want to know everything that's gone on. But if someone tells, you know, I don't have that, I can't see that information, they're not trying to put extra hurdles in front of you. The system is very piecemeal still. So, for some people, you know, a simple way to go is trying to keep your healthcare all within one system. But if you've got established relationships and your primary is over here, and hospital systems change, you know, it's, it can be really difficult.



Polly Dawkins:

Yeah. And what would you recommend to our care partners who are navigating this? You know, we're just saying be an advocate. Be the squeaky wheel. Yeah. With your healthcare providers, and if you're in a hospital, are there any other tips that you've seen care partners use to get what they need for their person?

Jori Fleisher:

I think keeping a binder, and that can look different for everyone, but I have people that will come in. They've got a binder and sort of, you know, a laminated front page that says, you know, my primary care doc is, here's the name, here's the number, my neurologist is my cardiologist, whoever it is that you see, my physical therapist is Right. And those can change, right? So, sometimes, it's one of those like plastic pockets, and you can update that file. If it's a Word file, you just update it when something changes. Having the medication list that you can bring the most updated medication list to whoever you are seeing. If you're getting imaging or, you know, a procedure or something in any place, if you can get that report, and you may be able to download that report off of an electronic medical portal, right?

My chart or whatever it is that you use to access or send messages back and forth. If it's a procedure, put that in there. If you have a hospitalization and you've got discharge instructions, the person came in on this day, here's what we thought was the problem; here are the tests that we did. We sent them out on the following medicines. Keep that in the binder. Right. And eventually, the binder can be a really great place to have advanced directives. So, if your loved one has a healthcare power of attorney, have a copy of the healthcare power of attorney form in there. But this is one of those other things that doesn't translate from one healthcare system to another. So, you might tell the primary care doc, listen, you know, I am my loved one's healthcare power of attorney in the event that they can't make a decision for themselves; I'm the person to call.

That may only mean that the primary care doctor now has that knowledge, but no one else around them does. Right. And no other healthcare system does. So, have that, give a copy to whoever you see, and say, can you scan this into your system? And give me back the copy or bring them a copy. Right. If you have a living will, here's what I want. Here's what I do not want. Right. Under no circumstances should you do the following, you know, or absolutely. Please. Right. If you have that, I encourage everyone to have advanced directives. Right. We never know what's going to happen. I have one; my husband has one. Right. Have that, keep that in the binder, and have a copy of those documents. You know, adult kids may want a copy, having a copy that lives at home, things like that. But I think that can help you keep everything together. And maybe you have a paper in there that says, in anticipation of my next visit with my movement neurologist, here are a couple of questions. Yeah. I love it when people bring questions in. I can't answer ten questions in a 30-minute session because I have questions that I



need to ask you, too. And I want to see how you're moving; it takes time to answer. But keep that running log of questions.

Polly Dawkins:

Yeah. We have worksheets that the Davis Spinney Foundation has created, and one of those worksheets is how to prepare you for your next doctor's visit. And so, you can download that and use that in your binder and use that.

Jori Fleisher:

We'll attest to that. I have people bring that one in.

Polly Dawkins:

Okay.

Jori Fleisher:

And the wear and care kit, I've seen that come up a couple of times in the chat, and absolutely. Absolutely. Yeah.

Polly Dawkins:

Yeah. Well, let's ask; I want to ask you another question. We've got so many good things happening in the chat as well. But let's talk about the topic of that. I'm seeing throughout the topic of caregiver or care partner strain. And last week, when we touched on that word, I saw your reaction, which was, oh, I'm so glad you said care, care partner strain, and not burden. Yeah. I'd love to explore what is care partner strain. Why did you react so strongly to not being burdened by those words? Tell us a little bit about that, and then maybe, yeah, we can, you can share some stories from your experiences. Yeah.

Jori Fleisher:

So, I think a lot of times, strain and burden are used interchangeably. And it may just be a question of semantics, but, you know, when we asked what are your roles as a care partner? And you all put in hundreds of different things, right? All of that goes to not just the joy and the privilege that comes with being a care partner, but the strain, it is the emotional and physical strain on someone's, you know, physical and mental health. It is sort of the sum total of all of those roles and all of the daily tasks. Yeah. And all of the daily concerns and future predictions, did I do this thing right? Should I have done this differently? It's all of that giant word cloud, right? Poured into kind of one thing, and people try to measure it Right. That one thing. How can you measure that?



Right? And there's, I would say there's no good answer. There's no one survey that measures that the best. People have tried lots of different ways, and caregiver strain is different across different disease conditions. So, for example, there's a lot of work that's been done among care partners of people with Alzheimer's. And when we look at their strain, it's quite high, right? To cope with someone who has cognitive changes. What's really interesting is it's taken many years; the sort of Parkinson's research has really lagged behind on paying attention to caregivers partners, sorry. But people are now, you know, and trying to measure that and say, what is the scope of this problem? Because we sort of have to understand the problem to be able to try to start attacking it in a way that makes sense.

Right? Right. And there's, I mean, there's a lot of different studies from a lot of different researchers asking the questions in a lot of different ways. And this probably surprises absolutely zero of the however many people, 227 of you, but care partners of people with Parkinson's have higher levels of strain than care partners of people with Alzheimer's. Mm. And I've submitted papers on this, I've written papers on this with care partners and had paragraphs in there where I try to explain why this might be true. And I've had care partners go like, Cho, how blonde is you? Why do you have to explain this to people? Of course, this is different than Alzheimer's. And taken out those paragraphs, submitted papers to journals, and had reviewers other academic people go, what? Why would care partners of people with Parkinson's have a higher strain than care partners of people with Alzheimer's?

