

Care Partner Training

Session 9: Uncertainty, Self-Efficacy, Anticipatory Grief, and Ambiguous Loss in Parkinson's

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 Care Partner Training Session Nine. I'm Polly Dawkins, executive Director of the Davis Phinney Foundation, and I'm here with Dr. Jori Fleisher. Hi Jori.

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

Hey Polly. How are you?

Polly Dawkins:

I'm great. How are you?

Jori Fleisher:

I'm doing so well.

Polly Dawkins:

Let's start off talking about uncertainty because living with Parkinson's has a lot of uncertainty, and certainly, for our care partners, our care partner community, you think, tell us a little bit about the uncertainty that you have seen being out in people's homes, visiting with them, hearing them in the clinic. What kinds of things do you see?

Jori Fleisher:

I mean, I think uncertainty is just a hallmark of so much of this condition. And it's like uncertainty at the macro level. Right? What will things be like five years from now, ten years from now? What, you know, what's coming down the pike? What research is there? Will there be a cure? Will this affect so and so? You know, will this affect my kids? What sort of bigger, broader uncertainty will I need to retire? You know, if they're the person living with Parkinson's, will the care partner need to retire? You know, what do you need? Will you be able to stay in your home? Home, right home? There's kind of that macro level, but there's also the day-to-day, moment-to-moment. You know, my loved one is doing great, except then their meds wore off. Right? Or my loved one is doing great, and they have a cognitive fluctuation and, you know, so and so wants to plan for this family event.

Jori Fleisher:

Or can you be here at this time? You know, what can we do? And sort of living in that space of I hope we can. I think we can. And there's also a chance that five minutes beforehand, the person with Parkinson's might be off, you know, in some of those different ways. And how do you still continue to live and thrive and plan and also sort of build in some resilience for what if, in that moment, I can't, we can't, right? And so, I think that sort of stop and start, how do I predict from moment to moment? I think that's just so abundant throughout this journey. And especially for folks who are more on the kind of type A scale where, you know, we feel better if things are planned. It can often, especially for care partners who really, you know, whether it's an internal, I want things to be planned or they feel the pressure of, you know, I need to handle this for my loved one with Parkinson's, they'll make a plan. And then because of the condition, right? It doesn't go to plan. And then it often can cause a lot of complex emotions.

Polly Dawkins:

Yeah. And sort of the mental toll and distress that uncertainty places on both care partners and people with Parkinson's. It has to be really hard to manage.

Jori Fleisher:

It's tremendous. I had someone describe, you know, we talked before and sort of the cognitive piece of this, right? What are the areas of cognition that Parkinson's can affect? And we talked about executive function, which is that planning, organizing, multitasking, kind of air traffic control, right? And contingency planning. And I feel like for people with Parkinson's and for their care partners, there's such a heavy drag on executive function if we're going to plan to do this, but if that doesn't work, here's our backup plan. Or we're going to go here, but I need to know where a bathroom is, so let me plan ahead to make sure that we strategize, or we've got this, or we've got extra meds just in case. And that is a huge load to put on people, right? In addition to just living and getting through the day and doing everything else that someone without Parkinson's would be doing.

Polly Dawkins:

Yeah. And I can imagine that that also creates a heightened sense of anxiety for a person with Parkinson's, which then impacts.

Jori Fleisher:

A hundred percent. It's this vicious cycle, right? That anxiety can be a piece of the disease. People are chemically predisposed to have anxiety because of Parkinson's, and if something goes wrong, or something doesn't go to plan, that could cause anxiety in anyone. But the more anxiety there is, someone has a freezing of gait where their feet get stuck, right? Or if they have tremors, anxiety is going to fuel those things, it's going to make that worse. If they're having cognitive fluctuations and then you pile some anxiety on top of it's going to make that worse. If someone's thinking about what they need to do the next day, it's going to affect their sleep.

Because they're not, you know, they can't wind down, and that's going to make things worse. And so, trying to tease all these things apart, I think, is a journey.

Polly Dawkins:

One of the ways that we see that people who care partners and people with Parkinson's who do manage uncertainty really well is building their own self-efficacy and resilience. Can you talk a little bit about what you've seen and why building those emotional and psychological muscles if you will be so important for care partners especially?

Jori Fleisher:

I mean, I think if people are continuing to go, you know, through this journey and planning, and planning, and it fails, right? It's not failing, right? But things don't go to plan. If the response is, I'm just going to keep trying that same thing again. I'm going to try to get control of something that maybe is not as controllable as you would want it to be. It's almost kind of setting you up to feel ineffective and to feel bad about yourself. Whereas instead, if there's a recognition of, I'm going to be flexible, I'm going to build in extra time, I'm going to recognize I might want to do five or six things today, but I'm going to be happy if these two get done. Right? It is sort of having that resilience of I have gotten through hard stuff, right? I've heard someone say like, you've gotten through a hundred percent of your bad days.

And it doesn't, you know, may not feel like it in that moment, but cultivating that resilience of I have done it, I have done hard things, I can do hard things can help people sort of get through that moment. And sometimes I think this, I've heard this in the context of grief, is it's not living, you know, week to week. It's taken this hour at a time, right? If there's a hard day, if things are really a struggle, you know, be in that moment, what's the best that I can do right now in this moment? And I think that sort of self-efficacy is realizing, you know, I have the skills, I have the psychological skills, I have the capability to get through whatever's thrown at me. It doesn't mean that if that thing happens right now, you know the exact right answer, but you know that deep down, you'll be able to cope. You will find a way that doesn't have to be the perfect way, but you'll get through it. You have that in yourself.

Polly Dawkins:

So, what you're saying is self-efficacy is really the belief in yourself that you can do this.

Jori Fleisher:

It is. I think it's a belief that you can influence, right? Your reality. You can in you, have influence over the conditions that affect you, and you can make change, right? You can; you don't have to be the sort of person that things happen to, right? Yeah. You can affect change to your circumstances, to your situation. You can change things if they're not going the way you want them to.

Polly Dawkins:

We were talking just a few moments ago about the uncertainty and all of the things that face you in a day and how you have to be ready to make pivots and changes to your day. One of our viewers, Helen, brings up the fact that this takes a toll. The uncertainty takes a toll on friendships and makes people draw away. And these are the same people that you should be leaning on for. So, it worked. Yeah. Have you seen anybody do that really well? Or how do you, how do you prepare your friends or your family members for the uncertainty that comes with life? Your life, your personal life.

