



Care Partner Training

Session 6: Guild, Anger, Symptom Management, and OFF

Davis Phinney Foundation

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

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

Hello, everybody, and welcome to our sixth session of our Care Partner training. Hello, Dr. Jori Fleischer.

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

Hi, Polly. How are you?

Polly Dawkins:

I'm wonderful. Great to be with you all on a Friday. Today's session is about guilt and anger, symptom management, and OFF, but before we hop into that, I wonder, Jerry, if I could ask you a question that came in in the last week, and it's such a good question for us to think about. Somebody asked, one of our care partners, asked if a person with Parkinson's has apathy, can it rub off on the care partner? And if so, what can I do as a care partner to work on my apathy? I seem to have lost interest in some things that I used to have done in the past. I do some, but it's just not the same without my life partner. Would you be able to comment on that?

Jori Fleisher:

I think it's such a great question. I think it's incredibly common. And I, you know, it might for some people feel like apathy looks like apathy, that loss of motivation to do the things that you used to do. And I almost wonder whether there might be some, what we would call learned helplessness, which is this, you know, you keep trying and trying and trying, and it just feels like you're not getting anywhere. And then it's sort of the like, I guess I don't have the ability to change this, so maybe I should just stop. Maybe it's just easier if I don't, you know, push, and try, and we sort of learn, you know, this idea of I can't, I can't make change. Right? And I think that is incredibly common. I see this so much in so many of our care partners, and I think it's a reflection of the disease.

It is not you; it is not your loved one. The apathy that your loved one has can be so all-consuming and so overpowering that it can feel like you are just, you know, doing the Sisyphus thing. You are trying to push the boulder up the mountain. You are trying to get them on the bike, get them to take their meds, and do the things right? And as the doc, I see them for half

an hour, an hour, and go, “Rah! Rah!” . And they say, I'm going to do it. And then they go home, and you're back to pushing the boulder up the hill, right? I think that's when you put your oxygen mask on yourself first, right? You, it's, you know, all of the analogies, but you can't pour from an empty cup, right? You are not going to be able to motivate your loved one if you don't have something that is giving you fire, that is giving you a reason to get up in the morning, and that you are looking forward to.

And even if that's, you know, something small, right? That's like your cup of coffee in the morning that you have, and no one bugs you for the five minutes, or it's a bike ride, or it's, you know, a phone call to connect with someone, right? Just knowing I have that to look forward to, what's the highlight of my day going to be? What's my intention for today? And all the other stuff that gets in the way and all of the other pushing the boulder up the hill. If that's a day that feels like that, you still have kind of that guiding star of, I got this today, right? And it's, this is finding the small wins, right? So, I might say, and your loved mind might say, sure, I'm going to exercise 30 minutes five times a week. Right? And maybe there's been five days in a row where they did zero, and you got them to do five today, and if you are beating yourself up and going, but she said 30 minutes five times a week, five is not, five is better than zero, five is categorically better than zero. You made the change. Celebrate that win. Right? Don't beat yourself up over that. I was able to make this happen. Maybe tomorrow, I can make it happen again. Maybe tomorrow, I can make it happen better. Maybe tomorrow it's just a bad day. But I know that I was able to do it. And to do that, I think you have to be able to have something that is for you.

Polly Dawkins:

Yeah. That really gets to the core ethos of the Davis Fit Foundation and Davis's mantra that every victory counts. And to sort of pause and notice those small things. And they may be small, they may feel small, but they may be monumental. And to notice them and take time to appreciate the little, little things. Because They'll start adding up if you can start noticing them.

Jori Fleisher:

They do. And I think it's just a whole mind shift, right? It's a whole frame shift of, you know, I'm dealing with this disease, you know, here's the reality, but it's also, I didn't think I could do this. And look, maybe I can do this in a different way. Right? Or we're able to do this together that we couldn't before. We have time for this. You know, what are those small wins? So, I'll tell you, when I have fellows and trainees in my clinic, and we see sort of our most complicated folks and families where other neurologists are like, I don't know what to do here. Every symptom is out of control. Everything is bad. Caregivers are, you know, really burden, and strained like, huh. And in every other clinic, our fellows are supposed to know the diagnosis, right? Or come up with a list of what could be the diagnosis, you know, what am I seeing what's happening?

In our clinic, we usually know the diagnosis, and that's not where the focus is. The focus is what can we do to make this person's better, you know, their quality of life better, where are the small wins? And so, I've told them, like, you don't need to have an answer about anything. You can come and say, here's everything that's going on right now in this person, but the only thing you cannot say in my clinic is there's nothing we can do. I will kick you out of my clinic as a trainee. If you say, there's nothing we can do because it's wrong. They're just fundamentally wrong. And anyone who comes into my clinic and is bringing that energy, I don't want them there because then they're not looking for those small wins. And that's, that's all of it.

Polly Dawkins:

I love that. Thank you, Jori. All right. We are going to shift our focus to this, the focus of the session today, which is talking about guilt and anger, symptom management, and OFF. And some of you may be wondering in the audience, why would you push guilt, anger with symptoms and OFF and some of that, honestly, we did because of scheduling, but some of it is because it actually ends up working pretty well. Because OFF times we hear from you all in the audience can be some of the most frustrating experiences for both you as the care partner and your person with Parkinson's, your loved one. And it may be the reason that some of you had the feelings of guilt and anger and resentment. So, feel free to tell us what you're thinking in the chat, and we'll answer those as we can get to them.

But please remember that when we talk about guilt, anger, and resentment with care partners, some people feel guilty for having those feelings. And we've also heard from our care partners that their person with Parkinson's has the feelings of guilt for doing this. So, there's a lot that we have to tease apart today. But you all who are care partners here, your job is so hard. So, please don't judge yourself for having those feelings and having those feelings of guilt or resentment. You aren't alone. And you're certainly not a bad person for feeling angry or resentful or anything else you may feel. And that time you spend feeling bad is probably not productive time. So, Jo, anything that you'd like to add to that?

Jori Fleisher:

I just echo all of that. I think if we don't normalize that, all of these feelings are part of the experience, right? We don't get anywhere, but the very best care partners are going to be angry at times; the very best care partners might have times every day when they feel angry, right? And they might be angry at the disease, they might be angry at circumstances, they might be angry at people around them for not stepping up. Right? They may feel guilty. All of the things, the very, very best of the care partners I've seen, right? And it's that they acknowledge it, and then you can kind of, then you can kind of move forward, right? If we just bottled up and say like, no, I'm not angry. I'm not angry. I don't know if you've met those folks, but I got a lot of people, I'm not angry, right? Oh, okay. You're just giving off some vibes.

Polly Dawkins:



Some really angry vibes.

Jori Fleisher:

Yeah. I, you know, if it is helpful, I think this is like a magical tool that I didn't know about. But there's something called the feelings wheel. So, all of us have probably seen, you know, those posters that they put up, like in a preschool classroom, of the cartoon faces of, you know, happy, surprised, angry, right? There's like nine or so emotions. There's this feelings wheel, and it's literally this like a color wheel, and it has hundreds. I think of different feelings and emotions. Oh, thank you, Samantha. Samantha found the feelings. Wheel. I actually got this as a blanket, a feelings wheel blanket for my child, who kind of struggles with naming emotions. And I was like, you know what? It's like going from an eight-color box of crayons to a 64-color box. Right? Right. Like, oh, I didn't even know I could do fuchsia. Right? And that's a thing, right? And it's okay to color with fuchsia; it's okay to have this feeling. And sometimes, being able to put the name to it OFF, is it anger? Is it disappointment? Is it, what is it? Sorrow, right? More. I see Betsy said, I feel more sorrow than resentment or anger. Yep. Right? So, being able to identify those feelings and kind of sit and name it for a second, I think, helps with the coping with it.

Polly Dawkins:

Maybe we could ask folks to throw in the chat. Tell us a feeling that relates that may not be in the eight-crayon box, that may be in the 64-crayon box. Tell us what other words that you use for grief. Yeah. Resentment.

Jori Fleisher:

Yeah.

Polly Dawkins:

Sorrow. Isolation. Sadness. Yeah. Fear. Yeah. Worry. Yeah. These, and does anybody feel guilty? I don't see guilt come through, even though that's a topic that we're going to be discussing today. Somebody says feeling in a bubble and cannot get out. Terror. Yeah. Those are some big feelings. Yeah. Anger, joy, what were you saying?

Jori Fleisher:

I was saying Priscilla wrote anger at myself for not being patient enough. Yeah. Sometimes, I think there aren't enough patients in the world for some of these symptoms that are just so challenging.

Polly Dawkins:

Yeah. You may be feeling anger that your life has been so disrupted, and now you have to take care of somebody else. Your imagined future isn't what you thought it would be. Anger that things take longer, and you have to wait. Or that you can't get in to see a clinician that you want to see, and that doesn't seem to be room for you. Yeah. Could you, Jo, talk a little bit about ways you've seen guilt, anger, resentment, some of these beautiful words people are using? Well, beautiful hard words show up for care partners in your clinic or in your in-people's homes when you were visiting.

Jori Fleisher:

Yeah. I think sometimes there's such intense emotion that sometimes I've seen people kind of take that, you know, I feel angry, I feel guilty, or I feel powerless and almost kind of disconnect.