You tell me, you can all put in the chat, right? Because this is not just cognitive, this is not just memory; this is not just anything. This is physical, this is neuropsychiatric, this is autonomic, this is constipation, this is urination, this is incontinence, this is hallucinations and delusions. This is all of that ambiguous loss and an anticipatory grief. And Tuesday could be a fantastic day, and Wednesday is a disaster. And Wednesday night is what is Thursday? What is Thursday morning even? I'm not even going to try to plan for what could Thursday be like. What is the next hour going to look like? Because I think one of the things that is so crucial and so determines care partner strain Parkinson's is the unpredictability. I mean, the only thing that is predictable about this condition is how unpredictable it is. The fluctuations, the motor fluctuations, which can be minute by minute, the cognitive fluctuations, which, as people, you know, go on and may develop mild cognitive impairment and dementia.

Right. The cognitive fluctuations where it's almost like someone bumps into a dimmer switch if you've ever accidentally, you know, leaned up against a wall, bumped into the dimmer switch, and all of a sudden, the light just goes off. Right? And you realize and go, well, okay, sorry. And turn that dimmer switch right back on. You didn't need to do that there. Cognitive fluctuations where a person with Parkinson's, their alertness level just drops. It's, you know, if you've been on a plane and, you know, that feeling as you're taking off and you go through the cloud layer, and you think that you've broken through, but whoa. Oh, nope, there's a few more. Right? There are just some levels. There are these moments of fogginess that you just cannot predict,

and there's nothing you can do. You're not the pilot. Right. The person with Parkinson's is not the pilot.

They can't necessarily predict when those, you know, when that cloud layer is going to be there. Yeah. You just kind of wait it out until you get through that unpredictability from moment to moment, let alone what stage is my loved one in? How long is this stage going to last? What's the next one going to look like? What should I be looking for? I will tell you, as someone who has these conversations on a daily basis, it's not that we don't want to give answers; it's that this is so variable from person to person that answers are, you know, very hard to come by. We can do our best; we can, you know, give prognosis with some, you know, basis behind it, some evidence behind it. But it's really difficult because of this unpredictability that you all live with daily.

Polly Dawkins:

We saw that at the beginning of the chat, right? The word that many people chose was uncertainty. And I think that is a, like unpredictability. I think those are very close, and yep.

Jori Fleisher:

I'll say, you know, we, this cracks me up every time because I think people think that we don't know this, right? But your loved one might come to the doctor, right? And I say, okay, show me your taps and your claps and your wiggles and your whatever. And I get them up, and I walk, and family is like, they have not walked that well in months. They're she this is not real. You know, this is, this is not how they usually are. We know that sometimes, people are showing off for us. And that there, you know, there's this secret reserve, and why can't they do that for you on a regular basis? Right. It's not; it's not under their control in most cases. This is just part of that fluctuation. You know, and so we know that even if we're seeing someone and they look really good that day, we know we are seeing just that snapshot.

Polly Dawkins:

Yeah. I often hear people talk about care partners talk about the sort of that performative or performance of their person with Parkinson's that out in public or in social situations. People say, oh, your person looks so great, and they're doing so well, but then some finite amount of time. And then that sort of show took all the effort available for the day, and the care partner, you all get the short end of the stick. Because when it's time to go home, your person is worn out from that little burst of being in a good situation.

Jori Fleisher:

And could be worn out the next day. Right? Yeah. And we recognize, I mean, I had a wonderful care partner was speaking at the NIH last week about what it takes to be part of a clinical trial

and how, you know, you might think a clinical trial visit might be, you know, two hours, but for that care partner and the person with Parkinson's, it's thinking about it the day before planning anticipation, the anxiety about where will we park? How will we get there? What's it going to look like getting there, having the meds lined up, having snacks, having everything, the transportation home, and then being exhausted the next day? Right? And we think all we're asking is just two hours of your time, you know? It's so much more than that. And the care partners are the ones who are bearing the brunt of that. And often there's other family members who are going, you know, yeah. They look so good. I don't know what you're complaining about with this caring, like, they look great.

Polly Dawkins:

I missed something earlier in the chat. Somebody asked, if you had made a comment about medication timing, and you said, does it really matter about when you take your baby aspirin the afternoon or in the evening if your dose is different? Like Parkinson's meant, somebody said, is baby aspirin something I need to know about that? I don't know about

Jori Fleisher:

Oh, no, no. I'm sorry. I was just giving random, off-the-cuff examples. Sorry. Do not take anything that I am saying as any particular medical advice for you or your loved one. I don't know. You, individually, all 232 people. I was just trying to come up with a generic medication. Exactly. You might have one that is not time sensitive.

Polly Dawkins:

That many people take. Right? Correct.

Jori Fleisher:

Great.