Jori Fleisher:

I think some of that is, you know, there is stigma, right? And sometimes, this happens in all kinds of life-changing conditions, right? Some, you know, people are diagnosed with cancer, and all of a sudden, the friends, you know, that were there before that you think would come and support you—crickets. Right? But I think there are other people in our social networks who sometimes lean in, right? And so, it's the Mr. Rogers quote, look for the helpers, right? It is communicated to people we really want to be there on time for dinner. We really want to meet, you know, we're going to, we're planning to meet you at the theater at this time. There's a chance we may be late. There's a chance. My loved ones, you know, Parkinson's is just going to, we're going to be in a bad way if we miss it. I apologize. Right? We're doing the best we can. And I think, you know, letting people know and just being honest because you are, you're doing the best that you can. And if it's someone who's not seeing that or feeling that, you know, that's not the person who's going to be a great source of support for you. Yeah.

Polly Dawkins:

Let's go back to talking about self-efficacy and the belief that we have influence over our outcomes and aspects. Tell us if you could draw on some stories from your experiences of people who have embodied the self-efficacy concept and are able to build resilience. Maybe some ideas for our audience and how they've done that.

Jori Fleisher:

Yeah. I mean, so, you know, and there's good research that shows that across socioeconomic characteristics, right? This is not a, well, I have plenty of money, so I can throw money at this problem so I can make things happen. This is not that, right? This is an internal I can do; I can make things happen. I believe in myself, right? And there's research that shows that people who have higher self-efficacy do better. They have better health outcomes. They're, you know, stronger caregivers in terms of how their loved ones do, but how they do, right? So, I have people whose self-efficacy may come from their spiritual practice or their spiritual beliefs, right? They, you know, they draw that sense of I can do anything, you know, and it's coming from that place. Whereas other people are, you know, finding mindfulness and going, this is hard.

I'm going to acknowledge that this is hard, and I am just going to be in this moment, right? No matter what's happening, whatever's happened in the past, I can't change what's happening in

the future. I can't change it because it hasn't happened yet. I believe that I can do something in the now. So, I have a lot of folks where, you know, some who've been yogis and sort of practicing mindfulness before it got, you know, all cool. And some people who felt like that was very woo-woo, right? They come to me, and they're like, Jori, I went to this course on mindfulness. I thought that that was granola. And I'm like, nun-huh, okay. You know, waiting for the, like, and then, you know, and then I actually tried these things, right? And it's, you know, sometimes it's as simple as going, I feel like things are out of control.

And I have care partners who literally will go in the middle of the storm, in the middle of the fluctuation, in the middle of the whatever, and literally just close my eyes, count to five, count backward, and breathe. And they just create a pause for themselves and just to be able to, like, hear their own breathing and see, right? Like, you can control that. And just finding those little pieces of things that they can control, right? So, I have a lot of caregivers where it's simple things. You know, there's a recognition of, I can control me. I think some of it is. I spoke with someone just yesterday, she's a very kind of Type A person: This needs to happen; here's how it needs to happen. This is what's going on. And her husband of many, many, many years has Parkinson's.

And he, it sounds like, has always been a more, eh, right? I think the apathy long predated his Parkinson's but has certainly gotten worse and has made the differences between the two of them really stark and, causes a lot of tension and a lot of stress. And there are times where I've absolutely seen her in crisis just saying, you know, I can't do it. I can't do it. I can't do this anymore. And she, with the help of a therapist, has realized like, it is okay, nothing is going to happen in this, you know, one moment, as long as he's, you know, safe. If she's frustrated, she literally has said, I will just walk out of the room. I will walk out of the room because I cannot control him. I can only control myself. And she said this. And I was like, yeah. Yes, yes.

And it seems obvious, you know, to all of us until we're in the moment, right? I can say as a parent, you know, there are times where I'm like, ah, why is my kid doing this? You know, how can I control their behavior? I can't control their behavior. I can model mine. Right? I can try to be self-regulated so that they can, you know, regulate. But I think it's, you know, how do you practice that? Even if it's as simple as I can control my breath. I can hear myself breathing, right? I can just feel myself relaxing. I think those can be really powerful. And other people are the ones who said, you know, I am not able to do X, Y, Z. Right? I can do lots, but I cannot lift my loved one for whatever limitation.

Right? They have gone and come to me with research saying, what I need is a Hoyer lift. I've done it. I need you to write a prescription, and this is what I want. Right? And if they would've told me in the visit, I'm having a hard time lifting my loved one, you know, hopefully, I would've, you know, come to that conclusion. But they're, you know, they're coming to me and going, here's the problem that I need to solve. Help me solve it. This is what I need. Right? So sometimes you don't need to be able to solve the problem. If you can identify what it is where you're struggling, then you can recruit the help you need. And I think that's also part of self-efficacy.

Polly Dawkins:

Maybe we should take a practice of breathing for five seconds, just all of us together. Let's just take a deep breath in and hold it out, for, it just feels good.

What are some ways that we, as care partners, can help our people, our loved ones, build these skills of self-efficacy and resilience without maybe using those words?

Jori Fleisher:

I think sometimes identifying when your loved one is doing something really well, right? And just saying like, I saw how you, you know, you just got up while you were gardening and like, that's hard for me, right? Look, look at how you just did that. I'm so impressed. Right? It's finding simple things that the person might not necessarily be looking or expecting praise for, but sometimes really simple daily things can feel so challenging that just having that recognition of, look, you can do X, Y, Z, right? Depending on who you know, who your loved one is, and how they are. What's their love language? Right.

How do they feel better? Right? Is it, you know, words of appreciation and things like that, but being able to say like, I know that this could have been a really challenging situation, and I noticed that you did the following really well, right? I really loved how you did this. I know you probably didn't feel like going to the thing today, or I loved that you actually told the doctor what you were feeling, right? Like, I know you didn't want to go to the gym today, but you did. And it seems like, you know, you look like you feel much more energetic. How do you feel? Right? And so, you are not necessarily leading them. But recognizing when you see all those positive things, right? Being able just to call that out.