And so, you know, we've had care partners where I might be meeting them years into the disease, years into the condition, and it just seems like we're talking. I've had people literally, you know, we're having a conversation person with Parkinson's is on the screen, for example, care partners sitting right next to them. And then we're in the middle of sort of getting to something really big, and a care partner just kind of gets up and walks away, no explanation, doesn't come back. And I'm just kind of sitting here hanging and going like, was it something I said? Did it, you know, and trying to talk through the next time trying to, you know, send a message and going like, are things okay? Yeah. And sometimes it is just the frustration or the feelings of powerlessness or the feelings of guilt. You know, if I, I'll speak for myself, but I think I speak for most healthcare professionals anytime that we are offering a recommendation, right? This is a suggestion, you and your person with Parkinson's make the decision. Right. And so, I think sometimes I'll ask people, you know, okay, like, how's constipation going? You know, what are we doing for it? And they'll be like, yeah, I know we talked about that last time. I haven't done anything. I, and then I see sort of frustration or anger build.

I'm not upset at like, we get we might, you know, I'm guilty of giving people sometimes 10 recommendations if you tell me 10 problems, I want to fix them all, and I might tell you 10 different things that you could do. There's other stuff in your life and things get in the way. And sometimes I feel like there's a guilt over, you know, I was given all this information, and I didn't do everything that was told to me. You can't possibly, did you do any of it? Did you do something for yourself? That's a win. Right? So, I think that disconnect I think sometimes I've seen a lot of not understanding when a person with Parkinson's is OFF, what they don't have control over what they may or may not be able to do.

So, it's I know you can do this. Come on, let's go, come on, come on, you can. I've seen you do it. And it's almost like, okay, when they're ON, they certainly can, but that, you know, that anger, which seems like it's directed towards the person with Parkinson's is really directed towards that unpredictability and trying to tease that apart. Right? I think that's really tricky. I think the apathy, which I know we talked about last week, but I think the apathy is one of the biggest wedge drivers between people, because care partners are like, but I'm trying to do the

things. We're supposed to do this, we're supposed to do that. We're, I set all this up for you. You just have to do it. And the person doesn't do it. And that can feel like, I have gone through all this trouble. I'm trying to do these things, you know, I've put all the planning, I've done, the logistics I've called, I've done right. And so, that can lead to a lot of anger, frustration, resentment that's really common. The sort of apathy in the middle is really common. Yeah.

Polly Dawkins:

Somebody said that she feels guilty that she didn't get involved sooner.

Jori Fleisher:

I think it's so hard. There are so many people with any diagnosis, right? Who don't want to tell people who don't want to admit or acknowledge the diagnosis, the symptoms that they're having. Don't want to acknowledge any need for help. Right. And I think this, this cuts across men, women, non-binary. Right? There's, I mean, people are not used to asking for help, especially for very, you know, for personal things. I've had, I had a younger gentleman with Parkinson's when I was in my fellowship, and he had a teenage tween age kind of daughter. And I remember that symptoms were obvious to me in terms of his Parkinson's I think noticeable to people out in the public. And we met for over a year where he kept saying, I'm not telling her yet. I'm not telling her yet. I'm not telling my daughter.

And, you know, it was not wanting to put that burden, not wanting to worry, right. And just, it was just an example of that sort of keeping things inside. And meanwhile, that very smart 12-year-old, someone when he finally told her, burst out in tears because she was convinced that he had cancer and was dying imminently. And that if something wasn't being said, and she was clearly seeing changes that they were holding something really bad from her and so, she was coping with her own guilt of why are they not telling me and what the, you know, all the terror. Right? And so, you can't feel guilty if someone is not letting you help.

You can't feel guilty if you know the person in one capacity and they're strong and they do everything for themselves, and they don't ask for help, and they wouldn't accept it. And you're going along in that vein, right? It's in the past, you can do what you can do now, and you can only do what someone lets you do.

Polly Dawkins:

Well, and for many of our care partners, I hear they're the ones who are still working and managing house and family, that there's not a lot of extra capacity to, to do the caring, the caregiving in the initial phases.

Jori Fleisher:

Yeah. That's, and a lot of, you know, I see a lot of folks where first several years, you know, and some, many, many years they're coming on their own. Right. And I've never met any of the family. I may have heard about them, you know, and sometimes I'm kind of wondering, I'm offering recommendations like, are you discussing this with anyone around you? Or what's, you know, what's kind of being said at the dinner table? Like, what'd the doctor say? I'm fine. Right. If I was to fly on the wall, I

Polly Dawkins:

I might disagree with that, you know,

Jori Fleisher:

That's what I said. Or like, you're fine. And right. So, you can't change time, you can't go back. You can't be in the room, you know, if you weren't invited to be in the room. But you can offer the support of here's what I can do now.

Polly Dawkins:

What do you, how have you seen, or do you recommend that care partners can manage anger or the resentment that they might feel?

Jori Fleisher:

I think everyone needs to find some outlet that isn't directed at their person with Parkinson's. You know, in a similar vein to if you've raised little kids, little kids can be tremendously frustrating, right? I get really fed up. There are things I might want to say, right? But I can't say them to my kids or my puppy. Right. You have to, where can you put that energy,

Polly Dawkins:

Right?

Jori Fleisher:

So, you know, that might be going into another room and screaming into a pillow that might be going out into the garden and just taking it out with, you know, a spade or a trowel on the dirt, right? That may be going for a run or getting on a bike and just metabolizing the stuff.

You know, some people, like, I've heard the term procrastinate, right? There's something else that you should be doing, but instead you're like, I could eat cookies. Right. So, if you can convert, you know, that negative energy into, I'm just going to bake something and whisk the crap out of something, right? Whatever that looks like for you. Right? And for some people, they can take anger and they may sit and meditate, they may breathe, right? there are lots of

guided meditations and things like that. Some that are specifically focused on coping with really powerful, really negative emotions. I see someone put; journaling really helps punching a punching bag. Absolutely. you know there's a great book. It is not at all specific to Parkinson's but there's a book, and I'll throw this in here. So, Matt Hague is the author, and it's called The Comfort Book.

I think it's terrific. Some of the chapters are literally like two sentences. Some are page or paragraph; some are a little bit longer. But he is an author. He's written some great nonfiction, and also, I think of autobiography of some sorts, but has struggled with depression and a lot of really difficult life situations. And it's kind of come out the other side with a lot of positive psychology and things. But this book, I've given this as a gift to other people, is just like, when you just need a moment to yourself, it's like the literary equivalent of like a cup of tea or hot cocoa. And it could be you just flip through the book at random and you just pick a chapter and read. I like that one. That's helped some folks.

Polly Dawkins:

That's a good one. You mentioned journaling. Somebody asks a question if you've gotten yourself in pat asks this question to everybody. If you've gotten in this position and you've gotten everything set up and your person with Parkinson's is just extremely resistant, how do you manage This happens every day. It usually happens if I have someplace to go with my person doctor's appointments where there's a deadline.

Jori Fleisher:

Yeah. So, I'll tell you, Pat, there's no easy answer and you are not alone. And I hear this every single day. And I think it's very dependent on each individual person. Sometimes, you know, if there is, if there is a doctor's appointment, if there is a deadline, if there's a thing that has to happen that day trying to take anything else out of the day, if you know that it's a struggle to get to anything, make it that one thing. And maybe it's, you know, it's mentioned the day before or two days before, kind of depends on your loved one and what their level of anxiety around appointments might be. But maybe it's just written out, you know, it's on the whiteboard or it's on the calendar. The appointments at three, we're going to leave the house at two dressed and ready by one 30. Right?

And it's just the night before, I need you dressed and ready by one 30. Right? And maybe in the morning it's sort of, here's the heads up, and you give them that freedom until you get to one o'clock or so. And if you know it's going to take an hour, this is the thing that we're doing today. And after this, you can do what you want. But this is, we've made a commitment. We have to do this. Right? You can blame if it's a doctor's appointment, blame the doctors. If we don't go today, we're not going to get in for another six months. They're booked up. It's crazy, right? Whatever you have to do. But if there's a day where there's an appointment and there's also, you know, a haircut and there's also a PT or a trainer's coming or something like that, maybe

you plan ahead and just go, you know what, let's move the haircut to a different day. Let's, let's reconfigure. And I'm not above incentivizing, so if there's something that brings your loved one joy, right, we'll stop on the way home and get a milkshake, we will stop on the way home. And you know what? It's actually close to like the kids' baseball game, or it's close to the movies. How about we go see something afterwards?

Polly Dawkins:

Yeah. Boy, those are hard, really hard situations, Pat and some others are in. As somebody is saying, you know, find a caregiver support group, and that might, that might be helpful for you. Yeah. Yeah.

Jori Fleisher:

I see Marian said, it's okay if you do not get all your to-dos done. Hallelujah. Yes. Give yourself permission to leave some things un undo.

Polly Dawkins:

And Pat's extension question is, but how do I, how do I manage myself when I, that he knows it's important and it's the one thing at the anger part that she's experiencing.

Jori Fleisher:

Good. Go take a break. Two minutes, 90 seconds, go breathe in another room. Go ball your fists up, squeeze every muscle in the body as hard as you can for five or 10 seconds, and then let go. Go punch a pillow. Go take yourself out of that space. Get it out. Let yourself give yourself permission to scream as loud as you want into a pillow to punch something to do, you know something and get it out.

Polly Dawkins:

So, as we move on in this topic, the big question is what to do about all the anger, guilt, and resentment that our loved one may feel. Do you have any recommendations for our audience on how they can deal with that since they're the ones who takes on the feelings that their loved one puts out towards them?