Polly Dawkins:

A couple of other things as we're, well, as we're talking about strain and care partner strain and the effects of care partner strain or the effects of being a care partner on the health of a person who is caring for someone. Do you have some thoughts or data points on how caring for someone can affect the health of a

Jori Fleisher:

Absolutely care partner. I mean, it is real; it is taking a toll on people. We know this in general for care partners across all conditions, but we know this even within Parkinson's specifically, is that the rates of blood pressure, high blood pressure, our higher, even when we compare for

age. Right. We know that there's a big, you know, issue in the US in many developed countries with high blood pressure being a problem. Yes. And if you are a Parkinson's care partner, your risk is even higher. If you are a Parkinson's care partner, your risk of depression, and I see this all through the chat, your risk of depression is higher. Right. This is, and, you know, we'll get to self-care and putting that mask on yourself before you help someone else. Right. Not pouring from an empty cup increases your risk of back pain.

And this is, again, I had to convince that reviewer, well, why would care partners of people with Parkinson's have higher rates of back pain? I do; I'm sure any of you would volunteer to let that reviewer come to your house and just spend a day helping to care for your care partner. Right. Whatever stage they're in, there's just a lot of bending and picking up, whether it's objects or clothes or things or reaching or it's transferring of a loved one that's not invisible work. It takes a toll. Absolutely. The rates of back pain and arthritis are higher than they would be age for age, pound for pound, than someone who's not a care partner to someone with Parkinson's. So, it's real. We also know that in older studies that actually looked at care partners, people with Parkinson's and looked at those who had very high levels of strain, and those who had lower levels of strain, the care partners who had higher strain, their loved ones were more likely to be placed into a nursing home than people with Parkinson's whose loved ones had lower levels of strain. And that was adjusting, doing all they sat statistical analysis to control for, well, maybe the people with higher strain, their loved ones that are at, you know, worse stage or have more symptoms. They controlled for all of those things. And still, right? Some people have just a heavier burden to carry. Some people have a harder time carrying that burden. Right. And that is not a value judgment. It's just the truth. And it's not only taking its toll on you, but it can also take its toll on your loved one, which puts, you know, all the more importance on doing things like this, you know, or going for a walk. Right. Doing things that are just for you. Because if you are taking care of yourself, that makes you a better care partner to your person with Parkinson's and everyone around you.

Polly Dawkins:

Somebody asked the question earlier: is there a connection between the health of a person and a person caring for a care partner? And there, I think she said, is it? Is there data that shows that a care partner dies before a person with Parkinson's because of health issues?

Jori Fleisher:

I'm not aware of data specifically on Parkinson's. Mm. But anecdotally, I'll say just within my, you know, within my own practice and talking with colleagues, absolutely. I have care partners where, you know, we have looked at them and gone, you are, you're not, you don't look well, what's going on? Oh, well, you know, I was just in the hospital for a massive heart attack, or, you know, I just had this thing going on, or I had had back surgery, or I need back surgery, but I can't get it because who would take care of my loved one? Hmm. And so, they're, you know, deferring their own healthcare at the, you know, at their own expense to take care of their



loved one. And I've had people where the care partner is the one who winds up in an institution first, or the care partner dies.

Right. It's we need a crisis plan, just like an advanced directive. I think this is another thing that kind of goes in the binder: is what happens if something happens to the care partner and they're out of commission? Who is the backup? Is there a phone tree? Who do you call? It doesn't have to be a super long list. It can be, you know, if I'm in the hospital, my neighbor, daughter, son, friend, whoever, they're going to be the go-to person, and they know. Right. They're just on backup. But yeah, it is true. Absolutely. You know, we've had folks where they've had cancer diagnoses, you know, and I can't say, you know, this is related to their care partner strain, but they've had these things going on, and we're watching them dwindle as we're caring for the person with Parkinson's. And in my mind, in my team's mind, you can't separate those two. Right. Yeah.

Polly Dawkins:

We also know, don't we, that a person with Parkinson's who has a care partner does better off than-

Jori Fleisher:

Oh, absolutely.

Polly Dawkins:

A person who is alone.

Jori Fleisher:

Absolutely.

Polly Dawkins:

And not necessarily a spouse, but somebody.

Jori Fleisher:

Anyone. Right. It could be anyone. And the majority of caregiving in the United States, particularly in a lot of developed countries, but I'll speak just for the United States; the majority of caregiving is often women. Women, spouses, adult daughters, friendly neighbors, you know, other family members. And even though we think about Parkinson's as more common in men, one of the things that we found when we were going out to our home-bound folks in New York was actually we had more women with Parkinson's in the program, and those women were more likely to be alone. And I wonder whether, you know, maybe we don't have as many



women represented in some of the papers about Parkinson's and things like that because if they don't have a care partner to help make sure that they're getting to care, right? If they're out there on their own, kind of who's advocating for them, if not them? Right? And so, there are a lot of unanswered questions.

Polly Dawkins:

I'm hopeful that over the next number of weeks with you and some of our other experts, we can dive in, you know, really deep into how do we, how do we notice as care partners that we're not, not doing well? You all have used a lot of adjectives and described some of the challenges. But how do we notice, and then how do we come up with a plan to take care of ourselves as care partners so that we don't get to that critical stage? That's sort of one of my expectations: we're going to cover a lot of that, both the emotional side and the physical side of caring.

Jori Fleisher:

Yeah. There's so much here. Yeah.

Polly Dawkins:

There is so much here. And we're seeing your stories as there as they're typed in the chat. And I know many of you're saying this: is it hard to watch the chat and listen to the conversation? And I understand that. I also find it so active. Because you all have so many questions, we will provide transcripts for you. We will provide the video again so you can watch it again if there is time or if there are pieces that you feel like you missed. And we'll have summaries. There's something here I wanted to ask and address. What about joy? What about the denial of the progression of the disease? So, the person with Parkinson's denies the progression of the disease.

