



Davis Phinney Foundation Parkinson's Care Partner Training

Session 5: Parkinson's Depression, Anxiety, Apathy, Loneliness, and Isolation

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 back to our Care Partner Training program, and welcome back to you, Dr. Jori Fleisher. Thank you for introducing us to your colleagues, Serena and Kristen. We had great conversations with them during the last two sessions.

Jori Fleisher MDS (Associate Professor of Neurological Sciences, Rush University Medical Center):

Hi Polly. Hi everyone. Aren't they great? They're amazing. They're some of my favorite people, so thanks for having them on.

Polly Dawkins:

You've built an amazing team around you. Today, we have some really big topics on deck. Then, we're going to talk about depression, anxiety, apathy, loneliness, and isolation. There are a couple of questions, joy, that have come in about falling before we hop into depression, anxiety, and apathy. And I wonder if you might be able to answer the questions about falling that are applicable to so many people.

Jori Fleisher:

Yeah.

Polly Dawkins:

One of those questions that keeps coming up is how do we know when it's okay to leave our person with Parkinson's at home overnight, alone?

Jori Fleisher:

That is a good question. So, if someone is falling frequently, right, they're falling, and what is frequent is hard. But you know, if they're falling at least once a week, particularly, you know, most people are falling in their bathroom, or they're falling in their kitchen. If they're falling, we know that they can't get up or require help when they fall, and there isn't someone there overnight. That's when I would start to think, you know, someone should be there overnight

with them—or having a bed alarm. There are various different devices that people will use as fall alarms. None of them are completely perfect. But is it applicable for tripping as well as falling? Yes, because often the only difference is there is a piece of furniture or a wall that's nearby when that happens. Right? And so, a trip is just a fall that someone was able to catch themselves.

And often, that's environmental. It's not specific to the person, right? So, if the lack of balance is there all the time, right? If the lack of balance was there in order for that trip to happen, that lack of balance is there most of the time. And so, we just want to make sure we're making their environment safe, but also putting into place, you know, if someone is going to be on their own for hours and hours at a time, there is the risk that they could fall, be unable to get up. And the longer a person is down, that can become very life-threatening very quickly. So, if there can't be someone there with them, is there a way to have some monitoring system? Whether that's, you know, a various like ring camera, nest camera, all those different things that people, you know, can install sometimes just like a child or infant monitor system. There are various ones of those that I've seen people use pretty well. You know, the various different watches and devices and things that can track a fall. Again, none are perfect, but I would say something's better than nothing. Yeah.

Polly Dawkins:

So, you mentioned falling and being down for a while. Yeah. How do we know as care partners, how do we know when a fall requires an, an emergency room visit, or whether it's worth calling the paramedics? What's the line for you?

Jori Fleisher:

So, a couple of different things. If someone has fallen and they have been down, I would say for over an hour, or you don't know, I would call 9 1 1. Because when people have fallen and can't get up, they can actually start to really have significant muscle injury, something called rhabdomyolysis where the muscles are injured, and the muscles start to give off different enzymes kind of. And that can be really scary and can turn very quickly. So, if you don't know when they fell, I would bring them in. If they have fallen and they hit their head, I would bring them in.

If they have fallen and they're on a blood thinner and there is any chance that they have hit their head or something close to it, or they've fallen, they're on a blood thinner and they have a history of very large bruises I would bring them in because sometimes people on blood thinners you know, are on it for a reason. They need to be on it, whether they have a funky heart rhythm and they're prone to forming clots. It's not that the blood thinner is a problem, but it means that, you know, you or I might fall and have a nasty bruise, but it'll heal, but they may bleed into that area and that can be very, very dangerous. So, particularly if it's if they've hit their head, it's a great question. So, student asks if a low dose daily aspirin counts as a blood

thinner, no, I would not count a baby aspirin or 81 milli. But Plavix, Coumadin, warfarin Eliquis, all of these other sorts of newer ones anything that, you know, if it requires blood monitoring, all of those kinds of things, if your loved one is on that absolutely any fall with head trauma, if there's a cut on the head blood thinner or not, go to the hospital if they've lost consciousness, go to the hospital.

Melani Dizon:

Sure. I just wanted to, sorry, chime in real quick. So, somebody had asked that question and we barely, you know, touched on it last week. One of the issues was one of the care partners, not the primary care partner was with somebody when they fell, they hit their head, and they didn't do anything about it. And then the other care partner said, we've got to take, she's having to go to the hospital, got to go to the hospital. And ended up going to the hospital, everything was fine. And the person said, not only, you know, does it cost a lot of money, but that person, like, it was like four days to recover from that hospital visit.

Jori Fleisher:

Yeah.

Melani Dizon:

And I don't think you have an easy answer to that, unfortunately, but I think it is important to say, hey sometimes when you hit the head, you're just going to have to guess because the alternative is not great.

Jori Fleisher:

It is exactly that. So, I never say, and particularly I know we've talked about, you know, the risk of being in the ER being in the hospital for people with Parkinson's, it is real, right? We know that people, you know, you could sit in the ER for 12 hours and miss all of your doses of medications, right? So, I don't say go to the emergency room lightly. And I know this even within my own family, the complaints that happen of I went there, and they didn't do anything, and I sat for 15 hours. Great. Because you know what, when you hit triage, you looked stable enough that you didn't have to be rushed back. And as hard as that is, you know, sometimes it's, it's good to be the stable person in the emergency room. And exactly like you said, Mel, I mean, I have people that fall every day, right?

And then it is a judgment call of what are we going to do, and which falls, you know, do we need to take in? And it's still that same advice. And so, people who are falling frequently, you know, they may fall and hit their head once a month, once a week, right? And the first 10 of those, they may be fine. And so, it leads to this tendency to go, you know, they've done this before, they're okay, but unless you've got a home CT scanner, right? And you can see what's

going on in the brain, I don't I wish I had x-ray vision most days. You know, we just don't know. And so, really the best guidance is it's better to go if someone's had, you know, a head injury and be wrong, meaning that they're okay and there's no bleed, there's no stroke, there's no nothing like that, rather than miss it, because those are things that are very time sensitive. So, that's what we're trying to miss is if that means, you know, 10 emergency room visits that are a useless waste of time and expensive, but the 11th one you pick up on the thing that otherwise could have led to that person's significant decline or death for many people, you know, that's, that's kind of how they want to spin it.

Melani Dizon:

Thank you for that.

Jori Fleisher:

Polly Dawkins:

Yeah. Let's now segue into the content for today. And thank you for helping us with some of those questions that our community has had in the last few weeks. So, the content for today for those of you in the audience, feel free to throw your questions into the chat as they come up. If we can answer them today, we will. If they're applicable to most people, we'll also answer them. If they're not, if they're very specific to you, we'll take them offline and add them to the member area. For those of you watching today's topics are ones that are relevant and applicable to both you as the care partner and your person with Parkinson's. And symptoms often look the same when you have Parkinson's or not. Many treatments are the same and the impacts are the same. The consequences though, can be quite different, and we'll get into that a little bit later.

But for one example, if your person with Parkinson's is depressed or apathetic, and that means they're not exercising or exercising for them, it can have more severe consequences than it might have for a care partner who doesn't have Parkinson's. And we bring this up because a few people have asked why we're talking so much about people with Parkinson's when this is for care partners. And really what we know to be true is that in order to be a good and health care partner the more you all understand about your person with Parkinson's symptoms and what they're dealing with, the better your care and your understanding and ability to empathize will be, and the healthier you all areas, as care partners, both mentally, physically, cognitively, the better your person with Parkinson's will be. So, first of all, I'd love to start this conversation with a question we received from a participant who is a little earlier in the Parkinson's caring. She wrote to us, and she said, I'm having a huge negative emotional response to receiving so much information about advanced Parkinson's symptoms and care partner duties in later stages. I'm already overwhelmed with early and mid-stage issues. I want the learning from the course, but I'm having a very hard time with the emotional fallout. Jori, can you help us with that one?



Jori Fleisher:

Yeah. So, number one, I just want to validate that caregiver's feelings and also really applaud their courage for writing in and saying that we hear you, we anticipated that this would very likely be something that many people would feel. And so, there's something that as I'm in clinic with people a couple of things that I usually get to preface conversations with. And I ask people a thousand questions about which symptoms, you know, the person with Parkinson's is having. And I almost always preface this with, I'm going to ask you a ton of questions and they sound terribly scary. What I need you to know is just because I ask about this does not mean that your loved one will have this symptom, okay? Because Parkinson's is completely different for every person. And so, we're going to pause for a second. It's going to sound a little nut, but here's some audience participation.

So, if you are in the us, you have visited the us, if you have ever been to the Cheesecake Factory, I need your help right now. What I want you to do is open up the chat window and I'm going to have you type something in, but I want you to wait before hitting enter till I tell you, okay? So, if you have been to the Cheesecake Factory and you can remember what you ate, whether it's once or twice, or you've been there a couple of times, write down anything in your Zoom window that you have eaten at the Cheesecake Factory. And I'm going to give you a second. I'm going to count to three, and then we'll all enter them together when I say, so. Take a second, think about it. Okay, on the count of three, I want you to hit enter 1, 2, 3,

Polly Dawkins:

Oh my God. Yep.