Polly Dawkins:

I really, I like that. I hadn't thought of it in that way. And without using those big words, right? Self-Efficacy: you demonstrated efficacy there. It's like, I noticed I paid attention. I slowed down enough to notice that you did that.

Jori Fleisher:

And I think even, even during like the hard moments, you know, I've noticed if a friend who's just like an amazing listener, and I'll, you know, give some story and she'll just say, that's really hard. And just the validation, right? If you're doing this thing, and I hear that this sounds really hard, right? So, seeing your loved one, you know, and what, even if it's, you know, coming out of the doctor's visit and hearing the news that, you know, wasn't exactly what you wanted to hear, like, I feel like this was really hard. You know, how is this for you? Just being there with them and being able to be an active listener, I think, helps build resilience because they know that you're on their side, and we're going to get through this. Yeah.

Polly Dawkins:

Yeah. Chris asks for other examples of how we, how do we develop self-efficacy ourselves or in yourself.

Jori Fleisher:

So, I think it's different for everyone. I think being here, you guys have already taken, you know, steps like one through 15, right? You're learning so much. So, empowerment, right? Education is empowerment. How can you advocate if you don't know what to advocate for, right? How can you ask the doctor questions when you don't know what could be going on, right? And so, just learning about the condition, right? And taking in information and asking questions. I think that that is huge self-efficacy, right? You're not just being a passive, you know, kind of, I'll wait until something goes wrong. I'll wait until you know the visit, and then I guess I'll hear something. Or your loved one doesn't bring you along to a healthcare visit, and you're just waiting for the, like, what'd they say? Nothing.

Right? So, you are building self-advocacy, you know, right now. But I think thinking through sometimes what you are really good at, right outside of this space, outside of caregiving, doesn't even need to be your job if you're working, right? If you just kind of get to, like, what am I good at? What do other people tell me I'm good at? Right? Think about maybe that came completely, easily, and naturally to you. Or maybe it's something that you worked really hard at, and you overcame all kinds of things, right? There may be people who are just like effortless, amazing dancers, and maybe that's just a, you know, natural gift, but maybe that took thousands of hours of practice and, you know, bandages and bruises and all the other stuff, right? But they had the self-efficacy to keep practicing and to stick with it. And the resilience to make it through all the challenging times. What is it that you're really good at, right? Are you really great at cooking? You know that if you get like a cruddy recipe that is written poorly and you're like, me, okay, but I think I know what they meant, and here's what I'm going to do about it. You have self-efficacy in the kitchen.

Right? And it's because you've practiced it, right? You've practiced figuring it out. And I think part of self-efficacy is no one is going to get it, and no one is going to be perfect. Right? Unless you're that ballerina who came out of the womb [...], right? It takes trying and failing and trying and failing, and seeing if you can, you know, learn this way. Maybe not so much that way. All right let's try again this way. Right? Don't expect perfection. Because we don't, we don't see that in any other sphere of life. It's just learning from where I can get this information. How can I use this to empower me? How can I use this to empower my loved one? Yeah.

Polly Dawkins:

Randy has started a comment, and I was just going to ask you all in the audience, tell us, tell us outside of caregiving, what are you good at? Randy says, "Learning to ride a bike takes self-efficacy, takes resilience, right?" What? Tell us in the audience, what are you really good at? Singing, playing, bridge, choral, singing. What else? Books. Books. Organizing. There's illustrating children's books, gardening, cooking crafts, and dog training.

Jori Fleisher:

[...]

Polly Dawkins:

Photography. I have a stained-glass wheel. Look at all those things. Wood carving, gardening, listening. Yes. Grandchildren, grandparenting, electronic music.

Jori Fleisher:

Heather said, "Bipolar is my superpower." Nothing helps you learn to pivot, like living with mental illness. And Heather, you could teach us all about self-efficacy and resilience.

Polly Dawkins:

That's great. Thank you for your contributions. Do you have any ideas, Jori, about what people with Parkinson's and their care partners can do together to build or to get more comfortable with uncertainty?

Jori Fleisher:

I think trying, you know, doing activities together and recognizing, like, okay, this didn't go to plan, but we still were able to X, Y, and Z, right? I have a lot of folks where they'll tell me things like, you know, we've always had this on the bucket list, but I guess we can't do that now. And I'm like, why? Why? Right? I mean, someone who recently, they're dependent on a walker or a wheelchair, and they literally flew to Europe and went from Europe, they took the train, and they got on a river cruise, you know, and did all this stuff with daily activities and excursions and things. They can do that, you know, and I've had folks who are on hospice, right? Where we've been able to get them to the lake house, get them to where they want to be, to do the things that bring people joy.

It might not look exactly the way you imagined in your mind that it would look right. And we'll talk a little bit about ambiguous loss later on, which kind of gets into this, but that doesn't mean that a thing isn't possible, right? So, I think building in that resilience, if you're planning an activity and knowing it, may not go exactly to this plan, but that doesn't mean we're not going to do it. Mm-Hmm. Right? So, whether that's a big trip, whether that's we're going to take, take swing dancing. Yeah, no, we'll see how it goes. Right? Neither of us are great dancers, but it sounds like a fun thing to do together, right? I would think about, you know, are there things that together with your loved one, with Parkinson's, you've always wanted to do? Is there a skill you've wanted to learn? Is there, you know, a series that you've always wanted to attend?

Is there something like that, right? Where ideally, it's new, and it's a stretch for both of you, because I think then for the person with Parkinson's, they're not alone in that uncertainty, right? It's also something where they're not the only ones facing a challenge, right? If you can be there with them in that mental space, this might be hard for me too, but I'm right there with

you, and we're going to do this together. I think that, you know, I've seen people where, like, they take up playing bridge, and they didn't before. Or I have a couple that goes out swing dancing, and the person with Parkinson's is the far better dancer. She's way better, right? And so, it's been a learning experience for her husband to try to keep up. And you know, he jokes about having two left feet, and they navigate that together, right?

And there are days when they can't go. There are days where, you know, she's just off, and it's really hard to get into the car. And I would say when you do activities like that together, if there's something like that that you can find in this couple who dances, for example, they have developed an entire community, multiple communities that they go to these different dance halls and dance clubs and, you know, all kinds of cultural experiences. And people who are their dance partners, and like dance club members, are now among their tightest support group, you know, and tightest support network members. And these are not family or friends. These are not the people that they've known for decades. These are folks they've known for a year, but they see them getting out there together, you know, maybe struggling to get out of the car, maybe having a, you know, one bad day, having another good day the next, and people gravitate towards them, which I think is an amazing experience instead of what someone brought up earlier, which is people kind of falling out of that gravity.