Jori Fleisher:

Yeah.

Polly Dawkins:

Do you have any thoughts on that?

Jori Fleisher:

I think it's so hard. I think for some, you know, I think almost everyone, right? Getting a life-changing diagnosis, whatever that is, right? There is often an adjustment disorder around that, which could be sadness, denial, and anger, right? In all those stages of grief, we can have those around a diagnosis. And some people come out the other side, right? To some extent, right?

There's always you're always allowed to have any of those feelings. But come out the other side and say, okay, all right, most days I can accept that this is what I'm dealing with, and I'm going to do the following. Right. And they'll move forward. And there are going to be bad days and hard days and, you know, days that you just want to kind of curl out, right? But a lot of people kind of get through that. But yes, I see this in my own practice, and I think it's one of the hardest things is people who, you know, can't accept that this is the diagnosis.

Or can't accept that things have changed and, you know, we need to start meds, or we need to adjust meds, or we need, you know, something like that. And I think it's so hard, right? Because if you are not the person with the disease, you're not the person who has to take the medicines, right? I am not going to tell you; I just have to force it down, you know, to your loved one. You can't do that. They have to come to it on their own somehow. But you can provide an example. So, you can empower yourself with information if you're hearing them say things that, you know, are just not true. You know, gently sort of pointing those things out. You know, I happen to hear actually that there's been a lot of progress in the following, or did you see so and so down the block, or at church or at temple, whatever it was?

You know, she's got Parkinson's, and she actually said she's doing really well. I think she; you know, she just went on meds and whatever. She's going to a boxing group, you know, she's doing this. Like, they just came back from a trip. You know, I think as much of the modeling of that kind of behavior can be helpful. I think also, and this gets to comment, I think Glenda had in the chat of the person with Parkinson's, sort of not wanting care partners involved in their care and maybe not communicating honestly with their healthcare providers. Maybe, you know, not taking meds saying that they are, this is so tricky. But I'll speak as just speak as a doctor. If one of the people that I care for wasn't taking their meds the way that I understand them to be taking them, I would want to know for their own well-being, right?

Because if that person comes to me, say that they're on some medication regimen, and they come, and they say, listen, doc, this is not working, right? I am going to either add a new medicine. Because, clearly, what we're doing isn't working. I'm going to increase the dose of something. I'm going to change, you know, how many times in a day you need to take it, right? And so, if I think you're taking it three times a day, and I say, well, that's not working. Okay, we need to go to four, or we need to, you know, amp up the dose like this, but you're not actually taking it. And then one day, you actually start doing what I've told you: jump from not doing anything to the adjusted regimen could be dangerous. Hmm. Because my recommendation was based on an incremental change, right? And I've seen this happen, unfortunately, with people who I thought they were taking their meds.

They tell me that they're taking their meds, they're doing their things, something happens, they wind up in the hospital, and the hospital, most of the time, puts them on the medications that they see in the medical record. And they didn't know that the person actually wasn't taking any of that. So, all of a sudden, they went from zero to 60. Right? And now they're having weird

side effects, right? Or now they're, you know, they're just responding differently. And the question is, wait a minute, what, where is that coming from? Yeah. Right? So, all of that is to say because of HIPAA. So, the laws that are in place to prevent, you know, me from telling you details of any of my patients and dropping their names to protect your privacy in healthcare, your healthcare professionals cannot just divulge your information to anyone else who calls and is like hey, what's that guy on?

He seems to be doing well; give me his med schedule. We can't do that. But it can be a one-way communication. So, if you are concerned, if, you know, that your loved one is taking their medicines in a very different way, or, you know, is doing something that you think is unsafe, you can contact their physician and say, listen, I know you may not be able to say anything back to me, but I think you need to know this information. , right? And then it's up to us how we handle that. And it's not easy, right? Because I don't want to throw you under the bus and go, hey, you know, I heard from your wife that you're not doing anything you're supposed to do. Most people will try to be a little bit, you know, more tactful than that. But it is helping that person in the long run to get the care that they need and not get excessive treatment and not sort of go down the wrong path.

Polly Dawkins:

Wow.

Jori Fleisher:

And, you know, find the resources, find, find a community, right? Support groups are great for many people and are just like Parkinson's. Every support group has a different personality, right? And has, you know, different players and some people that talk too much and some that don't contribute. All of that. If you can find a community that feels like a good fit, right? Recommending that. If you know, that your loved one is never going to go to a support group, give up that ghost. Don't try and get them into a support group, but can you find a Parkinson's exercise class where they can go and they don't have to talk about it, but they're in a safe space with less stigma? And it might just come up, right? And they might just talk to the person next to them and go, oh man, you're still dealing, you're dealing with this too. Okay. And, you know, I think finding the community, the human connection, I think, is always the way that we move the needle forward.

Polly Dawkins:

Yeah. Sometimes, that's where you find out the best strategies are people are, other people are doing that. Let's look back at this topic of care, partner strain, and the health issues that are related to care partner strain. What do you see as the best way that our audience and our community can manage strain, manage these challenges, and the physical health challenges around care partner strain?