Jori Fleisher:

All right, so forgot. Love it. Yep, yep, yep, yep. So, many people wrote in cheesecake. But if we had, if we had made you drill down in which cheesecake, we'd probably get a whole variety. So, cheesecake, cheesecake, vegetarian hamburgers with all the trimmings way to go, French silk cheesecake, highly approved, all the cheesecakes, caramel, chopped salad, all of the things corn chowder. I didn't even know they had that. Pasta wraps, chicken lettuce wraps, Thai lettuce rolls, all the things. Brussels sprouts, meatloaf, shepherd's pie. Okay? You've all been to the same restaurant. You've all had the Cheesecake Factory experience. And just in the however, many people, 141 people who are here online with us, however, many people actually responded, look at the variety of things that given the same menu, you all chose differently. So, I tell people all the time that the symptoms of Parkinson's are like going to the Cheesecake Factory.

And so, you could go, and your neighbor could go every week for a year, and the two of you will still never have ordered exactly the same things, let alone in the same combination and timing, right? Maybe you totally, you hit barbecue chicken teriyaki rolls day one, right? But they never

order that. So, Parkinson's wise, some people will have hallucinations, some people will have falls, some people may have those early, some people will never have them, right? And the same goes for almost any symptom that we name. And so, why do I preface this with people? Why do we tell you about so many different things? If we can't guarantee that your loved one is going to have to deal with this, why should you have more chatter in your head? Because we know that the more you know, just to be able to say, wait a minute, my loved one is doing this thing.

Who do I even ask about this? Is this a Parkinson's thing? We don't want you to have to go to Uncle Google. We want you to know, wait a minute, they're constipated. Now where's, oh, you know what? I'm going to ask the Parkinson's specialist about this, because I remember constipation could be part of this. I remember apathy, depression could be part of this. I remember this could be part of this. So, we want you to know if these things crop up, and many will not, hopefully most will not be part of your journey, but if they are that you can calm some of that initial panic that many people feel and go like, okay, I know what this is. I at least know what my first step is and that this is part of this, and I have resources that I can use. So, I hope that that helps. I think the other thing to think about is if you are tuning in live, if you are watching this recorded and it just feels like too much, that is okay. That is normal. We are giving you a fire hose of information, right? This is all voluntary.

So, you can pause and shut me up. You can turn it off, you can join another day. There's a trainer that I like to work out with, and they will sometimes describe taking an emotional lap. He will just get up and just kind of shake things out right after a really hard set. If you need to just close the zoom, close the laptop, and go take an emotional lap, whatever that looks like, however, long that is, do it. That's what your body and your brain are telling you that they need. Please listen. So, if it's too much, it's too much. But this is always here for you. So,

Polly Dawkins:

Thank you so much for that. Thank you for that permission as well.

Jori Fleisher:

I hope people feel that permission. You don't need to get that permission from any healthcare provider. I hope you are giving yourself that permission, but if you need to hear it externally, please,

Polly Dawkins:

Dr. Jori said,

Jori Fleisher:

Yeah, tell other people I said throw me under the bus. It's fine.

Polly Dawkins:

Okay. Alright. Well, let's hop into the topics for today. As we keep in mind you, your missive here and your Cheesecake Factory analogy. That will, I keep going back to after I heard you use it the first time. Can you describe for us what are depression and anxiety and how are they different from one another?

Jori Fleisher:

That's a great question. So, depression, we, you know, we think about depression as people are always going to describe it differently in their own words, but feelings of sadness, feeling blue, feeling down, feeling hopeless, feeling worthless, feeling a sense of guilt. It is a low mood state and, you know, people can feel depressed intermittently throughout their lives, intermittently throughout any given day, right? Right now, there's a lot on the news. And if you're, you know, paying attention it would be hard not to feel sad or blue, right? And so, we're humans, we're capable of all of the feelings, right? So, depression is having those feelings, but in a sustained way where you're not able to kind of get out of that low mood. And usually we think about, you know, if someone has been feeling mostly that way, mostly sad down blue for a sustained period of time, two weeks or more we think about depression and depression, although we think about the mood piece often goes with other symptoms. So, either it can be excessive sleep or a lack of sleep. Someone who wasn't having these issues before and suddenly now is just unable to fall asleep.

Someone who may be extremely fidgety, they just kind of can't sit still out of the blue. This is new for them, just really kind of, we call it psychomotor agitation, that they're just, they kind of can't settle their body or psychomotor slowing, which can be very difficult to pull apart from the Parkinson's movement. But someone who was not sort of moving slowly before, but now is just sort of moving through their world, like they're moving through jello. Hmm. You just kind of see, it's like someone pressed slow-mo. while the rest of the world is on normal speed that they're just dragging, right? And so, when depression is very severe, it can lead people to feel like they'd be better off, or people would be better off if they weren't there. It can lead to suicidal, passive suicidal thoughts. Like, I wish I were dead.

My family might be better off if I were dead, and it can lead to active suicidal ideation and do to end my own life or harm myself, right? And so, that is, that's the extreme of depression, but it's really that sadness, that feeling blue, the things that brought someone joy, no longer bring them joy. And that is distinguished from anxiety. So, anxiety is an overwhelming sense of worry or nervousness that is not sort of that person's baseline, right? We probably all know people who just kind of function at a little bit more of a keyed-up level, right? And maybe they have longstanding anxiety, maybe they're just, you know, a little bit more kind of type a kind of

people. But an anxiety feels to the person different, and out of the norm they can say, I feel nervous, I feel anxious, I am worried about something.

Or there, you know just, just that more sort of keyed up. And anxiety, particularly in Parkinson's, can take a lot of different forms. So, there can be what we call sort of generalized anxiety where the person is just more worried, more anxious, more preoccupied, fixated on things that happened in the past and what that meant, and the implications or worried about things that are going to happen in the future, right? And it just kind of is like a blanket that covers everything. Or there can be specific anxieties. So, a very common one is around appointments and timing and driving and parking. So, I tell my medical students, if there's someone who's slated to see me as a new patient and we know nothing about them, and they arrive at the clinic 45 minutes early or more, that person probably has Parkinson's until proven otherwise.

Because it is so common in Parkinson's that people will go, okay, what time is the appointment? The appointment's at three, how long is it going to take us to get there? 30 minutes, okay. I don't know what the parking situation's going to be. I don't know what this is going to be. It could rain, it could do this. We should leave three hours extra, right? Where it's just, it would be normal to say, oh, I wonder what, you know, how I'll get there. Maybe we should leave a little bit of extra time. But it's an exaggerated amount of worry. It's disproportionate, you know, to what's going on. It can be worries about getting out of the house. It can be social anxieties. So, there can be a lot of different flavors, OFX, anxiety in Parkinson's or in general. But we can see all of those within Parkinson's.

Polly Dawkins:

What are the root causes in Parkinson's of depression and anxiety?

Jori Fleisher:

This is, I think, such an important question, Polly, because I hear from people all the time, well, like, yeah, you know, I'm depressed, but like, wouldn't she be depressed too if you were told that you had Parkinson's? Yes. Right. So, you'd be depressed too if you were told you had any life-changing diagnosis, right? And so, there's something that we call an adjustment disorder, which means something significant happens in your life and causes a temporary mood disorder like depression or anxiety, right? People can have this going off to college, right? That they're just; they don't know what to do with themselves. Things have fallen, right? Or something is happening in their life; they lose their job. They may have an adjustment disorder. What am I doing? I, how am I going to get up out of bed? Where is my meaning coming from? Right? You can absolutely have that around the time of a diagnosis of Parkinson's, all of the questioning, all of the, what is this going to mean?

That's different though, because Parkinson's underneath, you know, we think about it as a disease that's affecting dopamine, the chemical in our brain that regulates movement, but that's not the whole story. So, we know, and we've known for many, many years actually, that dopamine is not the only chemical in the brain that changes. Serotonin is a chemical that regulates mood, and serotonin is changing in Parkinson's. Norepinephrine regulates the state of alertness and anxiety, and that is changing in people with Parkinson's. And those are chemicals that just like I think we talked about before, how the dopamine levels change long before someone ever develops a tremor or slowness or stiffness. So, too, can these norepinephrine and serotonin levels change long before someone has movement symptoms long before they're diagnosed with Parkinson's and at any point in this journey. So, there are people who I will, you know, clarify.

Is norepinephrine the same as adrenaline? They're related. They're not exactly the same. That's a great question. So, there are people who will say, you know, I wasn't, I wasn't depressed. You know, in childhood, in early adulthood, often, you know, a spouse or partner will say, you know, no, they, you know, they weren't like this. Well, they've been like this for a long time. And I always clarify like, how long, how long have you been married? How long have you been together? You know, think back to then, when did this start to change? And it's never going to be a one day the switch flipped, but often 10, 15 years before any movement stuff, there may be, you know, what was into what was, you know, read as a personality change. But the person was starting to develop depression or anxiety. And that may have been their earliest symptom of their Parkinson's.

And again, at any point in this whole journey, there are folks who may never have depression, you know, for 10, 15 years of Parkinson's, and then may start to have mood changes later on. So, it's something that we want to be vigilant for. And just like, you know, the Cheesecake Factory, you may never pick depression off the list, right? But the hundredth time that you go, that might be the, you know, the thing that gets chosen. So, it could come up later down the line. We just always need to kind of think about it.