Jori Fleisher:

Yeah, I think, I mean, some of it is the same thing. I think there's a lot of stigmata around having a diagnosis around all the different symptoms, giving someone permission to name that and to normalize it, right? Like, no feelings are bad feelings. It is okay to feel what their feeling. And if you can be that safe space where they, you know, can say, I feel really angry, I'm really upset, you know, this is not fair. You're right. And just to sit with them and be there, you're not going



to take it away, right? They just to let them vent. That is huge. Many people do really well. Talking with a counselor, talking with a therapist, acknowledging that that is a common thing that's been shown to be helpful in Parkinson's, right? And it's not a marker of weakness. It is a marker of strength, right?

Here is this thing I'm coping with, here is something that can help me. I will go do that thing. You know, sometimes if that is just a no go and you're like, my loved one is never going to talk to someone about this, they are only going to talk to me, cool. Then find that support group or step back from that. I've got lots of people, I feel like I tend to hear this more from my men with Parkinson's. I'm not going to go sit around and sit in a circle, okay? Not every support group sits in a circle. But fine. You don't want to sit around and cool, go box, go to a boxing class, go to a karate class, go to you know, Parkinson's exercise class, if at all possible, right? Because so many times it is an informal support group without naming it, that people will find friendships and find mentorships from someone who's been going through it, where they will never go to a support group.

They will never go see a therapist, but they will talk to John and Bond. And maybe it's a couple of sessions, maybe it's a year of never even naming it before someone finally gets around to going, you know what? This thing sucks. Yeah, it does. And I've seen friendships blossom, but I've also seen like informal therapist duos blossom Yeah. Between people with Parkinson's, because it's a safe space, right? You as a care partner are often a safe space. But I hear this all the time, even in the clinic room, you know, you can't know what this is like. And it's true. We can't, if we don't have Parkinson's and every, every person with Parkinson's is different. No two pa you know, no two of my patients know exactly what the other person is going through, but they have a little bit more of a sense. And so, just to be able to feel that safe space and say like, look, today I'm just having an OFF day to someone who gets what they mean by saying, I am having an OFF day. And they know that doesn't mean that tomorrow is going to be an OFF day and that this isn't who they are or who they were or who they'll be,

Polly Dawkins:

Right? Right. We also at the Davis Spinney Foundation have, I think it's 108 individuals who serve as ambassador leaders. And those individuals are available. Some of those individuals are care partners. Some of those individuals are people with Parkinson's. Others are support group leaders or exercise professionals. Feel free to use that resource, and you don't have to be living near that person. We learned in the last three years that when we couldn't meet, we couldn't be in our support group, or we couldn't be at our exercise class, even having a phone call, even having a zoom, even though we're tired of looking at our own faces. Even having that type of interaction with somebody else's jury, as you said, who really gets it? Who understands where you are? So, please feel free to use that resource for folks who feel like you just don't have it near you.

Jori Fleisher:

And I saw, so Larry put into the comments, some people with Parkinson's can't acknowledge the real emotions PD brings with it, and then take out their suppressed emotions on their care partner, which is spot on. And I would say sometimes the flip happens too. Care partners can't kind of acknowledge Right. And are taken out of the person. Any suggestions on coping with this situation? So, number one way to go, Larry, because you're recognizing that that's a thing. So, that's already, you're already advanced placement territory, right? And so, I would say, you know, if you, if you know that this is going on, and I think this is like a therapy kind of trick, but you can try it out and play with it and see how it feels, right? Is to say the, you know, I hear you saying this, or I hear you, you know, complaining about this.

When I hear that I feel angry on your behalf, I feel sad, I feel frustrated, whatever you feel, right? Is that, is that how you're feeling? So, you can use that kind of, I feel statement, but in relation to what you're hearing from them, I hear you complaining about X, Y, Z. I feel disappointed that we can't do this thing we were looking forward to, or I feel guilty that, you know, this is that, you know, giving someone permission to use I feel statements. To use the emotions and the feelings wheel to be able to express it, I think if you can model that and your person with Parkinson's may pick up on that could go the wrong way. They could think that you're trying to be a therapist and it could them OFF. So, if that happens, just, you know, we try something else. But it doesn't mean you aren't allowed to express your feelings, right? So, it doesn't be, I hear you, is this how you're feeling? But you can say, anytime I'm feeling frustrated right now, I'm feeling sad, I'm feeling really proud that we just did this thing. I just wanted to let you know,

Polly Dawkins:

I hear some of our care partners say that it's the loved one who feels guilty and how to deal with their loved ones. Guilt. Guilt for putting, for having Parkinson's, and for putting them in the position of being a care partner. Caregiver. Do you have any thoughts on that?

Jori Fleisher:

I think it's really difficult. I think this is one that I struggle with in clinic a lot. And where I've found to be really helpful is turning to my colleagues in chaplaincy and turning to our colleagues in faith communities. If that's something that resonates with that person. Because a lot of times the guilt sometimes is why me? What did I do? I must have done something to make this happen. And, you know, I'm, I'm not a chaplain. I'm, you know, not, you know, any kind of those personnel. It's not my place to say any of that. Right. And sometimes one of our spiritual, you know, guides and advisors can be more helpful on that front. If a person come, you know, has a faith-based community that's important to them, I think just reassuring them there's nothing that you did to make this happen. Yeah. And what I hear a lot, what gets me every time in clinic is, you know, someone will say, I feel really bad that she has to do this for me. I feel really bad that I'm putting this burden on him. And the number of times that the care partner like looks at them and goes, you'd be doing the same for me.

I think just putting that out there and just for the person with Parkinson's to hear that right? That if the tables were turned, they'd be doing the same for you. Right? And this is, this is what that partnership means, whether it's you're an adult child to a parent, whether you're a spouse or significant other or partner, right? You're in it. And so, I think just reminding them that this is, you're there with them.

Polly Dawkins:

I've also seen that anger from a care partner towards their loved one really about symptoms like anger at the symptoms and then that makes the symptoms get worse and it sort of exacerbates, it's sort of a vicious cycle. Yeah. Any thoughts on how to break that? Or if you're angry at the person's inability to speak or inability to Yeah, it's usually around communication is what I see.

Jori Fleisher:

Yeah. I would do the, I need a minute. Okay, for your own sanity and wellbeing, I need a minute. Maybe it's just the walk around. Maybe it's just, you know, just go take that emotional lap. Maybe it's going to another room. But you're absolutely right because if someone with Parkinson's is anxious and they're being pushed, or we have to go, we have to go, you know, stop, stop, stop. You know, we need to do the thing. The more you push someone who's anxious, the worse the anxiety is going to get. It is those terrible old like goody bag things, the like finger traps where like the more you struggle, the tighter it gets. Hopefully people know what I'm talking about. That thing that is the anxiety, that is the freezing of gait is the more someone with Parkinson's is anxious, hyped up, nervous, any really, you know, extreme negative feelings or even extreme positive feelings can make the Parkinson's symptoms worse.

So, someone's caught in traffic, their tremor, is going to get worse, their dyskinesia is going to get worse. Even if there's like a game on TV and you're cheering for your favorite sports team and like they score a touchdown, right? The tremor could come out even more in that moment that we're not as worried about as much when it's good emotions driving symptoms. But if you are arguing with your loved one about their anxiety, you know, not intentionally arguing, but you're trying to allay their anxiety and you're seeing that it's just feeding the beast, stop, take that step away. Scream, punch something, whatever, don't hurt yourself. Right? but you know, take that distance for the second if it's hallucinations, if it's delusions, all the more, I just had a really difficult phone conversation yesterday with someone who feels that they've heard the message of you can't argue with hallucinations.

And then went on to describe, here's how I tried to talk the person out of the hallucinations that they were having and was so frustrated that it wasn't working and so, upset. You know? And just why aren't they getting it? Because they, a minute ago, they seem to get it. So, if I could just, you know, say it the way that I said it before, say it more loudly, they'll get it. And it's again, you know, whether it's a motor OFF or whether it's a hallucination, we can't move

people out of these. It's their brain doing it. You have to find a way around or take a minute and come.

Polly Dawkins:

Ellen has a comment that many people have responded to. She says, the one that really gets me is in quote, you should really quote better with your feelings and take good care of yourself. If I hear that one more time or you have to put the oxygen mask on first, I might scream because when I'm really stressed, I interpret all of this coming with an expectation that I need to fix myself just for having these normal emotions. It feels like they just can't hear how difficult things are and have to give me that as a suggestion to fix it. And he and yeah.

Jori Fleisher:

Yes. And I'm sorry because I know we've used the oxygen mask thing and pouring from an empty cup as well. And while I mean those things because they are true, you're a hundred percent right, right? Like that it does not help, and it does sort of put the onus back on you and add one more thing to your to-do list, I hope it's clear, you know, by session six, that is not what the intent of any of this is. Right? We see how hard people are working to the extent that we can as folks who are not doing it day in and day out, right? It is only recognizing that there is so much on your plate. And if that means that you have to let something drop OFF, something is not done as well, or something is just left undone, if you need to hear the permission to please let something be undone so you can do for you, please do that. Right? The laundry can sit, no one is going to care if something is wrinkled. If you have cereal for two or three meals, great, right? Like whatever that is, you know, what does, what does not perfect look like?