Jori Fleisher:

I think recognizing that it's real. That you're not alone. If you're thinking, oh my gosh, you know, this feels like this is just exhausting this fee, yes, yes, you are correct. Now what? Right? And some of it is kind of the basics that we overlook, which is, are you hydrating? Right? Are you eating? Don't, you know, so many times you're shuttling someone from moment to moment, an appointment to appointment, and you're skipping a meal, don't, you can't function well. Right? Carry snacks with you, not just for your person with Parkinson's, but for you. Right? Carry the water with you, whatever that is, get the movement in. We know exercise is so important in Parkinson's. We can have whole sessions on that. It's so important for our care partners. It's such a crucial piece of stress relief. And just like Parkinson's, there is no one right exercise that is the perfect exercise for care partner strain.

It's the thing you're going to enjoy, right? It's if running is miserable to you, right? So, if you see me running, there's a bear you should run to. I'm not a runner. Okay? That would not bring me joy. Find the thing that brings you joy, right? Find the community where you can let down your hair. You can share these concerns. You can be supported. If you have a pressure release valve, you will do better, right? Because our bodies are going to show the wear and tear, right? So, someone who has high blood pressure, they get in a traffic jam no matter what. They could have taken their meds all day long; their blood pressure's going to go through the roof. If you're diabetic and you get a phone call with bad news, your sugars are going to go through the roof, right?

Your body is going to show it's going to show the stress; it's going to show the strain. So, exercise, sleep. I think this is one of the things, you know, in terms of like what's specific about care partner strain Parkinson's is not just that you are caring for someone who may have a sleep that is disturbed in any number of ways, but your sleep may be disturbed because of it or your own sleep issues in any number of ways. So, I saw someone saying, you know, the biggest strain on me is lifting my loved one's legs in and out of bed to go to the bathroom all night long. If you are sleeping lightly, because, you know, that you need to keep that ear open to hear when your loved one gets up so that they don't fall so that you can help them. You're not getting into a good deep sleep. You're not getting restful sleep. It's disrupted all the time, right? If you're sleeping in bed with your partner and they have REM behavior disorder where they're acting out their dreams, they're kicking; they're punching, they're running from marauders, you know, all this stuff's going on, you could literally be beating up in your sleep. All of that takes a toll.

So, you know, how, what's the easy solution for this? There's no easy solution. If there was, you'd all have found it. Right? Recognizing that you do need sleep. People in healthcare are huge fans of telling you that you need sleep. And then we are the worst, right? And we get no sleep. It has real consequences. So, set a bedtime. Recognize that people usually need at least six to seven hours of sleep, if not more. If you are consistently going to bed right at 11 11:30,

whenever that time is, and you're waking up multiple times throughout the night, and then you're waking up super early. Add up the actual time you're sleeping and come up with a bedtime. Right? And it may mean that your loved one has to adjust their bedtime, right? And I think there, there is a thing about how, you know, we sort of, many people get to the end of their day for me. I put my kids to bed, and that's when I finish up the work. And I feel like, okay, no one can bother me right now, and I can just veg out. Right? But is that time that's actually restorative and bringing me joy? Or would I do better if I actually got six hours of sleep?

Polly Dawkins:

One more hour of sleep,

Jori Fleisher:

Right? It's probably better. You know, and I'm the worst at this. I will freely admit that. But I think recognizing that your sleep is at risk by being a care partner to someone with Parkinson's, and how can you try to help that? And maybe it is trying to catch up a little bit, you know, on an off day getting some help. You know, sometimes, people will have nighttime paid caregivers. It is expensive. It is hard. And maybe it's just every once in a while, maybe it's a family member or friend or a neighbor, you know, who just agrees they can come over at X period of time and you can take a nap, right? But I see that ask a friend, phone a friend, right? Bring in when someone says, what can I do? You could come for two hours on a Sunday, so I could just take a nap.

Polly Dawkins:

Yeah. That could feel like a respite. Yeah. Just sleeping. Yeah. What about the question of sleep disturbed sleep that, you know, if you are always worried about a person needing to get up and go to the bathroom and help with that, how do you, even if you're in a separate room to get better sleep? Because you do get better sleep in a separate room in some cases. Yeah. How do you balance the need for somebody? So, up in your gut and ear to that?

Jori Fleisher:

Yeah. A couple of thoughts. Number one, talk with their healthcare provider. Tell them what's going on with their sleep. Is it trouble falling asleep? Is it trouble staying asleep if the person is waking up to go to the bathroom? My favorite question is, are you waking up because your bladder is waking you up because you have to pee? Or are you waking up for some other reason, and you're up, so you might as well get up to pee? Right? Those are actually different things. One of those we may have, you know, medicines to treat the bladder that will help you sleep. But we don't want to use a bladder medicine if it's something else that's waking you up, if it's slowness or stiffness, or anxiety, right? So, treating the cause of, is it REM behavior disorder? The person is actively dreaming, and they, you know, whack their hand on the

nightstand that wakes them up or they're whacking, you know, and that wakes that wakes you up and so, you know, smack them, and say hey, stop doing that.

Right? What is going on in sleep? That's a great thing to put on that list that you bring to the doc or the healthcare provider and say, listen, you know, here's, this is what's happening. What can I do? Because there are so many different sleep disorders that affect people with Parkinson's, and many are treatable, right? If your loved one has sleep apnea, which can happen without Parkinson's, but is more common in people with Parkinson's, very treatable. No one is eager and chomping at the bit to get that sleep apnea c pap mask on and, you know, do a Darth Vader kind of thing. But it will drastically improve their sleep. It will drastically improve your sleep. And by the way, it lowers their risk of heart attack and stroke. So, bonus. Right. But in the short term and the long term, there are lots of different things.