Somebody asks does anxiety impact eating it? Can, this person says always hungry, the eating disorder always hungry. It's a good question. I think that's a very person specific question. So, some, some people may have anxiety. So, a very unique thing is what's called off anxiety. And this is where people don't have like a generalized anxiety, and it's not related to any one specific thing or event. As there, this is usually in people who are on levodopa, and as their dopamine levels are good, sort of in a healthy range, they're moving well, they're doing well, they're feeling good, they're not feeling anxious, but as their dopamine levels kind of fall back down, as that dose wears off and they get back into kind of that trough of their own inner dopamine level, instead of feeling like the tremor comes back, or the slowness or the stiffness is worse, they may feel anxiety.

And we don't think that it's, they look at the clock and go, my symptoms are going to come back in five minutes. Oh my gosh, what do I need to do? Oh my God, I'm going to feel bad. It's not that, it's actually that those fluctuating levels themselves can cause the anxiety. Again, not in everyone, but, you know, some people may have anxiety, especially around the eating. You know, there's so much out there about the protein interactions and timing and things like that. I feel like sometimes we give people anxiety about eating because there's a lot of conflicting information out there. And so, people are like, oh, but I need to take my meds in five minutes, but I didn't eat, which means I can't eat for this much time. So, sometimes I think there's a little bit of iatrogenic anxiety or the healthcare system is inducing it or causing it. Just not to say that the protein and levodopa stuff is not, you know, there, it's, but we need to balance that with quality of life and being able to function.

Polly Dawkins:

I've also heard people in our community talk about when you're talking about off anxiety, that if they ever go in and if they have deep brain stimulation, if the deep brain stimulation is turned off like a cloud of anxiety just comes over them instead of a wave, and it's very noticeable. Yeah. And would that be related to off anxiety?

Jori Fleisher:

It's exactly when, you know, so DBS is basically replacing your chemical medication with electrical medication. So, if you're getting a slow, steady amount of electrical medication, and then boom, we turn it off, you are right back to that off zone. And so, if you have anxiety as an off symptom, absolutely. If the DBS goes off, that anxiety is probably going to come back.

Polly Dawkins:

Thanks for that. We're getting some questions in the chat and also would love to talk with, with you about strategies as care partners. How can we help our person with Parkinson's manage depression and anxiety? And do you have any examples of people who've successfully done this? What can we do? Yeah,

Jori Fleisher:

I mean, so I think the thing to know is you know, bring in help and you're not just like, I think there's, you know, we have a bias, at least in the United States about mental health, right? We think if we look at someone with a tremor, you will never say to them like, come on, snap out of it. Like, you can pick yourself up and like, you can make that tremor go away, right? But we do have a tendency to do that around mental health. If someone expresses feeling depressed, right? Then we tend to go like, but it's sunny outside, it's a great day. You know, you get to see this. That's not where it's coming from, right? It may be situational, but there is an underlying chemical change going on for both anxiety and depression, right? And so, to really help

someone, we need to address both that chemical piece and the situational and the coping strategies.

And so, there's good evidence that for depression and anxiety in Parkinson's, specifically seeing a therapist. So, whether this is a trained psychologist or a social worker a licensed therapist, specifically one who's trained in something called cognitive behavioral therapy which really helps people identify kind of when, when their brain is telling them something that's not quite right and they're kind of getting into a spiral identifying strategies and being able to go like, okay, is it really the end of the world or am I just having a bad day and when I feel like this, what do I need to do? So, it's empowering people with strategies. And what they've found is that, you know, seeing a therapist who's trained in this and it's a pretty common form of therapy can significantly help people with Parkinson's.

Usually, the studies are around 12 weeks long, so this is not a one and done. You go, you talk to someone once and like, I'm better. It's not that this didn't start overnight. We're not going to flick a switch and make this go away. This is something that your loved one, you know, is going to live with. But therapy absolutely can be beneficial. If the person is seeing a therapist is consistent, they've been going for 12 weeks and they're still not feeling better, that's usually when we say, okay, the chemical piece is not, you know, is going to need help too. And that's where we would use medications, just like how we replace dopamine, because we know people are missing it. We can replace or boost people's missing serotonin, missing norepinephrine. And so, the first line treatments for depression are really those serotonin reuptake inhibitors or SSRIs.

Those are things like Prozac and I'm going to blank on all the names. Zoloft, things like that. Effexor Lexapro, sorry. Or s NRIs, serotonin and norepinephrine re-uptake inhibitors. They kind of recycle what you've got and keep it around for longer. So, those are things like venlafaxine or Effexor or duloxetine. So, the chemical piece is not, you know, I know there's, in many cultures, there's a very strong resistance to acknowledging mental health issues acknowledging those as, as medical, as biologic the way that other symptoms are and to treating them. But I would just encourage you, this is, this is part of it. And it is manageable, it is treatable. And in terms of, there have been great studies that looked at what is the number one symptom that impacts a person with Parkinson's, quality of life.

It's depression. Because I could come up with the most beautiful, perfect medication schedule ever, right? I could look at you and go, oh my gosh, you look like you do so well with this form of exercise and this, and we could do this diet. If you are depressed, you're not going to do any of it, any of it. Depression is the biggest risk factor for medication, non-adherence for therapy, non-adherence. So, it shouldn't be a big surprise that if we have someone who's depressed, you can try and fix all the other things, but if you don't touch the elephant in the room, you're done. We're not going to get anywhere. So, it's really important to treat.

Polly Dawkins:

So how do a couple of questions that come, come up in my mind and I'm seeing in the chat first, how do, if you've got a person who you're, you're loving and caring for and they're depressed, how do you help them accept that talk therapy might be the first step? Addressing this symptom will help with everything else sometimes as a spouse.

I think it can be number one. I just want to normalize that that is very, very hard. And in some relationships, it may just not be possible, and some individuals just may not be able to hear it from their loved ones. So, if that's the case, if you just feel like I have tried in all the ways and it's not working, I am not getting through rope in loop in your person's healthcare provider. And you can always, you know, call, send to my chart, me, send a portal message, say, you know, I'm, I'm concerned, I really think that they're depressed. You know, they're not hearing this from me. The person may not be able to respond directly back to you because of, you know, privacy laws, but hopefully they see that, and they can think about that as they're talking with your loved one, right?

I think normalizing it in the same way as this is just part of the list, right? You did not do anything wrong. This is not a failure. This is not a failure of your coping mechanism. This is not, you know, this is part of the Parkinson's, right? And I tell people that all the time. Like, did you try to snap yourself out of your tremor yourself? And if so, how did that go? Right? And so, why, why would we think that we could manage any of this alone, right? No one should be managing any of this alone. So, acknowledging that it's real, acknowledging that it's part of this and then indicating like there are resources. This is something that you can get past and through and live better with.

Polly Dawkins:

Yeah. The strategies that you've suggested for helping with depression, I imagine those would be the same strategies that we might think about doing for ourselves as care partners.

Jori Fleisher:

Yes. Yep. So, absolutely. It is, although there are studies specific to Parkinson's, the studies were done because that works in people who don't have Parkinson's. We know that therapy can work and can work really well. You were warning for incoming other terrible analogy. So, here's my analogy about therapy, which is if you are a woman, you can think about jeans. If you're a man, think about cargo pants. Okay? I used to do jeans for everyone, and I had a man go like, I don't care about jeans. Fine, whatever works for you, pick your own thing. Many of us can go into a store and look at a display of jeans or cargo shorts and go, those are definitely not going to be for me. But there might be a few different styles that you're like, maybe, and you take them into the dressing room, and you try them on, and some you try on and you're like, whoa, yeah, no, this is not a good fit.

And others you'll be like, oh, yeah, okay, alright, this works for me. It is the same thing with therapists, okay? You are not marrying your therapist. It is not a long-term relation. You don't owe them something, especially if you are meeting someone. Once you are having a conversation with someone, you are trying to figure out if they are a good fit, whether it's you, whether it's your loved one, right? This is what they do on a daily basis. They have plenty of people who they see long-term, but they also have plenty of people who they see once, and that person never comes back, comes. Most good therapists are not going to take that as a personal insult. They're going to say, this was not the right fit for that person. Right? And there may be people that continue to see them who they go, I don't know if I'm the best fit for this person.

Jori Fleisher:

Like, I have, they looked in the mirror. I'm not the best genes for them. Right? So, when you're looking for a therapist so Psychology Today has a great website where you can actually, it's almost like a dating app for therapists. You can type in where you are, whether you care about the gender of the therapist, what insurance you have or not, what particular issues you are specifically looking to talk about. So, there are therapists who specialize in people living with chronic illness. There are therapists who specialize in supporting care partners. There are specialists who, you know, people who specialize in trauma in L G B T Q and all of the following. So, there, I mean, truly there are therapists out there for every niche. It may be, it may take a few pairs of jeans. I'm going into fitting a few times, sometimes that right person, but they're out there, don't stop trying till you find that right pair. Right? So, and,

Polly Dawkins:

And the same pair of jeans that fits you probably doesn't fit, usually.

Jori Fleisher:

Wouldn't fit, right? And it's probably a conflict of interest maybe for, you know, the same person to be, you know, hearing the story from one side and hearing the story from the other side. I'll put in the psychology today.

Polly Dawkins:

I'll do, sorry.

Jori Fleisher:

Okay, thank you.