Polly Dawkins:

Yeah. What have you, what have you seen happen when care partners are unable to manage this part of living with Parkinson's?

Jori Fleisher:

It leads to tremendous strain. Huge strain, huge stress. I think particularly of one very, very dear couple who saw me for quite a while, and he had Parkinson's, his wife was a care partner, and she was very detailed, detail-oriented, very, very fixated on planning, you know, down to the minute. And if only we could plan to the minute, things would go to plan, right? It's not—it's the lack of a plan that's causing a problem. And it was very hard. This was clearly a lifelong kind of trait. It was very hard to make headway there. And, you know, as her husband progressed and as he had more fluctuations, both motor fluctuations and also cognitive fluctuations, you know, come on, we need to go. And, you know, we would even see this in the clinic room where we would wrap up the visit and say, you know, okay, we're going to see you in a couple of months, happy holidays, whatever.

And, you know, she would rush, and I would look at him and say, you can't get up right now. Right? And take your time. Right? Don't worry about who's in the waiting room. You just take your time. And she would just, you know, no, we need to get out. We need to move, we need to go, we need to. And it was, you know, those terrible, those little party favors from birthday parties where the more you pull your fingers out, the tighter it gets, right? The more you try to control, the more it's going to drive the person with Parkinson's anxiety, the more it's going to drive the freezing, the more it's going to drive the confusion. So, ironically, for her, and it was very hard, but it was a process of how do I let go of the control? Like, you'll actually have more

control if you can just let go of some of the minutiae, let go of some of the things. She would have a really hard time because he had a tendency to get dehydrated, and she, you know, really adhered to, we need to get more fluid into you.

And so, questions during the visit would be interrupted with, drink some more water, drink some more water, drink some more water. Here's your water bottle; drink some constantly. And it was like, right now, in this moment, that's not, it's okay, well, but if he doesn't drink enough, he'll wind up in the hospital. You're right, he might, but pestering every 30 seconds, you know, with forced water drinking, is probably not going to change his behavior. You are getting that pushback and the no; how is that making you feel? Right? And at the expense of everything else, right? And for that couple, eventually, he wound up being placed in a nursing facility. And it was a, you know, terribly difficult decision for both of them. And when she no longer had to be, when she no longer felt that she was in charge of every decision, and every moment, her entire demeanor changed. And she's still the same person. She's still anxious, she's still detail-oriented, but it was, I mean, it was a miraculous transformation to see her sort of be able to go back to things that she enjoyed, which she had completely cut out of her life, even when there was time to do them. But just because so much mental effort, so much executive function was spent on trying to control what was uncontrollable at times, right? And just when she had that space, it was a huge change.

Polly Dawkins:

She probably is a better care partner.

Jori Fleisher:

Absolutely. A better care partner.

Polly Dawkins:

Even though they're hard—

Jori Fleisher:

You know that there was a period of just like, oh, I know that he's drinking as much water. You won't [...] but you're going to trust that they are doing everything that they can for him and their, you know, quality of life. And you get to have the good part of your relationship back. You can go, you can be present. You cannot worry about, you know, the nitty gritty kind of stuff as much. And you can just be present and sort of honor the relationship that you have as husband and wife, as partners. Instead of feeling like she constantly has to be kind of, you know, giving the orders and checking on things, it kind of equalized the playing field a little bit more. And I think that was incredibly meaningful.

Polly Dawkins:

Yeah. Just drives a wedge in that relationship. And a hundred percent as a parent-child if it's a husband, wife, and just, yeah.

Jori Fleisher:

Because it's nagging, right? No one wants to be told what to do; no one wants to be nagged. And if you are the person who is doing the nagging, you don't feel good about it. And if you are a person who's, you know, on the receiving end of the nagging, not only do you not feel good about it, but you know, it really influences that relationship. And so, I think this is something that's so hard for care partners, you know, we'll talk about, I think it might be time to, you know, bring up bringing someone else in, bringing a companion, bringing a, you know, paid caregiver, someone else into the home because they can say the same things. They can ask the person with Parkinson's to do the same thing, and they will do it for someone else when they will not do it for their spouse, significant other, adult child, or whoever's the primary care partner, right?

Because that relationship is too deep, and it's too ingrained, and there's too much history. And so, you can be like, but you're supposed to do your physical therapy exercises. Come on, let's be big, let's do this stuff, right? And they're just not going to feel it. Right? And then it comes, you know, the physical therapist or whoever it is, and they're like, how are you feeling today? Great. And you're like, what? Right? You're not alone. This is everyone. Okay? This is all the time. Constantly it's like, I can't, I can't believe, you know, that my loved one will go for a walk when I haven't been able to get them up out of the chair, you know, for the last week. How come you'll do it for them and not for me? It's not even worth asking, right? It's just going to frustrate you. They may not have an answer. If they have an answer, you might not like it, but it doesn't matter, right? The goal is they're doing the thing that, you know, benefits them, and in that time, you do something for yourself, and you were able to affect that change. If your loved one is doing their exercise, taking their medicine, whatever it is under someone else's immediate direction, that was still your goal. Your goal is achieved, right? You got it done. It just had to look a little bit different. So, I would take all of that still as a win.

Polly Dawkins:

Priscilla asks, do you know of the couple whom he went into a nursing home, how he was doing, or how he felt about the change? Or do you not know the...?

Jori Fleisher:

I do. I know it was, you know. Initially, it was a difficult transition. And I tell, you know, I have a lot of folks where certainly most people, if you ask people with Parkinson's or in general, you know, would you prefer to age in place? Would you prefer to stay in your home with your family? Right. Or go to a facility. The overwhelming majority of people say, I want to stay in my home, right? And you know, certainly, we want to honor that and recognize that for some people and some families, there comes a breaking point where it just is no longer possible, right? It's not safe. Or the care partner, you know, physically cannot handle what's needed. Or

the person with Parkinson's, you know, has symptoms that just require extra help. And so, I think in that particular case, you know, he, he was sad.