There are medicines that we can use to treat behavior disorder. I see someone shouting out melatonin, so I cannot specifically recommend anything for your particular loved one. But yes, ask your healthcare provider; melatonin is, you know, often our first line go-to. And something else that I did not know about until just a few years ago actually was we think about melatonin. And melatonin is the neurotransmitter. It's a chemical in your brain that kind of shifts everyone's brain to tell them it's nighttime, it's time to wind down, it's time to get ready for bed. Everyone kind of gets a little squirt of melatonin as you get towards those nighttime hours. People with Parkinson's still get a squirt, but it's a little bit lower. And so, just like we think about replacing the dopamine that people are missing, we often need to replace the melatonin that people are missing.

But melatonin both helps people fall asleep, but it's also related to people staying asleep. So, a lot of times, I hear, and it's very common that people will fall asleep. Okay. But wake up at like two or three in the morning, and they can't get back to sleep. And they're like, I'm taking a ton of melatonin, and it's not doing anything. So, regular immediate-release melatonin, if it's a chewable form, it's immediate release. If it dissolves on your tongue, it's immediate release. Many are immediately released. That will help you kick in quickly and fall asleep quickly. But just like an Advil or a Tylenol, it's gone in a couple of hours. So, if the issue that you're trying to fix is not trouble falling asleep, but trouble staying asleep, there is actually time-release or extended-release melatonin. So, if you take it at bedtime, it doesn't necessarily help you fall asleep. It's sort of an afterburner. You take it, and then it kicks in later and helps with staying asleep. It may not last all eight hours, but it can help with some of that. There isn't really a good maximum per night of melatonin; I would say talk with your healthcare provider. Some people are on a mix of the immediate and the long-acting because they've got all the things. And that's also okay.

Polly Dawkins:

Have you done, have you experienced through your work, anybody who has really mastered how to turn health care partner strain around?



Jori Fleisher:

I've seen so many people, and I think there isn't, like, there isn't one secret. I think it's the people who do it best recognize how hard it's; they will admit to themselves both the joys and the privilege and, you know, being able to support their best friend in whatever, you know, relationship that is being able to support their loved one. And this can be really hard. And so, you know, they have built a community. You know, the people who do this best do not do it alone.

They just don't. I, you know, have an amazing family that I can think of where there are two sisters and a third sister who's also part of the picture but has her own health challenges, and really, I mean, the three sisters together helped care for their mom and would trade off and, you know, one was living out of town, but would come in, and tag team and, you know, the person who was living out of town would help with, you know, ordering supplies or doing things or having, you know, phone dates so that the person who's there, you know, in person had that respite. Right. And just, I mean, you have to build a team. Just like there shouldn't be any one healthcare provider for someone with Parkinson's. There are too many symptoms. There are too many things.

You can't; it can't just be one singular soul-care partner. And I saw that there were people who said, you know, I don't have family. Right? No one is alone. No one is alone. Is there, you know, do you have neighbors? Do you have a faith community? Do you have, you know, people on a Parkinson's Facebook group locally, a support group, someone Right? Build out that team because not only does your loved one need it, but you need it. Right? Yeah. And I think it's the people who prepared, you know, one of the best care partners I can think of is the person who said she had been told, you know, it's going to, it's going to change. How do I, how do I do this? How do I prepare for this? And really sort of thought ahead of, if this is happening, I'm going to do this. If this is, you know, I'm going to get things lined up and know what my options are.

Polly Dawkins:

Yeah. What, there was a question earlier: how do you have any examples or ideas of how you get somebody else involved? How do you get a family who's unwilling to be involved or a neighbor? How do you start reaching out?

Jori Fleisher:

I think so many times, I think there's so much stigma around Parkinson's, right? Like so many other things. And I think people are often they don't know what they don't know. And they may be afraid to ask, right? They don't want to ask anything inappropriate. They don't want to, you know, they may not want to assume that something is difficult, right? And so, I think sometimes, it's asking something else of the care partner, partner to be that person to say, hey, I could really use a hand with, right? And sometimes, it's, you know, recognizing. So, I am a long



distance from my family of origin. They're, they're all in Ohio. I can't help with day-to-day, hands-on caregiving most of the time, but I'm really good at ordering groceries from afar. I'm really good at, you know, I can set up a recurring delivery, you know, of that.

Or if there's a, you know, hey, there might be a trial that this person might qualify for. Could you just go read about this? There's a coordinator who needs to talk with someone and wants to run through a list of things. Can you just hear what that might be like? Or, you know, the doc says that, you know, my loved one needs to exercise more. Could take them on a walk. Could you take them to the boxing class, the cycling class, the dancing thing, take them with you to go see, you know, the kids' karate practice and get them out of the house and be engaged and social? Go for ice cream. Right? And care partner, you can do what you want at that time. Your to-do list might be this long. You do not have to do laundry. You could go get your own ice cream. Right.

Polly Dawkins:

Or exercise.