Polly Dawkins:



And many of these therapists ha seems to have been made available through telemedicine or virtual visits. Yes. That your experience, that that's an okay way to approach having a visit with it. It's

Jori Fleisher:

Absolutely, absolutely. You know, I don't think that being available on, on telehealth is a marker of quality in either way. It really is just actually, you know, a wonderful reality and one of the few silver linings of Covid is, you know, we have people that can do that. And for some people it means, you know, they just, they can't travel. A lot of care partners may not be able to take the time to travel and go and find someone for yourself, right? And have your loved know that your loved one is, you know, safe or occupied while you do that. But you might be able to find someone who's got nights or weekends or off hours and can do a video visit, right? So, I would, I would definitely, I would recommend the Psychology Today thing. I would say, I know there's been a lot of press, there's been a lot of advertisements around like better health and some of those kinds of more commercial things.

I've not heard great stories coming out of that. And they can, it seems like there, there's a bigger financial push on some of those things. So, I would favor going towards like the Psychology Today website. It really is just a directory that links you to a different therapist, learn more about them, check out their page and then just call, and ask. And you can say, you know, calling on behalf of my loved one, they have Parkinson's and are struggling with a, B, C. Is that something you're familiar with? Right? And many therapists will do sort of an intro, get-to-know-you visit, and then kind of go from there. So,

Polly Dawkins:

Before we move on to apathy, I would like to make sure that we've covered everything around depression and anxiety. Any stories, any things that you would say, don't do this.

Jori Fleisher:

So great examples of like, people who've done really well with anxiety. So, if anxiety is around a particular thing, so for example, if it's, when's the appointment coming up? When when's the thing come, you know, we have a thing, it's coming, what are we doing? So, a great thing that several of my care partners have done is they will have a whiteboard, a dry erase board, and either it lives on the fridge, or it lives in one specific place in the house. It does not move. It is sacred, right? And it's not a detailed minute by minute schedule of the day. But if there's a doctor's appointment, if there's a family event, there's something on there, it goes on the board. And that way if the person with Parkinson's is really fixated on what time is that? When is that going to be?

Jori Fleisher:

What are we going to do? It's on the board and they know, and you can redirect them. Like it's on the calendar, you know, honey, it's on the calendar, go check the calendar. And usually if there isn't a lot of cognitive impairment, people will start to kind of absorb that and go like, oh, I'm kind of worried about the day. Okay, I'm just going to go look at the calendar. Doesn't work for everyone, but for a lot of people, that can be really helpful. I think the other is trying to figure out, and this is really specific to each individual person, but how much lead time is the right amount of lead time before an event if a loved one has a lot of anxiety around events or travel or appointments or things like that. So, you may not want to tell them a month out, you know, here's when your next neurologist visit is. I have people tell me all the time he is been thinking about this visit and, you know, getting really worried for the last three weeks. I'm like, I don't. I hope I'm not that scary. But

Polly Dawkins:

So maybe just,

Jori Fleisher:

You know, put it on the calendar the week before. Right? You can choose how many days you're going to write stuff in on the calendar, even if it's a 30-day pre-printed kind of thing, just fill out the week ahead. So, that can be really helpful for a lot of people.

Polly Dawkins:

Yeah. Somebody Lynn mentions that they use brightly colored stickers that move around each day on the calendar to orient their person.

Jori Fleisher:

I love that. That's a great idea. Like a you are here kind of thing.

Polly Dawkins:

Yeah. Super. All right. We have gotten some questions in the chat, and we always get questions from our community about apathy, and it's such a frustrating symptom and people just feel loss of what to do to support somebody with apathy. Yes. Can you just frame for us what is apathy? Yeah. What did you see in your research when you were exploring this topic? How it affects quality of life and how you have helped care partners deal with apathy? What's what?

Jori Fleisher:

I think number one, so before I even describe it, I'm going to say I think apathy is one of the most misunderstood symptoms in Parkinson's. I think this is the one where there's the biggest discrepancy.

Between care partners and the person living with it. I think this is one of the biggest sources of tension in whatever that relationship is between the person with Parkinson's and their care partner. And I think it is one of the biggest unmet needs for treatment. So, what is apathy? Apathy is the loss of motivation to do the things that a person used to do or that used to bring them joy. It's basically like you have just lost your oomph. And so, so many times, I cannot tell you the number of times that I'm seeing someone in clinic and their care partner goes, he, she, they are depressed. And I say, tell me about that. And the person is sitting maybe not making great eye contact, you know, and I say, do you feel depressed? No. Do you feel sad? No. You feel blue.

Do you feel down? I use all the synonyms. Are you know, hopeless, are you, no. And it's, it's, it's that kind of, eh, apathy is, eh, it's the loss of oomph. I often will say, you know, someone who is depressed, if you say to them, you know, if you've got grandkids and you know, they do extracurriculars, you know, hey, you know, John's got a baseball game today. And normally the person with Parkinson's, you know, that's something that they really enjoyed. If they're depressed and you say, John's got a baseball game today, and they say, I don't feel like going, and if you took them and you brought them to the baseball game, they'd still sit there at the baseball game if they're depressed and just, you know, they might fake it a little bit, but they're still sitting there and looking sad and not enjoying it.

They're not deriving pleasure from the thing that used to bring them pleasure. The person who's apathetic. On the other hand, you could say, hey, John's got a baseball game today, want to go, eh, maybe next week. But if you get them there, but they're clapping, they're engaged, they're involved, they're enjoying it. If you lower the energy required from them to do the thing, if you bring the thing, the meaning, the joy, the activity to them, they still enjoy it. That's apathy, right? The capacity to have joy is still there. The capacity to find meaning from that activity, but the motivation to do this stuff, well, we'll just do that tomorrow. That's apathy. And to care partners to families, it's very hard to make that distinction so much of the time because you know, you'll plan an event. Do you want to go to the birthday party?

Yeah, sure. And then the day comes and it's, no, I don't want to go. Or you know how important physical therapy is. You know that Fleischer said you have to exercise. Like, come on, we're supposed to be exercising, eh, next week. But if you actually get them out for a walk and they enjoy it, depending on how hard you're pushing them, right? But there, you know, there's, there is joy. They're not just slogging the whole time and miserable, right? Or they come through at the end of whatever activity and say, you know, are you glad that you did that? You still may have to prompt them, right? Are you glad that you did that? Yeah, that's apathy. And apathy is one of the hardest symptoms to treat. Our medicines don't do a great job of this a lot of the time, whether it's levodopa, whether it's, you know our mood medicines.

It can be very refractory to treatment, meaning really sticky and hard to get at. But there are a couple things that seem to really help. So, there's actually some good evidence. Our team did a

study where we looked at music therapy for apathy. And this was during Covid this was with a music therapist and all on Zoom. So, all online we sent people out a bunch of musical instrument kits and they followed along and listened to music and played and did stuff. And other groups have shown this too, in populations with dementia and in other various populations where apathy is a big problem that music therapy can help. So, you may be able to find music therapy in your community, but what do you do tomorrow? What music does your loved one enjoy? Right? For most people, the music that sticks with them, their music, after which time everything went down the hill, right, is the music of their teens and twenties years, right?

So like, that's where people's musical heart kind of stays. And everything else is just racket after that, right. So, like, what do they like to listen to? Put that on, you know? And let them just listen to it in the background. Get up, dance, walk around, move to it, talk about it. Play music. If they used to play an instrument, play music. If you have kids or grandkids or someone around who plays music, bring them in, let them play, let them dance. That can be really motivating. I saw someone in there talking about exercise a hundred percent. There's so much apathy around exercise, but many people, once they go and some of that is the endorphins that get going, they will feel good. And particularly if it's a Parkinson's focused class where it's within the Parkinson's community, I think there's such a sense of comradery and such a sense of empowerment around seeing other people with the disease who are, you know, again, they've got a totally different Cheesecake Factory order, but whatever it is, everyone's been to the Cheesecake Factory, right?

They've all got PD and even without talking about it, they're doing something about it. So, your loved one may go like, I'm terrible at boxing, but look at that guy. He is really hitting it. Right? He can aspire to be that guy, right? Or that girl, or, you know, whatever it is. We had a study where we looked at karate for Parkinson's, right? Crazy. And this, this idea came from a person with Parkinson's who recommended and said, Jo, if big movements are good, right? Large amplitude movements, getting people moving bigger is good. Sure. And if Tai Chi has shown improvement works on balance coordinated movements Yeah, sure. And if aerobic stuff is good, yeah. And weight resistance doing heavy things, yeah. It's like karate's kind of all that stuff rolled together. Why wouldn't that be good? So, we tried it, and it turns out it really helped.

And a lot of it seemed to be not just the doing of the exercise, but the community and the comradery. And what I would hear from people coming back would be not, here's how I'm doing in karate, but I have to tell you so and so, you know, is testing for their green belt next week, you should see them. They're doing this. It's recognizing that people can achieve and accomplish things and improve in areas, seems to have really sort of, you know, slashed through the apathy that I was seeing in a lot of those folks. So, those are just a couple of examples. I saw someone in the chat put, the secret is not to give a yes or no question, such as, do you want to give a choice but not a yes or no choice? We can go here or here today.

Sometimes it's, I'll describe it as a contract. So, and I, I'll say this in the room with people with Parkinson's in their care partners, is there are going to be days where you person with Parkinson's do not want to do any of the things and your care partner goes. But she said, do all of the things.