He certainly wanted to be home. But he actually adjusted much better than I anticipated. I almost always tell folks, you know, especially if someone has dementia, especially if they have hallucinations or delusions, you know, if we've made that decision that, you know, we're, we're moving towards placement, and this is the right thing, right? It's saying you are making the right decision. This is the right decision for your family and your situation, and you're not giving up a caregiving role because you're still a caregiver. It's just going to look a little bit different. And just like any transition, expect that the first month is going to be hard and that things will happen that may make you question your decision, but right? If it helps to write stuff down, here's why we're doing this so you can come back to it, right? Self-efficacy, resilience. Like, I made this for, you know, we're doing this for a reason.

This is the right thing overall, even if it feels hard. And so, I know in his case, after like two weeks, things kind of settled down, and he was quite happy at this place, right? And every facility is different. And I've been, during home visits, we did home visits at some nursing homes and some, it's hard to imagine anyone being happy there. Right? And so, it's very dependent on the place and the staff, right? And the staffing ratios and all those kinds of things. But there are a lot of success stories with people transitioning to a facility. And you know, I have folks where they will go home with family for the weekend, right? Or they'll go home, you know, I have folks where they go home for Shabbat dinner on Friday night, or they go, you know, home for Thanksgiving weekend or for Easter weekend or things like that. So, I think people think about placement as sort of a binary, like they're there or they're home.

And it's not so black and white, right? They will live primarily there. You're paying for someone to be primarily in a place, but it doesn't mean that they can't come out. It doesn't mean they can't come home.

Polly Dawkins:

That's a nice way to think about it. Yeah. Alright. In keeping with the theme of uncertainty today, there are two issues that have come up over the last seven weeks, and we are going to address them more fully today. And those are the topics of anticipatory grief and ambiguous loss. And those are big words and big concepts. And I wonder if you might help us understand what those words mean so that we can talk about them a little bit more fully.

Jori Fleisher:

Yeah, absolutely. And I want to say if these definitions and these concepts feel kind of like a Venn diagram to you and that they overlap a little bit, maybe it's just because that's also my understanding of them. I feel like there's a lot of overlap here. So, ambiguous loss, and I tried to pull up a good definition, is a type of loss that's unclear or without closure. And so, this can be a response to, for example, like a psychological absence. So, if you know kids who have, you know, a parent who maybe is physically present but emotionally very distant, right? They don't

get the kind of emotion from that parent that they might hope for. They may have this sort of like, you know, I wish I had a mom like everyone else's mom, or I wish that my dad, you know, was present, and I don't feel like I have the relationship even though I have the person, I don't have the relationship, right?

Or it's a loss without closure. So, someone who has a really fraught or estranged relationship with a parent, and then that parent dies. It's not just the grief, but it's the, I had all this stuff that I needed to work out, and I never got to get closure on that. I never got to put that to rest. I never got to solve that kind of psychological angst. But another example of ambiguous loss could, you know, almost be, I think about this, at least having heard my mom describe these enough times, you know, sending a kid away to college, right? It is, it is a change, and it is a kind of loss, especially if they're, you know, farther away and you're not seeing them. This was what life looked like, right? And then there is this loss, there's a psychological absence, right? Of that closeness that was there before, right?

And it's not; it's not the same as grief, right? They're not dead. But it's, but it's a different kind of thing. Sometimes, this is also a loss of what life was supposed to look like. And I think that resonates a lot, you know, with my folks is this wasn't supposed to happen. I wasn't supposed to have Parkinson's. My loved one wasn't supposed to have Parkinson's; we were just about to retire. We had planned to blah, blah, blah, blah, blah. And this is not what life was supposed to look like, right? And I wish, I will try to look up this poem because it's been pivotal in my life. But there's a great poem. I will find it. But it was read to me in the context of, I grew up with a very close family member who has a severe neurological illness.

And so, my, my aunt and my grandmother have this poem that she read to us from when we were young, and it's, to summarize it badly essentially is, you know, I was planning to take a trip to Paris, and all of my friends have been to Paris, and they've told me how beautiful Paris is. And I packed my bags, and I did all this stuff, and I planned up my itinerary, and I got on the plane, and they said, welcome to Holland. And I didn't plan to go to Holland. This is not where I'm supposed to be. And, like, where is my baguette? Where is my this, where is my, yes, Debbie, welcome to Holland. If someone can find welcome to Holland, please post it here; I'm going to get off [...]. Right. But it's that ambiguous loss. And so, this, you know, resonates particularly, I think, with families who have, you know, children with neurologic illness, right? As my grandma forever. We just sort of said, you know, we live in Holland now. And I think, you know, thank you, thank you, Mel, and Holland.

Polly Dawkins:

This can be pretty cool.

Jori Fleisher:

Holland is great. They have tulips there. It's beautiful, right? And just because it's not Paris doesn't mean it's not an equally wonderful, meaningful, gratifying place to be, but it's not what we planned. And so, it is this like a beautiful embodiment of ambiguous loss, right? So that's

kind of, that's ambiguous loss. Thank you. And then anticipatory grief, and again, I think this kind of overlaps a little bit, but is grieving ahead of someone actually passing or basically grieving the person they used to be, even while the person is still with you? So, particularly in the case of someone with dementia, right? It's sitting at the kitchen table, you know, being mid-conversation, and the person has this cognitive fluctuation where they're just, they're in the days and just sitting there and going, you know, I miss my husband, I miss my brother, I miss them, even though they are still there, but it's not, it's not in that moment, that whole person who they necessarily used to be. Right? You're missing what things were, and your kind of grieving for the loss of them even while they're still present, if that makes sense.

Polly Dawkins:

Yeah. Well, yeah. That's hard. And I think about for those of us who are so close in this community, we, and maybe we aren't care partners, we're just like waiting for the other, the other shoe to drop. Like, when are we going to learn the news that it's like you're anticipating the grief that comes along with this and working and living with Parkinson's?

Jori Fleisher:

Yeah.

Polly Dawkins:

What impact does anticipatory grief or ambiguous loss have on the relationship of a person with Parkinson's and their caregiver or care partner?