That's fine. Give yourself permission that if something has to downshift a little bit so that you can go in the other room, right? Maybe it just means you throw on tv even though you know your loved one doesn't do as well. If they're sitting and watching on a screen, it's okay because you need to be okay. So, please give yourself that permission and you can tell people if you feel like they're telling you, you know, do this stuff, whatever you have, you have all of our permission now that you need it to say, what I need from you is what would help me right now is right. And maybe that's, can you just sit, can you just be here? Can you take her to this thing? Could you pick up the groceries? That would really help me feel better. That would help me put my oxygen mask on myself. Not you are telling me that, but you are picking up the groceries.

Polly Dawkins:

Yeah. Marian asks us if he, or she. I'm not sure. He says sometimes I'm concerned that my partner with Parkinson's doesn't pick up on my emotions. Is there an aspect of this illness that makes emotional connection go away?

Jori Fleisher:

That's a great question, Marian. I think there may be different things that can be going on. So, I do hear this, I see this a lot in front of me is care partners kind of expressing all of the things and the person with Parkinson's seems sort of not particularly stressed by it, kind of not, you know sometimes that's the apathy is it's just that diminished responsiveness, the diminished sort of motivation. Sometimes it is as simple, it's not super simple. But this was pointed out to me by a care partner who said, talking about her husband with Parkinson's. He doesn't look at me. He thinks that we're making eye contact, we're having a conversation and he'll just be looking off over here and I'm over here. And it was really upsetting to her, and it was really frustrating, and it happened. It didn't happen overnight.

It was so insidious and so slow, right? That it just, it's sort of, that's how communication was. And she kind of had this moment of going, he's not looking to at me when we talk. And so, she recognized this, and now, before there's any sort of communication, says, I need to see your eyes, look at me, look at my face. And then they'll go on from there. So, I would start with taking that step back and thinking about, is your loved one actually making eye contact with you? Because if they're not making eye contact and you know, they're kind of directed somewhere else, let alone if there's apathy or other things, they are not going to register your emotions. Right? But you can start by, at least, make eye contact, are you with me? And some of it may be the attention changes that go on. Some of it may be the multitasking is if you're talking about a complex task, they might be able to pay attention to the words you're saying, but not pick up on the emotion or vice versa. But maybe not both.

Polly Dawkins:

Thank you. That was helpful. Are there any questions that you've seen or topics that you think we should address when it comes to anger and guilt before we shift to symptom management and OFF?

Jori Fleisher:

Yeah, I think I don't remember who said it, but I saw something in the chat before about what about, you know, what if the person with Parkinson's anger is channeled towards you? Right. And I want to make a really important point. Sorry. The pink line is out my window. So, if you're hearing weird noises, I can't control the pink line and I tried to fix the lighting. I know it's bad. It's not working today. Sorry, I completely lost my train of thought about the anger. So, we knew that anger can be a problem. And the more people have started asking about this in Parkinson's, the more we know that, at least in folks with more advanced disease, so people who had Parkinson's going on for longer. So, there are more years of experience, the prevalence, how common physical aggression from the person with Parkinson's towards a care partner approaches 65%, 65% of people with Parkinson's at some point in time may lash out strike, try to hit, try to hurt.

And it's usually directed at, you know, the primary caregiver or someone close to them. Again, this is part of the disease and doesn't make it. Okay. And if this is happening, tell your healthcare team, tell the person's neurologist, right? Because it could be coming from lots of different places. It may be coming emotionally, right? They're depressed, they're anxious, and they just don't have the words to say it. And you are the closest target. They feel safe with you. So, they can express that full anger. And it's coming out in a physical way. It is okay that you are a safe space. It is not okay for them to be violent. Yeah. Similarly, the rate of sexual aggression is probably 25% or higher.

So, if this is happening, it is not you, you did not do anything to deserve this. You do not need to tolerate it, but you do need to get help. So, tell your loved one's neurologist. This is absolutely one of the things that if they are going to the doctor on their own, don't expect that they're telling me. If you're not there to tell me this is going on, please go with them. Please. You can always, you know, as we're stepping out of the door, I just have one other question. I, I'll follow you out. People do it all the time. We don't love it. because We're usually running behind and we don't want to have sensitive conversations in a hallway. Send a message ahead of time, right? Send a phone call, something, but let the team know that's going on. It may be a medication adjustment that needs to happen. Your loved one could be in pain and is unable to express that pain. Right? They could be depressed; they could be anxious. We can treat those things. So, you should have a punching bag. You cannot be a punching bag.

Polly Dawkins:

Thank you for bringing up those topics. And the question about accusations, about infidelity. Yeah. We look to that in the next session, aren't we?

Jori Fleisher:

I think we are. I think it's slated for the delusions and hallucinations talk. Yeah. So, Priscilla, hang in there with us because that's a big topic. You are not alone. It has a name. And we can treat it. So, there, because I know we got a lot to cover today.

Polly Dawkins:

Yeah. We're going to, yeah. Put a pin in that. But it might feel like a jarring shift to talk about symptom management and OFF, but I'm hopeful that you all in the audience will bear with us and understand that there is, there is a thread that we might be able to pull through these topics. So, let's talk about symptom management and specifically OFF for those I, I'm sure most people in the audience have been living ON/OFF for years, if not decades. But for those who might be new to this, can you just share a brief definition of medication fluctuation or ON/OFF and how that might show up in a person?

Jori Fleisher:

Yeah, so I will say it's number one, not everyone with Parkinson's has motor fluctuations or ONs and OFFs. So, if your loved one has had Parkinson's for years and years and you're like, I don't really know what they're talking about still, but that's okay, you're still welcome, can still be Parkinson's. But for many people when they are, they have their symptoms, their stiffness, their slowness, their tremor if they have it their changes in walking with right now just thinking about motor symptoms. So, those kind of things for many people, they may be going on for a while and at some point, they reach a level where they say, you know, yes, I'm ready to start medication for this. And they start the medication and hopefully many of those things get better, right? And the doc, you know, the provider says take this medicine.

If we're talking about levodopa or something like that, it's typically, you know, take this pill three times a day spaced evenly during the hours you're awake. Not because we like to annoy you with lots of meds, but because the meds just don't last all day long. You need them in your system. And the reason is everyone with Parkinson's is still making some dopamine in their brain, but they used to be making a level that was up here. The rest of us that don't have Parkinson's, we're making this level of dopamine up here. But as time goes on, dopamine level has come down and down and down and down. And what happens is when we start the medication, the medication is giving them dopamine, kind of boosting up the level of dopamine in their brain. But just like taking an ibuprofen for a headache, it's there for a couple of hours and then it's metabolized and gone a couple of hours later.

So, the dopamine level goes up, up, up, up, up, up, and it's a nice curve and then it comes down, down, down, down, down. And we go back to right where we started to their kind of baseline level. And then you take the next dose, and we go up. Then we go down again early on in the course of disease and early on in the course of taking the meds, you may not feel those ups and downs at all because the person has kind of been living with this low level of dopamine until they kind of got diagnosed. And then boom, we start the medicine. And even though the medicine does this in the system, there is still some lingering all the time. They do kind of add up on top of each other. And so, just, you know, as long as we've sort of got those hills going, we're above the threshold where a person feels good.

And so, they're staying above that threshold. And even if the blood levels and brain levels of dopamine are going like this, the person is just feeling a steady level of, you know, not good before I took the med. And they're like, better. Okay. And that, that phase can last years. So, that phase can last 2, 3, 4, 5 years where we find the right med, we find the right dosing. And people would describe this as a honeymoon phase because things are good and you should see that, you know, from the time that you start the medicine, the person is doing better, right? The medicine is not curing the disease underneath, but it's covering up the symptoms. But what happens as time goes on, I got lots of analogies for this. what happens as time goes on is I have people come back and tell me, oh, we've gotten to that point that Uncle Google told me what happened.

The meds have worn OFF, they've stopped working. Okay, I've told you how I feel about Uncle Google. He did not graduate from medical school. Okay? So, what's happened is, and usually I've got a slide for this, but I can't pull it up quickly enough to share it. So, if you imagine that the person's dopamine level is slowly decreasing over time, okay? And no, we don't have a good way to measure brain dopamine. I wish we had like a dipstick that we could just be like, ah, here's where you are. Here's how much you need to get back to normal. We don't have that. Okay? So, the way that we know what's the right amount of medication is seeing how the person responds. All the taps and the claps and the wiggles and the, all that kind of stuff, we're looking at their exam to see are they better and how do you feel?

Are you feeling better? Are you able to do the things you want to do? Right? So, the person's dopamine level is maybe here we're adding back medicine in the big picture to try to big bring them close to their baseline function-wise. But as time goes on, their own dopamine level that they're making is still lowering over time. Well, if we keep adding the same amount of medicine on top, it's like $A + B = C$, but now we've got $A - \text{something}$ over time. If B is still the same, then we're not reaching C anymore. So, it's kind of this math problem that's slow moving over time. And so, we need to keep pace by adding whatever we're missing an A onto B, which means we're, you know, changing the dose of the medications. What also happens is that as time goes on, the person's brain needs to see more dopamine to get over that threshold where they feel good.

And this is where we start to get into ONs and OFFs because before when they might have taken the pill first thing in the morning, within 1530 minutes, they're kind of in that good zone, and they just feel good all the time, right? Relatively. Now it might take longer, and they might be slow, stiff, shakier for 30, 45 minutes, and then we're okay for a while and then we start to look at our watch because it seems like it's getting to be time because the tremor the stiffness or the slowness or the shuffling of gait is coming back. Yeah. So, when the meds have worn off when we're sort of back to our own native dopamine level, that's OFF. And for some people, it's kind of a gradual, and for some people, it can look like someone has flipped a switch that you can tell when they're, they've gone from OFF to ON and they've gone from ON to OFF.