Okay, I want you to agree, and you can put me down as the person you know, who's making you sign this contract. Even on the days when you don't want to do any of the things you agree to do. At least two things, right? So, maybe you don't go to the event and do your physical therapy exercises and walk around the block and you know, X, Y, Z, but you have to do two, right? There cannot be a day of just nothing because that's a recipe for disaster. If we give into the apathy, the apathy is just going to take and take and take. I mean, I just think about it as like a monster that is just sucking the life out of people. And if that motivation goes, it's so hard to get it back once we get into sort of that routine of just, I don't want to do anything, so I don't do anything.

Polly Dawkins:

If you're able to break through, through some of these suggestions that you have and get beyond apathy for a day or for two or choice, does it come back? Is it persistent? Apathy will always be there.

Jori Fleisher:

It can, I mean, for some people it just seems to be like one of the symptoms of their pd, but we, you know, just like a tremor, right? The tremor might always be there, but if we find the treatment that really works for them, you know, hopefully it works for a while. And just like tremor at some point, it's not that the medication stops working, right? It's that the disease has continued to progress. Whatever symptom we had control of before that symptom has now gradually over time increased, which means we need to adjust the treatment accordingly. So, it might be for a while that the person goes to the boxing class, to the exercise class, to the dance thing, right? And then we start to get more pushback every week of I don't want to go, I don't want to go, I don't want to go. We need to find a new activity, right? It's not, okay, we'll stop going to dance. And that's just it. We're going to find something else.

Polly Dawkins:

So, somebody just asked in the, in the chat, how do I do all of this and deal with apathy while I'm taking care of the household too?

Jori Fleisher:

The simple answer in my opinion is you cannot, you have to call and back up. And I will tell you that what is really, I think one of the reasons why this is so detrimental you know, particularly

to couples is because the care partner winds up in the setting of apathy being the person who is constantly nagging. And you feel like you are the drill sergeant and all you're doing is telling them to do something. And it can feel almost like a parent child relationship, right? And that can put so much stress on the relationship. That's not how you want to feel. That's not how they want to see you. The people, people with Parkinson's will often respond and say yes to new activities or encouragement to do the same activities when that is coming from someone other than their primary care partner. And it can be totally frustrating because you can say the same words, it's time to go to exercise class, we need to go, no.

And then an adult child comes waltzing in or calls, you know, from out of town and is like, hey, dad, heard you're going to rock study heard you're going to this. Yeah, I'm just getting my coat on. What the right. That is not you. That is not a failure on your part as a care partner, that is a sign of how much you are in that primary role, right? And that they are going to tune out to some of that. You are a safe person for them to say no to. You've created a relationship where they feel comfortable saying no. So, that is a testament to you as much as it is so frustrating. But that's when outsource that outsource it. It could be a neighbor, right? And someone who goes to the gym with them. I know I'm giving all these examples of exercise, but whatever it is, right? You don't have to take them on every walk. You don't have to go to act every activity. You can have that time for yourself to catch up on the errands or just take the emotional lap, right? Sit down with a cup of tea or whatever. Ask someone else. Number one, there are all those people hopefully who are going, let me know how I can help, right? This is a way to take so and so, to their x, y, Z appointment. If they can do it every week or every month or whatever that is, put it on the calendar, right? Not just exercise class. Exercise class and gym is taking you, right? Whoever that is, because that's also a social opportunity for your loved one as well as it is an out for you. You cannot do all of this on your own. You cannot, you cannot.

Polly Dawkins:

Deanna and Betsy, both ask us the same question. What if we're the ones who are becoming apathetic? We as care partners.

Jori Fleisher:

Yeah, it's the same, right? You, I mean, I would take that as a sign that you have been working so hard and finding, you know, bumping up against that resistance about, you know, against the apathy so much. And it is so normal to feel like they know what to do. They know that they're supposed to do these things, they agreed to do them, but then they don't do them. And when this happens all the time, how could you not get frustrated, angry, upset, apathetic, all of the feels? Right? I don't know anyone who, I cannot think of any care partner who's loved one has significant apathy who doesn't feel that way at some point. And the ones who don't call in extra help are the ones who suffer the most. So, I certainly have people where, you know, they will not call anyone else. And it, they have a really hard time, right? And their person with Parkinson's has a really hard time. They got it.

Polly Dawkins:

Thank you. Yeah. We have many, many resources about depression, anxiety, apathy on the hub, on the website under care partners. And we'll be adding new ones today. Since we have two other big topics to get to today, let's move on. And not to say that these aren't important topics, but let's move on to loneliness and isolation. Can you tell a story a little bit about what are loneliness and isolation, and how do they differ from one another?

Jori Fleisher:

It's a really great question. So, and I sometimes find these kind of confusing, but loneliness is a feeling. So, loneliness is, you could be surrounded by people, right? But you feel like you don't have a good connection to them. You feel alone. So, if you imagine there are folks who, you know, live in a senior center, right? Live in a senior community. There's lots and lots of folks around them, but they just don't feel like they have a good connection to anyone, right? And maybe they have ample family and friends, but they don't, you know, they don't feel like people are getting it, and they've kind of withdrawn into themselves, right? So, that's loneliness, and it overlaps with, but is not the same as isolation. So, isolation is people often describe it as, you know, how connected are you into a community?

How many people, almost the, you know, six degrees of Kevin Bacon kind of thing, right? How many people are you interacting with on a daily or weekly basis? How often are you interacting with given people? And how many, sort of, how rich is your social network? How tied in are you? So, there are people who may have, you know, they walk into a party, and they seem to know everyone, right? And everyone knows them, but they could still go home and feel like people know them on the surface, but no one calls to check in. They feel really lonely, right? And there may be folks who talk to only one or two people every week and live by themselves, but that feels okay to them. They don't feel lonely that the amount of connection feels right for them. So, they might be isolated, but not lonely, if that makes sense.

And so, this has been a huge topic even before Covid. So, the Ministry of Health in the U in the United Kingdom created a minister of loneliness. This sounds like something out of a Monty Python sketch, right? But there is a minister of loneliness because they realized that loneliness, particularly among older adults, particularly, is an epidemic all on its own and is really a pandemic. So, pandemic means global, right? So, before Covid was a pandemic, isolation and loneliness were pandemics, particularly among older adults. So, Britain has a minister of loneliness. Japan has a minister of loneliness. I don't think the US yet has a minister of loneliness, although I have heard our surgeon general speak really eloquently about loneliness, both when he was surgeon General with under President Obama, and he's Surgeon General again Dr. Vivica McCarthy. And he is very passionate about loneliness as a pandemic. And it has massive repercussions. So, being socially isolated and or being lonely, the studies sometimes interchange them a little bit, can be as high of a risk factor as heart disease for death, right? So, people can be perfectly healthy, but socially isolated, and it is absolutely taking a toll on their



physical and mental health. They have higher markers of inflammation. They have all kinds of stuff going on in their body. Humans are social animals. Like we are actually wired. Our biology is set up so that we thrive when we are interacting with other humans, and we do poorly when we are not. So, this was recognized pre covid, and then covid happened, right? And the rates of loneliness and isolation, I don't need to tell you all this, right?

But they went through the roof, and we saw the repercussions for so many people, right? And the lockdowns were necessary, right? We saved hundreds of thousands of lives. And for many people, that may have been one of the first times that they were feeling really, really socially isolated. But what broke my heart was when we first entered Covid Lockdowns we recognized after doing home visits and things like that many of our people who we'd been visiting before and now we're just at home and far away, like we did not know what they were going to do. And calling and reaching out and going like, are you okay? Can you get groceries? Is someone, you know, is someone checking on you? Is someone there with you? How are you holding up and hearing from folks with Parkinson's that they were like, it's basically no different.

It just destroyed me. And so, for many of you, like you may have anticipated that that's the punchline, right? Is just, you know, if you are living with someone and feel like your world has narrowed because of having Parkinson's in your realm, you are not alone. You may feel very alone, but you are not alone. And like, connecting with something like this is a huge step, right? Look, how many people are logged in? Look how many people, you know, have been following along. This is, I think, an example of people saying, you know, I need to connect not just to information, but to a community, right? So, we also know our team has done work looking at connecting caregivers with other caregivers, and found that lo and behold, you know, we thought this would just be kind of a lopsided relationship where really experienced caregivers or former caregivers, you know, people who maybe their loved one has passed, right?

We are connecting them with someone who's in the midst of it. We really thought this would benefit that person who's still doing the caregiving. And lo and behold, we heard from both parties across the board just to be able to talk to someone who gets it, to know that I can pick up the phone and call someone and not have to explain myself, right? Having that, having that social connection is so impactful. So, it is a big issue in Parkinson's. Dr. Indu Subramanian out California has done a lot of work on social isolation and loneliness in Parkinson's. So, she's a great resource for this kind of idea. But certainly, people with PD with Parkinson's can feel this, but caregivers, absolutely. You know, we know that sometimes as Parkinson's comes in, sort of other people and connections kind of fall away. And so, it can feel like this is kind of, kind of narrowing the field,

Polly Dawkins:

And I would guess that it feeds off of one another. So, if you're feeling isolated and lonely, your person with Parkinson's is probably feeling that way, and it, and it may be over time becomes almost normalized.