Jori Fleisher:

I mean, I think I've seen it have a couple of things. Sometimes, it can really drive a wedge into the relationship. Sometimes, the person with Parkinson's may feel, you know, that loss really acutely, may feel stigma about it, may feel shame or guilt in some way, even though we all know there's nothing that a person did to make them have Parkinson's. Right? And if I'm the first person to tell you this, please, let me tell you again: There's nothing your loved one did to have Parkinson's. So, even that said, there's still often a, I'm sorry, you know, I feel bad that I have this, and it's making our life look this way. And you're not getting the retirement that you planned in Holland. Right? And so, you know, I'm sorry that, you know, this is not what we planned. And sometimes, that means that the person with Parkinson's may withdraw into themselves.

Sometimes, it means that there's anger, and even though that anger might be directed at the disease deep down and at that stigma or the shame or the guilt, it's directed outwards, right? And who's going to be the person who's most likely to feel the brunt of that anger? It's the person closest to them, which is their care partner, right? And so, I think people who I've seen cope with this the best are those who will, you know, will call it out and say, this is, you know, this is going on, something's not right. Our relationship is not what it used to be. And you know,

I want to be able to get past this. I want to be able to get back to that space. And they will find a therapist, whether that's individually, to be able to talk through that. And I think for the person with Parkinson's to be able to get some of that out, right?

Their own ambiguous loss, their own guilt, shame, stigma, whatever, right, that they're going through, which may evolve as time goes on. You know, and many people have never talked to a therapist before. So, let alone to cope with a, you know, a diagnosis and to cope with change, but then to, like, what, I'm supposed to just vent this to someone else? Yes, that's their job. They literally want you to go to them, and they are helpers. Therapists want to be able to help people process hard things. So, I think, you know, I've seen folks who have gone to a couple's therapist and talked about this together but also just, you know, seeing folks individually. And that can be really helpful. I think support groups can often be helpful, particularly if there's time where everyone's together and then there's time where, like the people with Parkinson's and the care partners, kind of have their own safe spaces. Because so many times, I think we don't talk about these complex feelings enough and how common they are. And so, people are living in their own bubble thinking, this is just me, or this is just us, or I'm doing something that's making them feel this way when this is a global, you know, this is universal to the disease at some point or another.

Polly Dawkins:

There has to also be feelings of shame for feeling that way. And that's just gets into a whole thing.

Jori Fleisher:

A group of all of the feelings and swirling and all of that. So, let's say you shouldn't have to untangle that, right? All on your own.

Polly Dawkins:

Care partners don't, you know, if you all don't deal with it, you may feel resentment, frustration, anger. We've talked about some of those feelings in our couple of sessions ago. And then you may end up taking it out on your loved one.

Jori Fleisher:

You may take it out on your loved one. You may take it out on yourself, right? Which impacts your feeling of self-efficacy. Because if the self-talk is just, I'm not getting anywhere. This is bad. This is terrible, right? Then, you're setting yourself up for failure. You're also setting yourself up for all kinds of health consequences. We know that caregiving takes a toll. And if you're just keeping this inside and just kind of simmering, right? Blood pressure goes through the roof; pain can increase depression, anxiety, and all of these things. So, you are not alone in these feelings. And, you know, trying to get ahold of it in any way that you can, but you don't, you

don't need to be alone in this. And I think the, you know, self-efficacy makes it sound like you should be able to do it all yourself. It's not.

Polly Dawkins:

Yeah.

Jori Fleisher:

Right.

Polly Dawkins:

So, in addition to therapy, talk therapy that you've mentioned in support groups, what are other strategies that you've seen care partners employ to help deal with some of these feelings?

Jori Fleisher:

I mean, exercise is a big one. I have a lot of people who metabolize their feelings by movement. And I think it's really, you know, movement can sort of be a form of meditation for a lot of people. Whether it's just taking a walk in their neighborhood, you know, if there's a time, especially if they need someone to back them up, right? Have a neighbor, have an adult child, have someone come over and just say, I need these 30 minutes. Right? It could be a bath, it could be a shower, it could be going to a rock-climbing gym. It could be going to a, you know, I have people who box, and they literally go, and they hit a bag, right? As long as you're hitting something and you're not hurting yourself, and you're not hurting anyone else, take it out however you need, right?

I have people that will just go downstairs, and scream into pillows, right? Humor. I see David put humor is very important. Absolutely. Absolutely. Right. And I think it's recognizing, you know, does that mean humor means being able to joke with your loved one about the situation in a sensitive way where you're laughing at the situation, not at them? Does it mean coming together at the end of a hard day or the middle of a hard day and just putting on something on Netflix, right? Whether that's a standup special, whether that's just something you can watch, whether that is looking at silly memes right online, you know, that brings me, that helps me with my Sunday scaries as I look forward to gathering the memes on Sunday night. But I think humor is so critical, and it's one of the highest coping mechanisms that we have.

Polly Dawkins:

Yeah. Janet asks us, how do you find a therapist who might have expertise in care partnering or caregiving, especially if you live in a rural area?

Jori Fleisher:

Oh my gosh, Janet. That is a, Janet, that's a great question. Hold on. I was going to find you a website. I cannot guarantee performance in rural areas, but I love that question. Oh, well, this just tried to find where I am right now here in Minnesota. Okay, so Psychologytoday.com and there is a button for the therapist finder. So, what is this? So, this is essentially like a dating app to find a therapist. So, you can select, I only want to speak with a man, a woman who speaks this language, who takes the following insurance, and who has expertise in depression, anxiety, PTSD, chronic illness, and caregiving. There's a ton of different filters, right? And if you're in a rural area, the pickings may be slimmer for people who are right there, but telehealth may enable you to find someone who can help with, you know, who you can reach and talk with virtually.

And yes, it's a little bit of a different experience than like being right in the room with a therapist where, you know, they might be able to pat you on the shoulder or hand you a Kleenex, but someone who gets it is better over zoom than being right in the room with someone and going like, they don't, they don't get it. That is not the right person for me. Yeah, but I think, you know, Janet, you also bring up a great point, which is caregiving in a metropolitan area is a very different experience than caregiving in a rural area, right? And I have had the horrible experience of, you know, having folks where we need to take away driver's licenses because of safety issues and, you know, repeated problems and they're rural and it's like, I've just cut off independence, right? In the city.