Polly Dawkins:

And I've heard about partial ON and partial OFF. Can you describe what that or dose failure?

Jori Fleisher:

Yeah. So, let's start with dose failure. So, dose failure is kind of easier, which means you know that the person took their pill, you watched it, you saw it happen, and yet either the med sort of kicks on or then it's just like it's gone. Someone flipped the switch way earlier than they normally are OFF, or you know, they took that dose, and it never kicked in, right? So, what is going on? Then? Most often, what's happening is the person took their pill in close proximity in close range to a protein heavy meal. And I am going to like to put the warning out here that this

is also another like uncle Google has lots to say on protein and Parkinson's and we disagree heavily. But what we do know is that protein is absorbed at the same spot in the gut as levodopa.

However, for many people with Parkinson's for a long time, they can take their levodopa. If this really doesn't apply to any of the other meds besides levodopa, okay, they can take their levodopa, they can have a burger protein and be okay, the meds kick in, they do fine. Why is that possible? So, the gut is taking both things in at the same time and is always having to choose a little bit. But if that person already, you know, their dopamine's here, we're giving them this much. If they only absorb this much, if they absorb 95 milligrams instead of a hundred milligrams, they're still well enough into the ON-zone that it doesn't really make a big difference. Okay? And for some people it will never become a problem. But for other people, I picture like, you know, when you go to the mall, those automatic doors they open, right? And lots of people can go through at once. That's kind of what the protein levodopa thing is like in the gut for many years. But for some people, at some point in time that automatic door is replaced by revolving door. And the way that we know that is the person was okay taking their levodopa with food.

For a while, right? They did great and now suddenly we're seeing dose failures where that pill, that dose did not kick in. And what we want to do is keep tabs, when did they have a dose failure? What did they eat close to that time? When did they take their last meds? And if you can, you know, for three days, keep tabs and go, okay, they take their 7:00 AM dose on an empty stomach that seems always to kick in. reliably They take their noon dose; it's not kicking in and they take a five o'clock dose. The times are random. You know, they take a five o'clock dose and that always kicks in. And my question is, well when are they eating? Oh, well they're eating breakfast at eight an hour after the seven, they're eating lunch at noon with the 12 o'clock dose and they're eating dinner at six 30 far away from the five o'clock dose.

Then we say, okay, we're starting to get that food interaction. This does not mean that your loved one should stop eating protein. I'm going to repeat that. Do not stop giving them protein. they will lose muscle mass. They will lose weight unintentionally. That puts them at high risk of falls and fractures. We don't cut out protein if that happens. And only if this is happening, we scoot the times of the doses or we scoot the times of when a person is eating protein away from the medication timing. But I have so many people who have had dose failures go online, Uncle Google says, ah, protein, it's the protein, and they cut out protein and they come to me, and they have lost weight. They're wasting away. And that is the worst situation to be in, be so tell your provider if your loved one is having dose failures or partial ONs is sort of that splitting the difference of its working, but it's only working for a little bit of time.

It's not working nearly as well as it should. That always makes us think about what are you taking around the time of that. Another thing that can cause dose failures. If you take an iron supplement iron blocks the absorption of levodopa and also worsens constipation. So, if you



need to be taking an iron supplement, again, just like the protein does not mean, Dr. Fleischer is not saying Stop your iron supplements. I am saying take it at a different time away from your levodopa. And if you need to be taking iron, know it's going to make the constipation worse. Adjust accordingly.

Polly Dawkins:

So, this sort of cycle of as, as per Parkinson's progresses of ON/OFF can lead to frustration and stress for care partners.

Jori Fleisher:

Yeah.

Polly Dawkins:

And especially as OFF times become more frequent and you're dealing with more troublesome symptoms.

Jori Fleisher:

Yeah.

Polly Dawkins:

Yeah. So, that's, this is sort of where these emotions and symptoms get wrapped together in one. Yeah,

Jori Fleisher:

I think, I mean, I think a couple of things. Sometimes the person with Parkinson's may be less aware of patterns in their timing and their response to medicine than you might be as the outside observer because again, like so many things, their brain is getting used to it. Their brain is adjusting. So, they may not recognize that like, oh, about 45 minutes after a dose, my tremor goes away, or my walking is better. But if you are observing that, you're observing it, you're, you know, you're probably right. If you track it for a day or so, two, three days, you just keep a little diary of like, they took their pill at this time. They seem to be better at this time, and they seem to be worse at this time. You know, this many minutes. That can be really helpful, especially if you're planning outings, if you're planning activities, if you know that there's something that's scheduled a time when your loved one is consistently OFF,

Polly Dawkins:

Yeah.

Jori Fleisher:

Try to reschedule because you're just going to get into the, "we're late, you're not moving, I know you can move." Come on, we have to go, we have to go, we have to go. And if someone is OFF, you're just, it is spinning the tire and you're stuck in the rut. Like you're just digging yourself in further. And also, if your loved one is consistently having off time tell they're treating neurologist we can't, I mean, we usually can't get perfect. But if they've got, you know, more than an hour or so of off time before the next dose, every single time, tell them, tell the neurologist, and thank you. I see Sam is putting different worksheets to track symptoms. There's something called a motor diary, the Hauser motor diary. It's pretty annoying to keep track of. It's literally like every hour or every half hour that you're supposed to like check when you took a dose and then indicate for that half hour or hour time period.

Is the person OFF? Are they ON and doing well, or are they ON and have bothersome dyskinesia? Sort of those extra fidgety, wiggly movements. If they're on, and they got a little bit of fidgeting and wiggling, but it does not bother them, it could bother you. But the dyskinesias, if they're not bothering the person, I would call that still on. Right. And so, if you can track, you know, it's really helpful to me to look at sort of one of those motor diaries and go, oh, okay, we've got the meds scheduled every five hours, but the person takes it, they kick in within half an hour, but then they're getting three hours and then they're off. So, that can be really helpful if I see that I know how to adjust the meds.

Polly Dawkins:

And how many, how many weeks of data would you like to see? Knowing it is an annoying thing to have to do.

Jori Fleisher:

It is an annoying thing to do. If I could get three days, even five days only, because we know every day can be so different, but three to five days, you know, and marking down, here's when meds were taken, here's when a meal was taken, and OFFs, ONs, whatever. We kind of think, a lot of us think in terms of that curve of the meds are on, the meds are OFF, the symptoms are this, the symptoms are that oh, so the title it's the Hauser Motor Diary. Dr. Hauser is a movement disorder specialist. So, he created this, we use it a lot in clinical trials. I'm trying to see if I find a good example.

I think, yeah. I don't know if we can share this. Let's see. Yep. I think we've, yep. Same one. Super same idea. There are other ways that people format this on a page. It is annoying. It is annoying to look at this for you. I get very overwhelmed. Don't, don't bring in 20 days of this. because That's going to be our whole visit. And I want to hear the other things that are going on, but if that's kind of the focus, you know, we're having lots of ONs and OFFs, this can be tremendously helpful. And no one is going to remember what happened at 3:30 PM last



Tuesday. Right. So, I don't you won't, don't just put it down. Give yourself those couple of days to do that.

Polly Dawkins:

That's good to know. I can't even know what day it is today,

Jori Fleisher:

I think. Oh yeah, yeah. It's Friday. I see someone asked a question about like can we address if Rytary or other things are as effective? So, so the challenge is, you know, all of us are kind of waiting for the holy grail which is hopefully there's a cure and short of a cure until then, why can't we have some way of giving someone dopamine back that mimics the way that their brain does it? So, a slow steady 24 7 release Right. Would help in so many different ways. We don't have that yet. So, what we have right now, and this will change soon, so asterisk, TBD Hope on the horizon right now the most common and the most predictable and the most easily manageable way that we can adjust things is with regular old immediate release carbidopa levodopa. So, usually that's 25 dash 100, or it's you know, different formulation, but that's the most common dose.

It lasts about four hours in a person's bloodstream. It has to go from the bloodstream to the brain. There are other formulations of this. So, there is what's called Sinemet. So, Sinemet is an old brand name for Carbidopa levodopa. It doesn't even really come in brand anymore because it's been around for so many decades. It's just easier for the rest of us to say Sinemet instead of Carbidopa levodopa 375 times in a day. And in case you're wondering, or if you're someone who cares about etymology, it's called sine because when they added Carbidopa to levodopa, levodopa is the dopamine. Once it gets to your brain, it's dopamine. If we just give you a big amount of dopamine, takes a lot to get it to the brain and it causes a lot of nausea. The Latin root of which is emesis. So, when they figured out that they could add in this other little enzyme carbidopa and put that attached to a smaller amount of levodopa, it's like the booster rocket on the spaceship.

We just add this little thing, it gets the rocket where it needs to go, and then this other thing falls off. We don't care about it. We don't know what happens to that. So, the carbidopa, the 25 of the 25 dash 100 is getting it where it needs to go and preventing the nausea or the emesis. So, sin without emesis vomiting, Sinemet, there you go. That's why it's called that. That's why we refer to it as that. But you can call whatever you want. There is a Sinemet CR, which is supposed to stand for controlled release most movement disorders think it calls for think it stands for crappy release. It is a little bit longer lasting, but not by a ton. And it's a little bit unpredictable. So, when, when will I use Sinemet? Most of the time if someone is going to bed, okay, but they're waking up within a few hours of bedtime and they're having motor symptoms that are making it difficult for them to get to the bathroom.