Jori Fleisher:

Right. Or exercise or sleep. Right. You can, you know, it's finding those windows. And I think once what I've seen a lot is, you know, I don't even know what to ask for. I'm so overwhelmed that I don't know what to ask for. And it can literally be, can you spend an hour with your dad, your mom, your, whoever that is, can you just take them for an hour? Right. And often, hopefully, that hour goes long, and that caregiver, who maybe wasn't as involved before, gets a little bit more of a glimpse and a little bit more of a perspective of what that person with Parkinson's is going through and what you are going through. It's not going to be the full glimpse because they're only getting that one-hour snapshot. Right. But it's something, and that just kind of kicks open the door a little bit and opens for the opportunities of, you know, oh man, thank you so much. You know, they really enjoyed that. Do you think you could do that? Could we set up like a recurring date, do you think? Once a month, once every, you know, how about every weekend, right? Could you come and do something?

Polly Dawkins:

Right.

Jori Fleisher:

And I think just sharing that can be helpful.

Polly Dawkins:

Seeing folks in our community who recommend, you know, come up with a list when you are not stressed out. Yes. A list of, oh, I'm just emptying the dishwasher. It sure would be nice if somebody could empty the dishwasher for me. Write that on the list so that the next time a person asks, what can I do to help? Or perhaps more specifically, you have to ask for help. Learn to ask for help. Can you come over and empty the dishwasher or do the laundry for me?

Jori Fleisher:

And things that maybe the person with Parkinson's used to do. Right? So, if they had tasks around the house, right? If they were the person who got out the chainsaw, cut down the fallen trees, and cleared the driveway, right? If they're the person that mowed the lawn, or if they're the person that did the meal planning, and that's just not your jam. Right. Put those things on the list. Yeah. Right. There might be a kid on the block, and will they mow the lawn perfectly? No. Right? But it's something off your list, and someone may, you know, really enjoy being able to contribute in that way. And it doesn't need to be that all of the things go to one other person, but I think that's out. Right. Spread it out. Have the community better.

Polly Dawkins:

That's not on you.

Jori Fleisher:

Right, right? Sometimes, right? Perfect is the enemy of the good. If it's done, it's done. Doesn't have to be done the way that they would have done it or the way that you would do it. But now it's not something that you have to do.

Polly Dawkins:

I also got a comment from a care partner who said that they also of all the things they want to be able to do so that in those moments when you're feeling good, you're both feeling good, and you're thinking, what should we do right now? You don't have to spend time thinking about it; you go to your list of, oh, these are all the things we wanted. We wanted to go to the museum; we wanted to go to the movies; we wanted to do this thing. Yes. And keep that list of aspirational things when things are going well to do.

Jori Fleisher:

I love that. I've heard someone phrase it was like, have small adventures and big adventures. Right. And so, it's like, you know, okay, it's fall. Right? You might want to go to the apple orchard, but that's like, that's like a several-hour commitment, maybe, depending on where you live, right? Or you might just want to go grab a bag of candy corn if that's your gym, right? All, you know, the different things, right? You might just go, want to go look at leaves in the



neighborhood. Having that list makes it easy if you have one of those windows; if you have that good fluctuation, you have that good day, right? Lean into that. And I think it kind of brings up this idea that I talk about a lot in our palliative clinic with folks who are at, you know, advanced stages.

But I think it applies to all of us, which is this idea of energy conservation. You can't do all the things, right? You can't possibly do all the things. And so, recognizing, like, what are the things that's really worth your time? I have people that, you know, they want to go on a trip, and they'll talk about getting through the airport and blah, blah, blah, and blah, blah, blah. My, you know, my loved one, they might struggle with their mobility and really have a hard time walking, but they don't want to use a, you know, a wheelchair in the airport. And my question is, do you want to exhaust yourself walking through O'Hare, JFK, whatever it is? Like, is that where you want to spend your energy for the day and make it to the family event only to be exhausted?

Polly Dawkins:

That's a good point.

Jori Fleisher:

Or do you want you, do you want that, you know, there's a finite amount of energy? Do you want that energy to be there for the birthday party, for the celebration, right? Most people would rather be able to get up and dance, get up, participate, you know, be part of the thing than have impressed the people they'll never meet again at the airport by not being in a wheelchair. Right. Who cares?

Polly Dawkins:

Yeah, it threw the airport a lot faster, right?

Jori Fleisher:

Honestly, it, you know, when I, when I've had folks that have said like, okay, fine, I'll do it. And they're like, oh my gosh, it was so much more pleasant to travel that way. Yes. You've earned it. You are not taking that away from anyone. They have imagined that they have a never-ending supply of wheelchairs. If you have a loved one who could use that wheelchair, you are not taking it away from someone else who needs it. There are plenty that this is not a pie. Yes. And you get to board early. I think you get to, you deploy later, but still, you don't have to, you know, all this stuff.

Polly Dawkins:

You don't have to carry your luggage yet. Baggage claims and all that. Yeah. One of them, somebody who was just about to leave, said, I hope you've left enough to talk about in the rest of the sessions, the rest of the sessions as I imagine, and look at the topics. And we're going to do deep dives on specific topics at the next sessions. And so come prepared with your questions on those. Anybody in the chat has ideas about care, partner strain, maybe some things that you've encountered, or things that you can; you've done that help with your ear strain to make you feel. I know David; David has said he comes up with a strategy for exercising and being silent. I think you said silent walking. And let's see. Boy, these chats are full. I can't find it all. But anybody has other strategies that you use to help you fill up your buckets and deal with strain: meditation, spiritual reading, prayer, local theater group. That's fun.