Jori Fleisher:

I think it does, right? I mean, we heard that from a lot of people, was just, you know, well, you know, where am I going to go? Like, who am I going to talk to? And no one's going to get it, but we were hearing from everyone, no one's going to get it. And who am I going to talk to? There's no one out there who could, you know, explain that, you know, who could understand this? There are over 1.2 million people with Parkinson's just in the United States alone, and we're still probably underestimating that number. You are not alone. The worldwide prevalence rates. So, the number that people have modeled out is that by 2040, we think there will be at least 12 million people with Parkinson's in the world. You are not alone. This is the fastest-growing brain disease in the world. You are not alone right now.

You'll be even less alone in the future. But it takes a huge amount of courage to be able to say, I am living with this, and I am feeling alone. I'm feeling disconnected, right? So, just kudos and all the gold stars and the credit to all of you live and recorded and everything for connecting to the community in this way and in all of the ways that you may have already are all of the ways that you will in the future, right? So, I think, you know, how do we, how do we treat social isolation and loneliness? We recognize it, we normalize it, and then we get our butts moving. You pick up a phone, you go to a support group, you join a Zoom group, you join a social media thread, or, you know, whatever it is that feels right for you. I'm not on TikTok.

So really the answer I know much to my younger sister's chagrin and disappointment. Right? But like, if, if Facebook is not a thing that you feel comfortable with, I'm not going to tell you to join a Facebook group, right? That's not, that's not for you. If an in-person support group doesn't feel great, don't do that. Right? There's lots of different ways to connect with people, and it doesn't just have to be connecting in the Parkinson's community that can serve many purposes and sort of fill your cup in some ways, but that shouldn't be the only way, right? There are lots of great people out there who aren't even in the Parkinson's community. I don't know many of them, but

Polly Dawkins:

Yeah. Yeah. And I think it's finding commonalities that things you used to love doing. So, may be quilting, it may be music, it may be some sort of exercise, chess, just find your people and try and that may even help to destigmatize Parkinson's in that community. You just happen to be a chess player who has Parkinson's as opposed to a person with Parkinson's first, or a care partner. A care partner who quilts No, you're a quilter who happens to be caring for somebody. Yeah. Do you, did you see any examples when you were out doing community visits that care partners employed to reduce their own feelings of loneliness and isolation? Other than what we've suggested?

Jori Fleisher:

I mean, I found people who, you know, may have visited a support group and felt like this group isn't quite for me, or that they didn't quite click, but they were like, sitting in the back of the class and, you know, chatted it up with one person and maybe they were sitting in the back of the support group and going, I don't like this one. Yeah, me neither. Lemme get your number. We should just go out for coffee. Right? So, people who made connections with each other and would just call each other on the phone, or I know of an amazing group of four couples who for a very long time before covid and then through Covid, were couples where, you know, one of the members had Parkinson's and the other was the care partner. And they were meeting these four couples and having shared dinners on Zoom together, eating whatever they made at home, zoom, whatever.

But they set up a time and they all jumped on Zoom. It wasn't adding anything more to their daily schedule because they would've been making dinner anyways, right? They would've been sitting at the table, but they could turn on Zoom. And if their loved one with Parkinson's coughed or, you know, had a tremor while holding a soup spoon or whatever it was, didn't matter, right? Because they got it. And so, I think there are so many creative ways to work around this. So, I've seen a lot of folks where they may find, you know, an activity for the person with Parkinson's to do, and in that 45-minute, hour, whatever it is, maybe there's a com, you know, a class offered at the same time. Maybe they just go read a book in the library, right? Maybe they do an exercise class, maybe they just go walk lapse, or they call a friend during that time. They throw in a grocery cart, you know, an Instacart or Peapod kind of order during that time, right? Finding a way that if your loved one is occupied, you can do something that isn't just keeping the house up, cleaning, doing the laundry, cooking the meals, doing all the doctor's appointments, something that feels at least in part for you.

Polly Dawkins:

Chris puts a comment in that many people have reacted to the panelists, but maybe Chris hasn't seen the reactions that they say that when we socialize with our friends and our friends are still working, traveling internationally, writing books, doing all the things of life, and they ask me, what do I do? All I can say is, I keep the house up, I clean, I do laundry, I cook meals, I get us to our doctor's appointments. Other folks are like, yes, yes, yes, yes. Yeah. Any thoughts there?

Jori Fleisher:

I mean, I think, you know, Chris, it's, it's totally true. And I hear this all the time, and I don't think there's a way to gloss over that. It's not, it's not everyone's experience, right? So, for some people, you know, they may hear this, like the person who had the reaction, you know, an email and said, that's not where I'm right. So, other people may be going, well, you know, I'm still working, I'm still doing this. I'm, I'm still traveling, you know, when my loved one has Parkinson's, and that's great. And Chris and others, you know, may feel this way. I think if you are feeling like it's all that you can do to do all of these other things, and there isn't any

something that you are doing for you that's left, how can we find some little window of time, right?

What, what could that look like? You know if that's all you're doing, right? So, can you hire a caregiver? Can you bring in a neighbor or a friend or you know, if your loved one likes to play chess or games, or paint or do something, I mean, I have a lot of folks where they've literally found, you know, a high school student or a, you know, friend's child who does that same activity, and they'll come and hang out and do that thing with the person with Parkinson's so that you caregiver are not washing the dishes during that time. You are not folding the laundry during that time. You are doing something for you, right? So, it's not always free, it's definitely never easy. But it is the only thing that is going to keep you and sustain you. You have to, this is, this is putting on the oxygen mask for yourself before you put it on for others.

You have to find some little window so that you can answer to yourself, what did I do today besides clean the house and, you know, make the meals, and do the doctor's appointments, try, you know, some people will do gratitude journals and things like that. I get on a kick and then I forget about it for a while, right? But can you even just pause for a moment to yourself at the end of the day and go, what did I do for myself? And if that was, I, you know, sat down and I sipped on my cup of tea for a while, or I walked around the block once, even if it was three minutes, right? Whatever that is, it's something, making a point of noticing it and trying to say, it's four o'clock and I haven't done anything for myself today. What am I going to tell myself when it's, you know, 10 o'clock at night, whatever that is, finding some way to sneak that in.

Polly Dawkins:

You know, Jori, I was visiting with a friend with Parkinson's and her care partner this morning. And she has a little 11-year-old neighbor girl who comes over all the time, and she's teaching her how to sell. And so, her husband, the care, her care partner can go off and do his own things and play his music and be who he wants to be in the world for that moment. And his person with Parkinson's is with somebody socially interacting, teaching a skill to a youngster. Intergenerational, I just thought that was a beautiful story and way so beautiful. And not sort of what you normally would think of. Like, oh, how do I get a little neighbor kid over here? And

Jori Fleisher:

Right. And I mean, honestly, you know, so I have young kids. I have a nine-year-old who loves chess, right? And he would love, go play chess with someone who isn't his dad or his grandfather's family member to be able to get out there and play with someone, right? And so, there may be people around you, right, where you may feel like, oh, I'm asking, you know, so much of someone, I would love it if someone wanted my kid for half an hour, right? that is a gift to their parents. That's a gift for your loved one, right? It's someone else, it's someone new, it's a different experience. It is strengthening that social network and it's giving you something.



So, you know, I think we limit ourselves sometimes and go like, you know, who do I want to let into the circle? You know, who do I feel like, you know, will be safe and, you know, is going to get over any stigma that might be there? And sometimes I think we put so much pressure on that, and kids are incredible and resilient and funny, right? So, look around the neighborhood, you know, if you've got kids in the neighborhood, if you've got neighbors, and if you see a working mom who's pulling her hair out, right? Like, hey, does your kid want to come over for half an hour and eat a cookie? Right? Whatever that is, you know, you are not asking a lot from them. You may be giving a gift, right? To that kid to give them an experience with someone else. You may be giving a gift to that person who's going, oh, you know what? Look at this. You know, they're giving back in a way they're doing something right? And maybe it's like, I'm going to give them a dollar every time that they come over, right? Whatever that is, you know, if that's what it takes, it may be really, really worth it. And create a wonderful relationship. So, yeah,

Polly Dawkins:

I know Mel wanted to jump in and ask a question.

Melani Dizon:

Yeah, I just wanted to comment because somebody had asked about palliative care earlier. And then I heard someone had said, you know, I've learned that when I ask for help, the person agrees that act brings them so much joy that I asked them. And it contributes to that person's sense of purpose that they get to help. So, that is a big thing. But palliative care, I don't know. Not, it's not the case for every single community, but there are times, like, I volunteer for our hospice and palliative care, and there, there's nonstop lists that I just go on and it'll say, palliative care you know do the dishes and lighthouse work for this family. I'll go do it like it. And then the person that is sick and the care partner has like time to spend together that is valuable and wonderful, and they don't have to worry about the dishes.

So, part of palliative care that a lot of people miss is that services become available to you that you didn't know existed. So, look at palliative care, people with Parkinson's are able to get palliative care, and it is a whole host of different things that people can do. So, I would recommend, especially for people who find it hard to ask for help, you're not asking for help from people that, you know, you're just saying, going to palliative care, and they're saying, hey, these are the services we provide. So, check out your palliative care, check out your community hospice, your community care network, and see if there's a way for you to get help in a different way that's volunteer. You know, you don't have to ask your friends none of that, but that you could get some really good help.