If that's why they're waking up. If someone goes to bed at 10 and they take a Sinemet CR at 10 and they wake up at 1:00 AM it's probably still going to be on board, if they take it at nine and they're waking up at two or three in the morning, it's not going to be on board anymore. It's, that's still going to have worn off. Right. So, it's longer acting, but not super longer Acting Rytary, which I think Larry had asked about, is the same Carbidopa levodopa. It is the same molecules, but inside a large capsule. And they're large. There is some of the immediate release, some of the controlled crappy release and pellets of the controlled release that are covered in like Jawbreaker film so that they dissolve a little bit later. So, you basically get like a wham bam. So, pharmacokinetically, you're supposed to get a fairly quick kick in just like the regular yellow pills, but you've got an afterburner that should last longer. So, hypothetically it should be much longer lasting. And it is longer lasting than the yellow pill. The problem with Rytary is it's still kind of unpredictable. And all of us hoped when it was coming out that this was going to be like a once a day, twice a day kind of thing. And in the clinical trial that got it approved, the average number of times that a person had to take Rytary in a day was 3.6.

So, if your loved one is taking the pill three or four times a day, this is not saving you anything. And in fact, it is very expensive. So, it can be hard to kind of get that timing right. But does it last longer and is it a good answer for some people? Some of the time, yes. Just like lots of different things that we have for Parkinson's can be a great option for the right person, not right for someone else.

Polly Dawkins:

Great. We've got some questions about OFF times and what symptoms could be visible during OFF times. And we've got a couple of questions about cognition and OFF times.

Jori Fleisher:

So that's a great question. So, I see Mary Lynn said, my person with Parkinson's says increased cognition challenges along with increased slowness and shuffling in the evening. So, absolutely the slowness, the shuffling tremor, stiffness, harder time doing activities of daily living. You know, maybe a person can feed themselves easily, cut up tough pieces of meat, you know, sign checks, do all kinds of stuff like that during the day when meds are on. But if they're in an off period or getting towards the end of the evening and meds have worn OFF, everything may be slower. Everything may take two or three times as long to get done. It's, you know, that moving through molasses kind of slowness when someone is off. So, those can certainly be part of it. And the cognitive, so we used to think of OFF times as being just related to the motor symptoms, the slowness, the stiffness, the tremors for a lot of people, their tremor comes back out as their meds wear off.

And that can be the cue. And that's when they know, you know, they took their pill and 20 minutes later the tremor is better. Right? So, now they're on. But some people have non-motor OFFs, which means as their sim as their meds are wearing OFF, they may feel crampy belly pain.

They may feel sort of a bloaty discomfort pain. They may feel kind of tingly, weird, funny sensations in their feet or hands. They may feel anxiety. And this one I think is so, it's very misunderstood because if you knew that your symptoms were well controlled when your meds were working and you look at your watch and you go, oh man, my meds, you know, I know that they're going to wear off soon. I know my tremor my stiffness or my sours is going to come back. It would be reasonable to go, ah, wait, what if I don't have my meds on me?

What going to happen? I'm not in a good place for me to be off and to get anxious. And just like, yeah, you'd feel depressed too. If someone told you that you had Parkinson's, there's sort of the adjustment and like within a normal realm, you'd feel anxious if that's going on. But for many people, as their dopamine levels drop, they also get anxiety. That is a chemical response that you could have, you know, you take away all the clocks, they don't know what time it is. But like clockwork, that curve sort of comes down and they have this anxiety that is not, oh my gosh, it's, you know, five till three and I need to take my meds and here's what's happening. They just feel a sense of anxiety that is not related to any particular thing. They just feel more anxious and keyed up and worked up.

And when the meds kick in, that gets better. And so, to get to Mary Lynn's question about cognition, sometimes cognitive slowness, we can see that people just kind of is moving so slowly. There's something called bradyphrenia. So, bradyphrenia is the thinking equivalent of bradykinesia. So, bradykinesia is, movements are just slower and smaller. Bradyphrenia is the person's quality of thinking. The thoughts are fine but getting them out takes longer. You can almost like hear the gears in motion. You ask your loved one a question and you see that they're just kind of processing. Right. And so, that can happen more when someone is in an off period sometimes. So, there's something else called cognitive fluctuations. And these don't always overlap which makes it tricky. They can, but they don't always, someone could be motor on and all of a sudden, you're in the middle of a conversation with them, they're talking about something, and you just see this like they're just staring or they're getting the words out. But the conversation just, it's not what it was moments ago. It's like someone bumped up against a dimmer switch on a wall and just, and there's nothing that they did. This could be beginning of meds, this could be on, this could be OFF, this could be any time. And there's nothing we can do to snap the person out of it. We just have to wait for it to pass.

And so, we see that a lot, this is sort of one of these hallmarks of Parkinson's, dementia and dementia with Lewy bodies is that fluctuation from moment to moment and kind of alertness and level of thinking is not something that we really see in people with Alzheimer's or frontotemporal dementia or other things. It is very specific to Parkinson's and Lewy body. And if your person is having cognitive fluctuations every once in a while, that does not mean that they have dementia. But it's something to notice and to bring up with their treating provider and say, you know, I notice there are times when this could be going on, So I think that's really important to recognize.

Polly Dawkins:

That. That brings up a question about if you notice that your loved one is starting to have changes and symptoms and their meds aren't really working all that well, whether that's related to meds or not. What do you, what are the steps that care partners should take?

Jori Fleisher:

So first of all, if you are not directly sort of helping with the medication organization, administration, giving it, you know, to your loved one which many people are not. Right. And that's okay. And for, you know, a lot of people for a long time, they can handle their meds on their own. And I will tell you that medication adherence, taking the meds, the right meds at the right time on time, every time we expect should be great in Parkinson's. because I've just told you the meds kick in, people feel it, they feel better, the meds wear off. They know people are people.

We are not as human beings conditioned to stop what we're doing and put a pill in our mouth at a specific time of day every day, let alone multiple pills, multiple different times per day. We are all busy. And if we're not busy, if your loved one has apathy and you're like, they're not doing anything, why are they missing their meds? They don't feel like it, they don't feel like getting up and moving. Right. It's just not, it's not something that's resonating with them. So, I have a lot of times where a care partner comes in and they come in hot, they'll come in and they're just like, I don't know what medicine you're thinking about, but this is not working for my loved one. And we sort of take the step back and it's, you know, maybe, maybe they could be spot on, but before I switch everything up, do we actually know that they're taking it?

Because I've seen this all too often, which is, you know, we will take what the person says or what the care partner says at face value. If you tell me my loved one is taking one and a half pills three times a day every day, and it's not enough, right? Then my thought is, okay, well then, we go up on the dose. Maybe we're undershooting, right? Maybe A plus B is not equaling C, and so, I have to give you more B or maybe we need to add in another medicine, sort of a booster to help out with this. Or maybe we need to move the doses closer together. Maybe they're wearing off and we just don't have them kind of clumped together enough to get a really good effect. Right? But it turns out maybe that person is not actually taking them the way I think they're taking them. Maybe instead of the one and a half, three times a day or four times a day that I think they're taking, they're taking one pill twice a day when they get around to it. And what often happens is something goes wrong. That person winds up in a hospital for some other reason. And hopefully they're in a hospital system, they can see my notes and they go, oh, okay, hold on. I'm going to put them on their Parkinson's medicines. Yes, they're supposed to be taking one and a half pills four times a day. And also, someone just added this new medicine because that's what we think they're doing. But actually, they went from being on very little notes to now we've put them on what we think they should be on. And that is a huge jump because I was acting on misinformation.

Polly Dawkins:

Right.

Jori Fleisher:

And so, if you think the meds aren't working first, see if you can figure out how your loved one is actually taking the meds. If they're managing that on their own, are you refilling that 30 day supply every 30 days? Or is it closer to 45 or 50 days? If so, something's going wrong because there should be enough to get you through one month in a one-month supply. If you're not recognizing, you know, they're not taking it. Or if they're going through really quickly, and you're getting the, like, we cannot refill this, you know, do this refill request because it's too soon. What happened to those other pills where they go, what's happening? Right. Are they taking more, and could that be causing a problem? Right. That we don't necessarily know about. They were so, trying to get a better sense of that. And when we did home visits I mean, I think that that was the biggest thing we saw was almost every person, you know, who was, had so much courage and said like, yes, you can see how we do this. Right. And it could be an alarmed pillbox with, you know, five compartments a day. Or some people it was a Ziploc bag that someone had dumped all of the pill bottles into, and a couple times a day they reached in the bag and then grabbed the pills that they thought they were supposed to take at that time.

Not ideal. Please don't do that. Right. But being able to go, okay, now I get it. This is what's happening. Right. If I know how you're taking them and you're, you know, the person is being honest, then I can adjust the pills accordingly. But a lot of times there's the, like, I'm taking it this way, but actually not, okay, I'm going to go off this direction because I believe you. And then we're getting like farther away from each other and that's causing problems. So, number one, what are they actually doing? Not coming from a place of judgment, just a what are you actually doing? If they're not taking their meds on time, I see everyone is putting all these things in there. Yes. Pill cases. So, I love pill cases that have a built-in alarm because phone alarms are great, but phone alarms go off when you are in the garage, in the garden doing something, you're at work and the pills are someplace else.