Jori Fleisher:

Interesting. Well, man, if you're doing improv in that theater group, I think improv is one of the most amazing skills to help living with someone with Parkinson's.

Polly Dawkins:

Yes. And singing with a chorus. Audiobooks. Audiobooks are great. Escape Bridge meditation group. Yeah. Lots of meditation. Interesting. Somebody says that the strain comes from the family, not from the partner, not from the person with Parkinson's listening to audiobooks together. That's sort of a fun way to do it. Using the calm app, exercise, swim, read books, pickleball. I've heard a lot of pickleball players.

Jori Fleisher:

Oh, baby swim classes. I imagine that's someone.

Polly Dawkins:

Peloton bike, a yoga program, and a caregiving service that comes in for four hours per week, and that four hour that is yours.

Jori Fleisher:

Yeah. I think that's so important. Peter said that you know, it can be a really difficult transition and a whole acceptance process to, you know, let paid caregivers come in. And I think planning, you know, planning for that if that is happening, having a list of what they can do to help, and then being able to say, and now I get to go. Right. Maybe not on day one. You know, making sure that your loved one is safe and adjusted and things are going well, but if someone is there, take that time so that you don't have to be there. I see so many care partners that stay and hover when, you know, an aid is there. And it's doing a disservice, you know, to everyone involved. Use that time for you. Leslie is off to her yoga class day. Leslie, go Enjoy.



Polly Dawkins:

All, if you have questions related to today's topic, please put them in here, and we'll see what we can answer today's topic of care partner strain and what it means to be a care partner. Other questions we'll get to in future sessions.

Jori Fleisher:

Scroll back through and see.

Polly Dawkins:

There are so many; you all are being amazed with your comments. Incredible. Sure. A couple of you are asking for some logistics, how to use the hub on our website, and what the password is. The password for the hub is the word care partner. All lowercase should be very straightforward. And Melanie has just put that in there, and you'll be able to click on that link. We'll also send it out again with this recording, and it will allow you to get into the hub.

Jori Fleisher:

It's not a question of whether meditation is good. For a person with Lewy body with dementia? So, we can certainly take that. I think it may depend on each individual person. Meditation, in general, has tremendous benefits when it's been studied, you know, in lots of different conditions. And sometimes, that's guided meditation at the, listening to someone, you know, talking and sort of having like guided visualization and things like that. That may be a little bit easier for someone with Lewy body dementia than just kind of a let's sit still, you know? And not having as many prompts. Because attention can be attention, and concentration can be tough with Parkinson's, dementia, and Lewy body dementia. So, if we think that the person, you know, is just going to sit and kind of think about a mantra and be able to focus on that depending on the person, that might be a little bit too much to ask, but a guided meditation, a calm app, a Peloton meditation, you know, happy space, headspace, all there, all these different ones. Those could be really great.

Polly Dawkins:

How do you manage changing roles? I think we're going to talk about change on Monday. Anything you want to say ahead of that?

Jori Fleisher:

It's a huge part of this is how do you maintain your relationship, you know, whatever that role is, whether it's parent and child which often, you know, I hear from a lot of my adult childcare partners that they are straddling this line of, you know, they are my parents. Still, as I take on more care, I feel like I am becoming the parent to my parent. And, you know, how do you

navigate all of that? Or if it is, you know, your life partner, your spouse, your significant other, right? How do you still find time and space for intimacy while also having to take on, you know, activities of daily living and hygiene kind of things? And that can be really hard. There's some really great work out there. So, someone I'll, I'll shout out is Dr. Sheila Silver.

So, she's a phenomenal therapist and educator. She's got a lot of talks, and her specific area is sort of Parkinson's and intimacy and how people can navigate relationships that are changing. And, you know, Parkinson's can affect sexual function in lots of different ways. So, I have a lot of people that, you know, come to me with questions about sexual dysfunction and things and, you know, what can I do? What should I do? What can't I do? All of this. And I refer almost everyone to check out some of her work. So, Sheila, S-H-E-I-L-A, silver, like the color. And I think she has a bunch of things on YouTube as well, but I think her work is phenomenal acknowledging that yes, there are changes and, you know, just using touch, holding hands, being together, you know, for a moment I saw someone asked, you know, is it worth learning to, to do massage for my loved one? I can't speak to that necessarily. I don't know anyone who's gone out and, you know, taken formal courses, but touch is, you know, incredible, right? And the skin is our largest organ. So, you know, I have a lot of people that benefit from formal massage therapy, and what an amazing way to connect, to be able to give your loved one a massage, and maybe they can do some of that back. Right? So, I don't think there's anything wrong with it.

Polly Dawkins:

Yeah. Somebody asks about how, you know, what's coming without becoming depressed. I think we're going to talk about that as well. But any, that's sort of living in the future and being depressed about what you don't know what's going to happen,

Jori Fleisher:

Right? I think it's, you know, someone put in there finding the things that feed you deeply, right? Is what is bringing you meaning, and, you know, how can you do those things in addition to everything else you're doing, right? How can those be fit in those moments, whether it's exercise, whether it's sleep, whether it's, you know, eating, a meal?

Polly Dawkins:

Thank you all for being here, Jori. Thank you so much for spending two hours this afternoon with us. It's such a pleasure.

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