Jori Fleisher:

That's such a great point, Mel. I think that one of the corollaries, just to add onto there, is this, you know, this depends on every person and every situation. But many houses of worship, many faith communities may have similar, you know, kind of volunteer lists. You know, I know the congregation I belong to has basically a like, join this committee. If you want to be available, we will call you. If someone is sick and they put out an APB and say, you know, so-and-so needs help, and you basically just can, you know, say like, what can I do? Can I bring you groceries? Can I wash your dishes? Can I do your laundry? Can I, whatever. And I think sometimes those are interpreted as it's an emergency. Someone is acutely ill, you know, I can't avail myself of that when living with chronic illness.

And that's just wrong, right? If you heard of someone in that situation who needs help, I think most people would not distinguish and go, well, they have this all the time. They have this all the time. They need help. Right? You need help. If someone, you know, has, has an acute event, people often come out of the woodwork, right? You get more casserole than you know what to do with. We forget about people who are living chronically with disease, right? The casseroles are not showing up on your doorstep all the time. You need them more than ever, right? So, avail yourself of those kinds of things. I often know lots of communities will have various different parent lists or mom lists or things like that. I know the suburb that I'm in, you know, there's an email listserv that goes out all the time of, I need this.

We're getting rid of this thing. You know, here's this, I got a teenager and they're driving me nuts. I need to get them out of the house. Right? You can post things to list like that and say, looking for an afternoon, you know, companion to come hang out with my loved one and do the following. Or I have a person who loves to go biking. Do you love to go biking? Would you like to go biking, you know, with my loved so that they're with someone doing something, an activity that they enjoy, and you care partner can do whatever you want during that time.

Polly Dawkins:

Yeah. And I see comments that people are saying that sometimes it's not direct family members, that direct family members are just not able to cope and able to do the hard work when it's help is needed. Yeah.

Jori Fleisher:

Yeah. I, you know, I think everyone experiences chronic disease, disease in general very differently. And some people just may never get to that point of accepting and seeing things the way that you unfortunately see them when it's 24/7, right? Or it's a day-to-day kind of thing. It's not your responsibility to try to get them to understand. You can provide them resources. You can send them to you know, the Davis Finney website. You can send them wherever they need to go. But yeah, if it's not coming from immediate family, you're not alone, but don't stop there. Don't take that as a sign that there isn't anyone who can help. Right? It may be



unorthodox; it may be someone that you didn't suspect. But there's someone out there who wants to help. So,

Polly Dawkins:

Any other stories that you have from your work and visiting folks in the community or from your research about loneliness and isolation and how it impacts quality of life?

Jori Fleisher:

Yeah. I mean, I think some, so other examples were, as Mel said, like there, you know, palliative care services I'll offer things. They're also just like various different volunteer groups. So, I didn't even know that friendly visiting services was a thing. But when I was doing home visits in New York our social worker was brilliant. She went, you know, this person could really benefit from a friendly visitor. And I was like, well, yeah, well, good, and right, we're all good, right? And I thought friendly visitor with lowercase, you know, f and v, and she was like, no friendly visitor with a capital. And I was like, I don't know what you're saying. And there were programs. There are programs for friendly visiting, and some of those are through vat, you know, various palliative care networks. Some of those are through hospices, some of those are through faith organizations, but there were just random volunteer networks that are out there.

And so, you know, we had someone and he, you know, wanted to do bible study. It brought him tremendous meaning and joy, and he struggled, and the people in his community weren't coming to him anymore, and he wasn't able to go to them. We found him a friendly visitor who came a couple times a week and loved it because this was a learned scholar, right? And so, it wasn't like, okay, I am volunteering my time. Look how great I am this, this friendly visitor, like lived for this. And it brought so much meaning to the person with Parkinson's, kids, pets, you know, even if they're not related animals bring lots of joy and can really help people cope with isolation. So, I had a lot of folks who for better or worse family members may have adopted a new puppy during the pandemic, and then life started to get busier again.

And they were like, I don't have the time for this. And they dumped the poor puppy or kitten, you know, with a family member with Parkinson's. And although it's an adjustment and maybe not, you know, perfect for everyone, sometimes that was really, really meaningful. It was sort of the unexpected gift. I've had folks who, you know, have Parkinson's, maybe they, it's too much to have a pet, but they will go volunteer at an animal shelter. There are, you don't have to be able to walk. So, there are a ton of shelters where they found that just like human voice, even if you can't get down on the floor, you can't sit, you know, all that. They have programs to have kids go read to dogs, and it really soothes a lot of anxious dogs and shelters. So, I've had people that go and have an appointment every week and they go read to the dogs, right? The dog doesn't care. You could read People Magazine, or you could read Moby Dick.

Polly Dawkins:



You do.

Jori Fleisher:

You bring whatever you like, right? You could sit and put an audiobook on if vision is an issue, but being in proximity to, you know, something, someone that brings you joy. And

Polly Dawkins:

Does being near an animal, I might have missed that. Does that help with loneliness and isolation? Yes. Yeah.

Jori Fleisher:

Yep. Absolutely. I mean, we want to make sure that, you know, don't, don't get a puppy. Don't, you know, get a kitten if it just feels like this is just another thing that I have to take care of, right? This is not saying that that is a good solution for everyone. I say this as a working mom who just got a puppy recently, you'll lose more sleep initially at the beginning than you think that you might. And so, it's not, it's not the perfect solution for everyone, but there are a lot of older dogs in shelters, older meaning not sort of in puppy hood that often get overlooked for the cute fuzz, you know, fluffy, fuzzy puppies. And they are maybe you know, a calmer, less jumpy, less likely to prompt falls solution for a lot of people.

If you feel like you have that bandwidth in your life to do that. But visiting someone who has one, or a neighbor who has a dog or a cat or something and is willing to bring them over to visit pets can really make a difference in loneliness. I don't know if people have studied fish. I don't know if fish make a dent in loneliness. I know some people find them very calming for anxiety, but I don't know that I would rely on like a fish to help with loneliness. But that might just be my bias.

Polly Dawkins:

We are here without many more questions in the chat that I've seen. So, I'd like to ask you in our audience, if you have more questions about depression, anxiety, apathy, loneliness, or isolation before we move on to talk a little bit about homework in our next session. So, and Jori, of course, if you have, if you have things that you think we've missed in this call.

Jori Fleisher:

No, I just think the, you know, I hope someone is watching this and is like, oh my gosh, it's not depression, it's apathy. Oh, right. I hope someone gets that kind of like aha moment. And you know, sometimes there's certainly people who are depressed and are in denial, but I think it's very common in Parkinson's for the care partner. Go, you're depressed. No.

Polly Dawkins:

Are there any somebody ask; Ana asks if there are any depression meds that are contraindicated with Parkinson's or with Parkinson's meds?

Jori Fleisher:

Oh, that's such a great question. Okay. So, I see Ann said, are there depression meds that don't work well with Sinemet? There really are very few interactions with Sinemet. So, with Carbidopa levodopa, that's a great question. However, here is the thing that I usually warn folks about is there is a different class of medications for Parkinson's. So, the MAOB inhibitor, which is Eigne or Rasagiline, Rasagiline is much newer Rasagiline. It also goes by the brand name of act. Okay? So, at much higher doses than we usually use in Parkinson's, saline has a mechanism of action. It can work as an antidepressant. If your loved one is being prescribed that for Parkinson's, they're usually not being prescribed it for depression. We're prescribing at a low level. However, eigne is notorious because it interacts with a ton of things, a ton of other medications, especially antidepressant medications.

And don't ask me why it's weird chemistry aged cheeses, and particularly red wine. So, there are chemicals in there that interact with engine, especially at high doses. Does this mean if your loved one is on a low dose of Eigne, they're on a dose of engine for Parkinson's, but they cannot have a glass of wine? No. Talk with your doctor. Make sure you know, you can ask them, but it does not mean they absolutely cannot. But Eigne does run a risk of what's called serotonin syndrome. So, if person is on engine and is on a higher dose of antidepressant medications, it is not a guarantee that they will get, but there is a risk of what's called serotonin syndrome, which means that even someone with Parkinson's who may be stiff at baseline, they suddenly have a new pattern of being very stiff. They could be very shaky.

They could have a fever; they could be very confused. This is not a like, oh, I wonder if my person's had serotonin syndrome for the last couple of months. No, no, this would be like a woke up one morning and we started this new medicine and all of a sudden something's going on. Okay? But Rasagiline is the newer, newer by, like it's been around still for 15 or 20 years at this point. Rasagiline is a much cleaner version of Line. It's still technically in that same drug class. And so, the f d A put the same warning on reline or ECT that it put on Edline, which basically says, at least in pharmacist language, if you have a patient who is on reline and is on any kind of antidepressant, scare the crap out of them right now, tell them they're going to die.

This has actually been studied extensively the risk of Rasagiline, which the dose is like that. Okay? The Rasagiline dose is very, very, very small, and it does not have the same kind of interactions that Eigne does. And yet I feel like there was a paid course in pharmacy school that everyone attended that was on scare the bejesus out of every person with Parkinson's on Rasagiline and any antidepressant. We commonly have people online and plenty of other Parkinson's meds and antidepressants at low, medium, high doses, and they're just fine. So, if

your MD has not told you this, please take this from me. We are aware if your pharmacist goes, did your doctor tell you? Your doctor knows this is the bane of our existence. We get a thousand calls about just this every day from pharmacy being like, we just want to make sure, you know, we all know now, you know, it is okay if Pharmacy is watching.