So, you snooze because I'm going to go there in five minutes or you turn off the alarm because I, I'll go get it in a minute. And then life happens, and you don't get it. Right. So, if the alarm is separate from the pills, eh, but there are lots of different pill boxes that are built so that you can put different pills in different compartments and set different alarms at different times. Many of them you can set to vibrate so that if you're out in public you don't want it to be like sounding off to everyone, but they'll feel it. Great. You can use that. There's some, there's one, Amazon has a thousand of them. I'll just tell you that. So, if you're like, where can I find these? You can find everything on Amazon or online anywhere. But I think there is one that was like designed by a person with Parkinson's for people with Parkinson's. I will find it for you as I'm thinking about this. Hold on.



Polly Dawkins:

What's special about it? does have make it easier to take OFF into account?

Jori Fleisher:

It's a little bit easier to manipulate. Okay, hold on. I have not actually, I have not actually used this. I am not endorsing; I have not been paid off by anyone. This was shared by a patient to me as an alternative to the older version that I used to recommend. And they were like, no, this one is smaller and easier to use and it's a little bit easier to open. So, it's called tab time. And hypothetically is designed for people with pd and it's the pill box with different compartments with alarms that you can set. If you know that they're taking what they're supposed to be taking and it's not working, that's why you have a Parkinson's specialist. Right. and hopefully you have a Parkinson's specialist if you are talking with your primary care doc and they're like, oh no. You know, if you're talking with geriatrician or a general neurologist medicine is so specialized and the volume of knowledge that we have and the volume of knowledge that grows on a day-to-day basis is like drinking from a fire hose even within any given specialty. So, people in med school get maybe 10 minutes on Parkinson's.

That 10 minutes was what we knew about Parkinson's that someone saw fit to teach a med student at that med school that year. If might have been outdated then if that person has not stayed up to date with Parkinson's, they may be treating your loved one based on the state of the art from 1965. Right. So, I have, I have people who I care for who are healthcare professionals with Parkinson's who tell me, you know, I I'm not going to increase my meds beyond one pill three times a day. That's the dose. That's what I do for my people.

If they need more than one, you know, pill three times a day, it's not going to be helpful. And I'm like, what are you talking about? So, there, there is no dose right there. There's no right dose, there's no right medicine combination. There is no textbook for this or cookbook for this. There are lots of textbooks, but everyone is different. And so, you can meet a hundred different people with Parkinson's, and they'll all have a totally different regimen. Right. And I saw someone put in there that it's kind of I forgot how you framed it, but someone put it in there very well that it's like the wild west or we're just kind of like throwing stuff and seeing what sticks. I like to think it's more of an art, but there is a lot of trial and error because everyone is different. Everyone's chemistry is different, everyone's gut is different. If your loved one is super constipated, they may not be absorbing the medicine as well. So, treat the constipation, get them going, get them hydrated. That's you're the better people will do. But talk, talk with the person who's adjusting the medicines and say, I think we need an adjustment.

Polly Dawkins:

Are there other non-pharma things that a person can do to help manage symptoms.

Jori Fleisher:

To manage kind of the ONs and OFFs? Yeah. I mean, like for some people, meditation, mindfulness, can really help, especially if it's tremor, if it's freezing, things like that. You are sometimes using those different strategies. A lot of physical therapy will work on, you know, what do I do when I'm off? So, that can be very helpful. I think those are kind of the big things or recognizing that, you know, if, you know during an off period that your loved one, you know, isn't walking as well, right? Maybe. Right. If you're planning to go to the airport and they're going to have a long-time walking and you don't know what that timing is going to be like, and it could overlap with an off period, have the number to call in case you need one of the, you know, airport scooter guys that I'm always in the way of. Right. Or a wheelchair. No one knows you in the airport.

Okay. It doesn't matter if you use one of those things, it doesn't matter if you use a wheelchair. The point is going to the place that you want to go. Right. And getting over whatever that travel time is, whatever we need to get us to Right. To the destination. So, if you know that off time is going to overlap with that, what strategies, what scaffolding can we build in to help get over that off time? And I saw someone put in a really good point, which was like the teaser, the asterisk that I hinted at about, you know, hope to come in the future. Someone said, what's the status with approval of the transdermal patch? Are you optimistic based on the trial data you've seen? Thank you, John. That is a great question. So, transdermal patch, my understanding is, so this is this idea that I mentioned of we want people to be able to get dopamine at a slow steady rate.

24/7 people have this for diabetes, right? Everyone has seen those patches that go in the back of someone's arm. It's a slow-release insulin all day long. We want that. It's been much more chemically and pharmacologically challenging in Parkinson's for lots of reasons. Levodopa just doesn't work the way insulin does. And you need bigger amounts of it and it's harder to get that in a little tiny patch. And so, what's been in trials, two different companies have tried a patch that goes basically on the belly on the skin, is connected to a teeny, little tube and the tube's connected to a fanny pack. And the fanny pack has cartridges of the levodopa gel and it's just being pumped through the skin all day long. So, it does look very promising that clinical trial data was like the hot topic at some of the academic meetings.

And what they found was, you know, it's not the end all be all, it's not the holy grail yet. But in people who were part of the studies and had to have a certain amount of off time to be in the studies, and I don't want to misquote it, I want to say it's usually it's at least like four hours, four and a half hours of off time during the day. Many other treatments we can like get people out of off time. But on that Hauser motor diary, right? There's OFF, there's on and then there's on with bothersome dyskinesias, sometimes it's very hard not to overshoot the target. So, we're like, we gave you less off time, but you were wildly dyskinetic the whole time. Well, is that



really a win? So, with the transdermal patch, they found that people got an average two and a half more hours of good on time.

That wasn't on time with bad dyskinesia. So, it is really promising. It's not without side effects. A lot of people, I don't remember the exact percentage, but a significant number of people had kind of like hard skin nodules that formed underneath the patches and some pretty wicked looking black and blues. For many people they were like, I don't care. It's not bikini season. My Parkinson's is better controlled, you know, sign me up for the patch. For others they were more bothered by it. So, I think we are still months to maybe a year out from FDA approval. Once something is FDA approved, then we have to figure out like, is Medicare our insurance is covering it? What's that going to look like? How much is that out of pocket going to be? But I think that it will be approved. I'm hopeful. I have a lot of folks that I have in my mental list of once it's approved because they would be great candidates for that, and they might not be a great candidate for something like deep brain stimulation. Right?

Polly Dawkins:

So, we've been talking a lot about off and symptoms of off what have you noticed that this, the toll that this takes on care partners?

Jori Fleisher:

I mean it's; you never know what to expect, right? And so, I think that unpredictability and even, even if you know, your loved one generally has two hours of on time and then, you know, has off or whatever that is, right? Even then, even if you know that that's the schedule, that's still a really hard schedule to live with, right? To try to live in two-hour increments and not do anything or accept that, you know, it's going to be harder to do things in the off time. That is really challenging. And I saw someone else that put in the comments like, how am I supposed to move food around and all I, this is why I have a dietician in my interdisciplinary clinic is because it's impossible, right? There are ways that we can find to do some of those things, but it is so hard.

So, there's, you cannot overstate how difficult it is both the predictable fluctuations and the unpredictability of it. So, I think it's resetting those expectations a little bit and giving yourself and giving your loved one grace. And, you know, we might have previously wanted to do five or six things in a day. The stuff on the to-do list is going to need to be left undone, right? What is, what's the bare minimum that we can do and still feel okay with, right? And if there's something that at the end of the day, you're like, I really wish that I would've done that, well then can that be the thing tomorrow that you work towards? Right? And if other stuff falls to the bottom of the list, so be it. Right? I think it's trying to realize that like Parkinson's is going to set the schedule kind of. So, for my type B kind of folks who are more go with the flow, I feel like they're better with it. If you're type A

Polly Dawkins:

That's a good,

Jori Fleisher:

If you're type it's really hard because you want to plan stuff out, you know? And if you, if you yourself have a lot of anxiety, the way that people cope with anxiety is trying to control things. So, if you have anxiety about the inability to control things and your response is to try to plan and overplan and control things, it's not going to work so well because that's the day that the OFFs are going to be at a completely different time. Right? And so, finding ways where, can you loosen a little bit, right? Where can you just kind of take a step back and go, okay,

Polly Dawkins:

Yeah. Somebody asked a question about a symptom during off time of appetite changes or hunger. Is there any literature or have you seen anything change with hunger or appetite during, OFF times?

Jori Fleisher:

I have some people that get really hungry when they're off. I have some people that have no appetite when they're off and vice versa. So, I got, I think it's all over the place. I don't think there's a consistent thing. I did see someone put in there something about having a sweet tooth and really like going for all the sweets and things. So, that is also, that is very common. And some of this may be kind of frontal lobe changes. So, the frontal lobe is kind of what gives us like our filter. It's sort of what makes you a grownup, right? Teenagers are still developing their frontal lobe. They do kind of crazy things, and we hope that they make good choices, right? But our frontal lobe develops and gives us filter and helps us make good decisions. And the frontal lobe can be affected in Parkinson's.

And one of the ways that the frontal lobe can be affected is it does kind of relate to appetite and what people go towards. And so, we see people gravitating more towards sweets. So, if people had a sweet tooth before, it can like turn up the knob. And other people that like would've gone for the pretzels or the chips before are now Parkinson's cookie monster. Right? And so, we see this, some of it can also be that Parkinson's changes people's sense of smell and taste. And so, more subtle things are kind of lost, right? But sugar and especially like hypersweetened stuff, hypersweetened processed foods are meant to trigger like "ping, ping, ping, ping." Like a pinball machine in your brain of like, yes, we've got the pleasure centers, this is good, right? Have more of this. And so, in someone who's losing dopamine where they can taste the thing that lights up the dopamine pleasure centers, they're like, ah, yeah, yeah, yeah, yeah, this is good. Right? They can recognize that and so, they may, they can taste it, whereas

they may not be able to taste other things as well and it just generates pleasure and that reward system more than other things do. So, all things in moderation.