You know, we could get buses, we could get, you know, pickups and things like that, but it is so much harder, and resources are fewer. So, I don't in any way want to [...] that our rural folks face so many challenges. And it is actually an area of interest, like within the National Institute of Health grants, you know, that are research studies that are enrolling people, they literally will say like, and what are you doing for underrepresented populations? And rural populations are included in that. Yeah. So, we see, we know you're out there. We're trying to get to you. I think this is another reason, and I'll just put on my advocacy hat. You know, telehealth works, right? We're proof of this right now, right? We're all on Zoom, right? Even if you're watching later, you went online, and we're doing the thing, right? And so, we can connect with people who aren't right next door, but call your congresspeople, call your senators, keep telehealth in place, especially for folks where it's not like you can go next door and find a Parkinson's specialist. It's not like you can go down the block and find a therapist who specializes in Parkinson's care, you know, Parkinson's care partnering, right?

Polly Dawkins:

And you may not have to leave your person to do it, so, right. You are doing it.

Jori Fleisher:

Yeah. So, the other thing I'll say about therapy, which I think if I haven't said before, has resonated with some of my, like folks, is think about finding a therapist, like finding a pair of jeans or for our men if like pair of jeans doesn't resonate cargo pants, right? So, you could go into the store, right? And if you're a woman, you've often like had the experience where you

can look at the wall of jeans or the stacks and go like, those are absolutely not going to work for me. No. Right? And then you pick a few pairs, and you're like, maybe these could maybe work, and you try some on in the fitting room, and you're like, eh, not what I thought, no, this is not going to work. You put it back; you're not marrying the jeans; you're not making a long-term commitment in the fitting room.

You took them to the fitting room, you put them back, right? You try on another pair of jeans or cargo pants, right? And so, whatever works for you in the analogy, right? Finding a therapist who feels like a good fit. I have a lot of people who are like, what if I don't like them? How do I break up with them? And I'm like, you're not breaking up with them. This is their job, and you're not the first person to meet with them once or twice and go, I don't think it's the best fit. You, I think people put a lot of angst around, like, how will I tell my therapist that I don't like them? It's like, you're coming to them because you've got other stuff to manage. Don't make this a whole other thing to manage. Thank you so much for your time. I've decided to go in a different direction. Then, you find the next person on the list. You pick out the next pair of jeans, and you try it on. Yeah.

Polly Dawkins:

I wonder, from those of you in the audience in the chat, would you share with us some strategies you've used or techniques you've used to deal with those feelings of uncertainty or ambiguous loss or anticipatory grief? Does anybody have any ideas? And while we're soliciting ideas from the audience here, jury, do you have any other things that you've seen community members do patients and care partners do?

Jori Fleisher:

I've seen, I've got a couple of people who journal. So, I saw someone, you know, wrote writing as something that they're good at, but journaling. And sometimes the journaling is like, you know, here's what I think I did really well today. Right? And sort of having a gratitude journal, which has all kinds of benefits. There are lots and lots of benefits to practicing gratitude, right? And I've also seen people where if they're having a bad day, if they're struggling, if they're feeling whatever that emotion is, they will literally write it down on a piece of paper, and then they will burn it, right? And they will like the therapeutic effect of just scribbling, right? They didn't listen to me, and they didn't take their meds, and then they wore off, and then we couldn't do what we wanted to do. And then they literally light it on fire in a safe, contained way. Not encouraging anyone to go pyro, right? But in a safe, contained way, you know, just being able to see that pass. I mean, I have friends who have gone through, you know, a difficult divorce, and it was very therapeutic for them to take, you know, pieces of things and stuff, you know, that was related to that relationship and just one by one sort of drop it into the fire and just kind of have that go away.

Polly Dawkins:

Yeah. So, Jori [...] meditation; people are saying meditation, another maintaining a sense of humor. Laura says, look at what we have been doing right at the moment or what has been going right at the moment and share my appreciation with my partner. I think that's, yeah, that's lovely.

Jori Fleisher:

I mean, there's truly so much science around gratitude. It kind of helps build neuroplasticity; it helps shape your brain if you take time, no matter how hard the day is, to find something small. And there's some great like, apps out there. So, there's, I forget the name of the one that I use, but day one, I don't know if I can show the little icon in case people are looking, but it's that little bookmark looking thing.

Polly Dawkins:

Your Peloton app. Oh yeah, sorry.

Jori Fleisher:

But exercise also works. But there are all kinds of little like gratitude journal things that you can keep in an actual journal. But you can do, you know, if this way, if you're someone where like getting that little reminder on your phone every morning of like, don't forget to be grateful. Right. You can set it for whatever time of day you want to be pinged. And there's really great evidence that even just coming up with three things, they could be teeny. Right? On my commute, I went straight through two green lights that usually I get stopped at every single time, right? I had smooth whatever it is, right? They don't need to be big, but then the research tells us that when you get into this habit, you go through your day recognizing like that, you're more on the lookout. You're sort of alert to gratitude, right?

Your kind of looking for what are all the things. And even on really bad days, I'll speak for myself, that there are just times where it feels like nothing goes right, and there's chaos and there's all kinds of things. And as long as I remember and I haven't crashed, you know, and like, okay, well, I guess there's this thing and I guess, you know, I cooked this thing and it didn't totally, you know, one kid ate it. So, that was great in this. And the more you start to do it, the more you find these little things. And some people really like to be able to go back through a gratitude journal. Some of these apps will ping you and show you things. You can load photos to some of them to have just a visual reminder of what made you grateful. Right? But whatever that is, I have people that will collage and scrapbook, right? And just, you know, tearing up paper and putting, you know, things together. Sometimes the tactile stuff can really help and kind of get your brain out of that circuit.

Polly Dawkins:

I think that's very akin to our founder. Davis Phinney talks about, you know, at the beginning of his diagnosis 23 years ago sort of redefining what victory meant for him and pausing and

noticing those little, those little moments. So, noticing gratitude and things, you're grateful and noticing the victories. And so that's where the David Phinney Foundation tagline: every victory counts. It's about noticing those little things and adding them up. And all of a sudden you start to see a pattern, a pattern of wins, if you will, of victories, or a pattern of gratitude of things that you're noticing around you.

Jori Fleisher:

It's completely right. And there's, I mean, there's a great quotation, I think it's Jamie Tardy that's like, success is a series of small wins.

Polly Dawkins:

Yeah.