Sorry. Yes. Anyone watching? I'm sorry. I'm not, I value our pharmacy colleagues tremendously, but I don't know why this is such a sticking point, because it is like, it's funny to us in a sense because we're like, there are so many other things that interact with each other, like this doesn't, why are you obsessed with this? And why do you keep scaring the crap out of every patient? So, Rasagiline and antidepressants totally fine. Totally fine. And just like any medicine, if you start a new medicine and you suddenly develop some new symptom, let the prescribing doctor know, right? It may be something else going on. It may be the medicine, it may be a known side effect, it may not. But let the prescribing doc know but know that it is okay and more common than not to be on those. Another

Polly Dawkins:

Question about Betsy asks us, are there, since there's not a lot to do pharmacologically with apathy, are there any food or diet approaches that could help with apathy or help boost moods?

Jori Fleisher:

That's a great question. It's probably more of a Kristen question, but I'll tell you what I know from listening to Kristen, our dietician enough. I think the thing that's out there the most that helps is being well hydrated. So, we know that dehydration absolutely makes people feel more fatigued and have a lower mood. So, hydrate, hydrate, hydrate. I say with two caffeinated beverages on my desk and no water bottle hydration really, really is important. And when people are constipated, that can also affect mood. When people are constipated, that can affect absorption of their medicines, including their antidepressants. So, if you can treat the constipation with hydration and good nutrition, lots of fruits and vegetables, right? Getting things to move along, is it directly impacting mood? Probably not. But it's indirectly helping your gut function better, helping energy levels be better. And that should help mood.

Polly Dawkins:

For both your person with Parkinson's and you

Jori Fleisher:

Yeah, for sure.

Polly Dawkins:

Great.

Jori Fleisher:

Yeah, I personally, I saw someone put on their potentially no caffeine, no processed foods. All I will speak to is, I don't take away caffeine from my folks. For some people that is a big quality of life measure. So, I will never take away caffeine. Caffeine can sometimes make tremor worse in the moment. It's not harming you underneath. But if you're very caffeine sensitive and you're very tremor predominant, they might drink their coffee and shake a little bit more. If that doesn't bother them, the person with the tremor don't let it bother you. But if they're drinking a lot of caffeine and they're having trouble sleeping, especially if they're drinking a lot of caffeine and it's getting later in the day, then we adjust it. But yes, Randy, I also agree in all caps with you, I have all of the caffeine right. And so, yes, I don't take away anyone's caffeine. We just move around it, right? Hydrate around it.

Polly Dawkins:

I mean because there is water and coffee. There's

Jori Fleisher:

Water and coffee. Coffee is dehydrating. But decaf is fine. If that's your thing. Half calf can work for some people. Sometimes. I've got folks where we've successfully, we've, we've managed that bridge of like a half calf thing, or every cup of caffeine. They do a cup of decaf as the next one. So, you do you green tea is wonderful also for sure you can get your caffeine fixed there. So,

Polly Dawkins:

Susan asks us about moods and increased issue with moods when starting on insomnia meds. I know you talked a lot about insomnia, meds, and caution there. Can you just talk about moods and insomnia meds?

Jori Fleisher:

I think I would kind of need to know a little bit more of the details of the situation sometimes. So, sometimes if we're treating insomnia, like with something, almost any sleep medicine, basically I try to counsel people and say, listen, we're starting a medicine or we're starting a therapy because you're telling me you're not sleeping well. And they're like, but what are the side effects? I'm like, well, the side effects are you may feel sleepier in the morning because it is a medicine to try to induce more sleep. And so, the first couple of mornings people may feel a bit groggier. They may feel a little bit kind of out of it as their brain is adjusting to that, you know, change in chemistry. So, some, that's often kind of the mood thing that I hear. If people

are really sleeping poorly, I mean, any of us, if we've had a bad night of sleep, you may, you know, have a shorter temper the next day.

You may feel really fatigued; you may feel really down. The sleep deprivation in someone with Parkinson's absolutely impacts not only their mood, but their mobility. So, someone can have a bad night of sleep and their walking is a mess, or their tremor is just much worse. So, you know, I would say that's really important to think about. Oh, can I answer Sharon's question really quickly? Please? Thank you, Sharon. Okay, so is it, Sharon asked, is it better to use melatonin or Tylenol PM for sleep melatonin? So, even though they're available over the counter any medicine that has a PM in it, the PM component is Benadryl or Diphenhydramine. That is an anticholinergic medication that in adults over the age of 60, but especially in people with Parkinson's, that PM component of whatever it is, jacks up the risk of confusion, dehydration, constipation, urinary issues, hallucinations.

So absolutely melatonin, you know, Tylenol PM, Advil PM, or Mucinex PM. We don't want any PM for anyone with Parkinson's. That alone can often wind people up having new confusion, hallucinations, wind people up in the emergency room. And it's one of those things that we think about it as it's over the counter, whatever, it doesn't really count as anything. Please tell your healthcare professionals if your loved one is taking any over the counters. Those are still chemicals that you are introducing into your body that aren't there to start with. We want to know about all of it because those can have a very profound effect.

Polly Dawkins:

We're going to do a deep dive into sleep on October 27th for those of us watching this live. So, we'll get more into sleep issues. Then. I do have one question from Larry in the chat about isolation and avoiding being isolated in their community. Larry says, I'm finding it challenging when meeting new people in our community and how to bring up the Parkinson's issue. Should we just be upfront about it or let it come up on its own? I don't, I realize this is an issue. I don't want to grow isolated in our community and we realize people can be uncomfortable around a person with Parkinson's.

Jori Fleisher:

Yeah, I mean, so first of all, Larry, I think, you know, this is such a common question. It's a really important question, and I think it's a really a common concern of like, how do I bring this up? I think the most important thing is, you know, you're living with it. This is a daily reality for you, for your loved one. I think bringing it up in a very sort of matter-of-fact way and just going like, yeah, you know, my loved one has Parkinson's. You know, sometimes we're running behind or, you know, we might be slow, but we're really excited to be here. You know, can't wait to get to know you, whatever. It's, I would sort of bring it up and then move on, right? Because the more, the bigger of a deal you make it may contribute to some of that stigma that someone might already have.

The more you kind of normalize it, the more it's like, oh, okay. Right. So, I think it's so hard because with Parkinson's, depending on the person and what they've got from the Cheesecake Factory, right? It can be a more obvious thing, right? Many people, they can't hide their Parkinson's, right? But there are other people walking around with other difficult diagnoses that you may never know, right? Because it's not externally obvious maybe, right? And so, sometimes being upfront and disclosing the diagnosis as just part of, you know, hi, I'm me, I've got this. How are you? What do you do for fun? Right? Can also give someone else the space to say, oh, you know, actually I'm living with such and such, right? And so, you may find that the more you tell people, you know, in just that kind of casual, here's what it is next that people open up to you and kind of share some of their challenges, and that may help solidify that community,

Polly Dawkins:

That idea, that idea. Jury, as we wrap up, we have a couple of homework ideas. I bet you have for us. And I, I'm also thinking about the Cheesecake Factory analogy again. And you know, we're talking about this as a choose. What are you choosing to have when you go to Cheesecake Factory? And I wonder if, you know, if for those of us who aren't dealing with lots of symptoms, if we walk into Cheesecake Factory and say to the waiter, just give me whatever you got, you don't actually get to choose what's on that menu. It just happens to you. Yeah. And you might end up with that lettuce wrap with pork in it, and you didn't want that.

Jori Fleisher:

Yeah, totally. It's such a great point, Polly. Obviously, no one is, no one is choosing this. No one is choosing to go to the Parkinson's Cheesecake Factory. No one is choosing to walk in that door, right. And you don't get to choose which symptoms. Right. So,

Polly Dawkins:

The analogy still helps me. It helps me think about it, but I, it just occurred to me like, oh, I would always choose this thing. But you don't get to Yeah.

Jori Fleisher:

Yeah.

Polly Dawkins:

Super joy. Tell us what things that you'd like us to think about as we walk away from today's really important session. Yeah. And before we come back together again next week.

Jori Fleisher:



I think you know, recognizing if you, if you feel like the descriptions of depression, anxiety, or apathy resonated in your loved one or in yourself, just kind of taking the time to acknowledge that in the next week, think about, you know, how is this affecting me? Just kind of going, oh, okay, you know what, maybe they do have anxiety or maybe I have been feeling depressed. Right? If we can put a name to it and know that you're not alone. And then, okay, was there any strategy that jumped out today? Was there any resource? Was there, you know, anything where this could be the next step? Or I'm going to talk with my loved one if I think this is going on. Right? I think that can be really helpful. I think the other thought would be if you are feeling socially isolated, if you are feeling lonely, can you make one connection this week that you wouldn't have otherwise?

Right. Is there someone who you've been meaning to call for a year, right. Or a letter you've been meaning to write or an email you've been sitting on. Can you make one reach out, one connection this week they might not have otherwise? Or is there an activity that you can do? Is there five minutes, 10 minutes? I would love for it to be more. But is there some amount of time that you can carve out for yourself this week to refill your cup, to help cope with any of those symptoms, to feel more connected either to others or to yourself? I think any of those would be great.

Polly Dawkins:

Thank you for that, Jori. Have a great weekend. Everybody in the chat. Thank you for being here. We are so grateful to all of you for showing up and providing us with great questions and connections with each other. We will see you all back in a week's time. Thank you. You well, everyone. Bye. Take care.

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