The other is if, you know, if they're not doing so much on like the savory foods or healthy things, it's not you're cooking if you're the cook, right? It is changes in sense of smell or taste. So, do not take it as an insult. Which can be really hard for folks. And a lot of times people show their caregiving through cooking, through feeding, right? And if they don't like the thing that you're putting in front of them, that can feel like a direct insult It's not you, it's not your cooking, it's the Parkinson's.

Polly Dawkins:

That's a good point.

Jori Fleisher:

Yeah. Yeah. Extra sauces, hot sauces, different seasonings, try different things. You know, your person might have been a meat and potatoes kind of guy and like they don't do fancy things, right? Like cardamom, right? But maybe now is the time to try playing around with other spices, sauces, or things to make it a little bit more interesting.

Polly Dawkins:

Do you we were talking about food. Do nutritional choices or hydration or constipation play a role in OFF times?

Jori Fleisher:

Absolutely. So, if someone is really constipated, they're not going to absorb their meds as well, so they'll have more off time, right? So, we can get them moving. If we can get their gut moving, they will feel better in all the ways. If they're dehydrated. Same thing. You need a good amount of water in your body to be able to absorb and process and metabolize meds correctly. So, the hydration for sure, and again, it doesn't have just to be plain water. It could be flavored, it could be anything, whatever is getting fluid into the person. If they really love sweets, watermelon, right? It's mostly water. It's 90 plus percent water. Lots of fruits are bringing a ton of water with them or water with slices of fruit or things in there, sorbets, things like that can help hydration. Getting rid of the constipation can really help with the off periods treating if there's underlying depression or anxiety, not just in the OFFs, but just there all the time, getting that treated can really help,

Polly Dawkins:

I'm cognizant of time here. We've got so many other questions we could address with off. I feel like you've really tackled the biggest, the biggest topics around off and symptoms. Anything that we're missing about effective treatments or surgical treatments or drugs for off?

Jori Fleisher:

Yeah, I mean, I think just recognizing, you know, off time can be more common as Parkinson's goes on. And you know, sometimes we, you know, we go through all the different meds, and we try different combinations and we're, you know, it feels like we're just kind of banging our head against the wall. We're not making headway; we're still getting lots of off time. So, that's a time to ask, you know, the treating neurologist, whoever you're seeing, you know, what other interventions are out there, is there something else better? So, right. Hopefully when the pump comes along, the pump, you know, may be a good option for some people. There is a different pump, which is out and available. So, it's called dupe. It's been around in Europe for much longer and it's been in the US for a while, and it is a tube that goes through the wall of the stomach.

So, it's not a like sticker patch that fits on the skin. It's a tube that goes through the wall of the stomach into the gut, and it is giving a slow, steady drip of levodopa gel directly into the gut, you know, all the time. Thanks Sam. So, it's effective. It works. Why don't we prescribe it to everyone? Because a lot of people don't want a tube. They don't want, you know, something in their stomach. It can clog, it can dislodge, it can kink. It's not that the medicine, like medicine was the science, makes sense. And biologically it works, and it makes sense. It's the implementation, right? It's getting it so that it stays in place. It works all the time. It doesn't clog. It doesn't get infected. That's why in the US we don't tend to prescribe it as much.

So deep brain stimulation, I mentioned sort of the surgery. So, deep brain stimulation has been around for years and years. It is a newer version of surgeries that we used to do in the past where even though it sounds counterintuitive in the past, there are areas of the brain that we know are causing, you know, that's kind of where the Parkinson's is going on. And they would basically like make a scar. They would injure the brain tissue in that area, sort of jam the circuit board and people did better for a while. The problem is we don't have a cure. And so, the Parkinson's is continuing to change over time. And so, I almost think about it if you've got that like multi-pack of band aids, right? Imagine that you have a birthmark, and you don't like it and you want to cover it, okay?

And it's small, right? So, I got a freckle okay on my hand. I don't want people to see it. I could put one of those teeny, little pinkies sized band aids on there if that thing is bound to grow slowly over time, right? For years, the pinky sized band aid might be fine. I would hopefully change it, right? Every once in a while. But you'd put that on there and you wouldn't see the birthmark underneath. One day I will look down and go, eh, it's peeking out from underneath the birth right underneath the band aid. It's not that that little dinky pinky sized band aid stopped doing its job, okay? The Parkinson's grew beyond what that treatment could do, right?

So, it's, you know, another analogy to think about the meds stop working. No, the meds don't stop working. The Parkinson's evolves and the meds need to evolve with it.

So, in the analogy, we can put a second little pinky band aid right next to it cover that up for a while, right? We could go to a medium-sized band aid, we could just slap you know, cast on the hand really not see it for a long time. Right? And so, deep brain stimulation is in that continuum of the symptoms are changing. How do we want to, how do we want to cover this up and adjust? So, the brain is communicating cell to cell with both chemical messages and electrical messages. So, the medicine that we're giving is changing the chemistry of the brain. Deep brain stimulation kind of skips over that step and is stimulating the electrical circuits of the brain and is giving electrical medicine to replace some of not all of the chemical medicine. So, for some people with really bad ONs and OFFs, deep brain stimulation can be a life changing thing. And just like the medicine time may go on, they may have a honeymoon period where the programming and the stimulation settings and everything is just right and they're awesome. But underneath the Parkinson's is slowly changing. So, don't be surprised if underneath down the line, the parameters, the stimulation stuff needs to be adjusted. It's changing the band aid.

Polly Dawkins:

Got it. Thank you. That's where we're wrapping up here. Jori. Are there topics you've seen in the chat or topics you were hopeful that we could cover today around symptom management and off that would be helpful for our care partners?

Jori Fleisher:

Yeah, I mean, I think as annoying as those motor diaries are, if your loved one is having fluctuations, if they're having ONs and OFFs, right? Even if you just want to keep the diary, if you don't feel like they're in a place where they want to discuss it, but you are noticing changes, it may be helpful for you to just kind of keep that diary for a little bit and see how much of the day are they actually off. Because it can, for some people it can feel like it's a huge amount of the day and they look back and they're like, okay, altogether it was maybe an hour. Or you may feel like, I don't know if it's that bad and you look back and you're like, man, it's like four hours of the day, you know that they're off. Right? And being able to kind of validate what you're feeling that it's real, it's there. And then that gives you that leverage to be able to talk with your person and to be able to talk with their treating team. Plan less, plan less, right? Which doesn't mean hope for less,

Jori Fleisher:

It just means know that you're not in control of all the things. Right. And give yourself that grace and that breathing room and the space that like, if you need to wiggle the schedule, you can wiggle the schedule, right. And let stuff be undone. Yeah.

Polly Dawkins:

Super. And then if in addition to keeping a diary for a few days planning less, any other suggestions between now and our next session that you would ask our care partners to think about? Maybe doing one of the one other thing?

Jori Fleisher:

Yeah, exactly. We, you, have too many things to do. So, pick any of these, not all of these, right? Maybe check out the feelings wheel. See if, you know, and for me it was like an “aha” moment, right? Maybe it is not for you, and that's okay, right? But if it helps to pull that up and as the week goes on and you're like, oh, what is this feeling I'm feeling? Is there a better word for this? Right? That may be helpful. If not sometimes thinking about if you're feeling those difficult emotions, anger, guilt, right? Hopefully we've given your ideas of what to do with them, but sometimes it's just hard even to recognize. So, if you can name the feeling you're feeling, what does that physically feel like in your body? Right? And so, sometimes the physical cues, I know I get stressed, it's immediately in my shoulders, they're rock hard, crazy.

Sometimes I don't realize it. My family will look and go, ugh, take them out of your, like, take them out of your ears, right? What does guilt feel like to you? Right? If you're feeling guilty, do you feel kind of a pit of the stomach? Do you feel, you know, tightness, discomfort in here? What does that feel like? Right? And just being able to recognize, can you name those emotions, or can you name, see here's the feeling I feel. Here's, here's what that means when I'm feeling this. because it may be more of a cue and a way to help you get ahold of, if I'm feeling this, okay, I need to take a step out. This is what this is. I need to go away. I like Marian's suggestion the most.

Polly Dawkins:

Boy did Marian say that.

Jori Fleisher:

I love this. Marian says, make a Ta-da list instead of a to-do list. If you get one thing done, say ta-da and celebrate it. Yes.

Polly Dawkins:

That's awesome.

Jori Fleisher:

Scratch my suggestions. two Marion suggestions. Marian, I'm going to make a ta-da list. I think that's fantastic.



Polly Dawkins:

You were here today, ta all of you, all of you, you were here, you showed up ta. Wonderful. Well, thank you all for being here. Thank you all for sending your feedback, sending emails, sending your suggestions, encouraging one another. It is so wonderful to hear from you and know that we're all doing this together, that you may feel alone, but you're really doing this together. We will see you back in a week's time. In the meantime, have a lovely week, Jori. Thank you for being here for us.

Jori Fleisher:

Oh, it's such a pleasure. Thank you all for being here. You are such an inspiration, and you make me look forward to this every single week. I'm so inspired and amazed by all of you.

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