Jori Fleisher:

Right? No one wins the Nobel Prize because they were lying in bed one day and they were like, I have this idea. Right? It didn't come out of nowhere. It was years and years and years and years of probably failing and failing and testing and failing and testing and failing and, you know, all this stuff. And tiny, small wins along the way that led up to that. So, I love that it's finding those wins. Right? And the more you pay attention to them, the more you see, and the more you see, the more you realize, like, you know, maybe Holland is pretty great.

Polly Dawkins:

They have those stroopwafels, those cookies.

Jori Fleisher:

Yeah. Those are awesome.

Polly Dawkins:

They're pretty great. Susan said that instead of running an errand yesterday while husband was exercising, I spent a half hour reading at the library. It was wonderful. It's like, yeah. It was taking time out, noticing.

Jori Fleisher:

Dry cleaning can wait.

Polly Dawkins:

Dry cleaning can always wait. Yes. Yeah. MPV mentions that they use faith, dark humor, and more gratitude. Somebody else mentioned that Facebook groups for caregivers have been really helpful.

Jori Fleisher:

Just don't believe everything you read on there.

Polly Dawkins:

So true. Take the good—

Jori Fleisher:

Take the good, leave the questionable.

Polly Dawkins:

How do we know? Because you're, I know, educating yourself here.

Jori Fleisher:

If they're trying to sell you something, I would just think twice.

Polly Dawkins:

I always, always, yeah. Any other trusting the process of small wins as [...].

Jori Fleisher:

Love it. Yeah. Someone gives a shout-out to the feelings wheel, so I'm glad that's helpful.

Polly Dawkins:

Somebody else mentioned, oh, gratitude wheel. So, that's fun.

Jori Fleisher:

I have folks who used to be avid readers and felt like, you know, whether because of their job, because of, you know, caregiving responsibilities, whatever it was that they just did not have time for reading. But if you ask them, like, are you checking Facebook? Are you checking Instagram? Are you checking? You know, are you doing, how many times in an hour do you need to check your email? Really, really? Right? Can you, or, okay, right, same, right? But like, are you, so for example, you know, I had someone tell me, you don't actually need to watch the news. Right? And this felt very jarring to me, and it felt, I heard that and was like, no, but then how will I know what's going on? Right? And there's this great book called *Make Time*, and the whole point of it was like, you know, there's a lot that's been engineered with social, social media and the news and all this stuff to like, make us feel like we have always to be connected. Then if we're not always checking all the things all the time, we're going to miss something. But it's actually the opposite. Like, if something big is going on, you're going to know, right? Eventually, if you know, two minutes later or an hour later, right? You're going to know. And so

instead of watching the news, if you're watching the news first thing in the morning over breakfast, take 10 minutes and read a book, right?

And it feels like, well, how much can I get through in 10 minutes? You're right. But then how meaningful was that 10 minute of news? But 10 minutes adds up. And if you take 10 minutes while you're, you know, sitting and having lunch or 10 minutes while you're waiting for them, you know, laundry timer to ring you know, read something, right? It could be a magazine, it doesn't matter. But does it something that brings joy and just brings you into a different space? In that moment?

Polly Dawkins:

Laura mentions to us that she massages her partner's back and legs in the morning, which helps him with mobility, and it's a good way to connect. And I think that physical touch—

Jori Fleisher:

Yeah.

Polly Dawkins:

Develops intimacy. Go ahead.

Jori Fleisher:

Yeah, they've taken like dual massage lessons. So, you know, the care partner being able to massage the person with Parkinson's and having connection that way, but also the person with Parkinson's learning to massage their care partner, right? So, what a gift to be able to give each other. Yeah.

Polly Dawkins:

Folks in the audience, do you have questions about uncertainty, ambiguous loss, or the concept of anticipatory grief—any of the topics we've talked about today? Your other questions unrelated to today, we are going to address next week. Anybody have any big universal questions for us? And if you've raised your hand, we can't, we can't see you, so please go ahead and put a question in the chat. Somebody has asked us how to learn to cry, how to learn to cry over it. I don't know the answer for that. Do you?

Jori Fleisher:

Think giving yourself the space to say it's, okay? Right? Crying is it's a natural mechanism. It's built in, right? We kind of train it out of people. But it's a way for your body to process stress and strain and emotions, and even good emotions, right? So, for some people, they just, they feel like they need to cry, and they can't. So, I was just going to say, I see [...] said someone said they cry in the car. I have people that tell me that they cry in the shower. I have other folks that

tell me, you know, they'll cry during like heavy exercise, so they'll cry on a bike, right? Or putting on music that, you know, like that song is always going to get you right, and you know that you need to let it out, but you kind of can't get to that place. So, you know, if I think everyone has seen, right, the horrible commercials for like animals and shelters, right? And can you please donate and, you know, save the puppies and all of this in Sarah McLachlan playing in the background, right? That song every time, every time. So, if there's, you know, if there's a song that gets you and you know, that will sort of help unlock those tears, so that process, put that song on repeat, right Put that song on Spotify, wherever you need to put it. Yeah.

Polly Dawkins:

Ellen asks us, when does feeling grief and loss and being upset actually become depression?

Jori Fleisher:

That's why it's a great question, Ellen. I'm so glad that you brought that up because I think when does it become depression, and when can it be complicated grief? Which are different things? So, I would say, you know, when does it become depression? We ask people a lot of different things that are symptoms of depression. So, you know, are you feeling sad and blue down? And that feeling is there for most of the day, you know, most days for two weeks or more, right? Or are you feeling a sense of guilt or worthlessness, or people would be better off if I wasn't here, right? Not even active suicidal ideation, which absolutely, if you're feeling, you know, suicidal, please, I don't know if people know about this, but if you or anyone you know is expressing feelings of self-harm or suicide, there is a new national emergency number 988. 988 is the National Suicide Hotline.

It is 24/7. There are people there all the time. I believe you can actually even text 988 and get text support. But share that far and wide. I don't think they've publicized it super well. But if you're feeling that way, if you are suddenly, you know, not sleeping at all, right? Or your sleep is, you know, really, really struggling to sleep, or on the flip side, sleeping, you know, tremendous, tremendously more than you did before. Or the same with eating. You're, you know, overeating, or you just, you've lost your entire appetite, right? These things that kind of go with that moving through life at just this frantic pace or psychomotor slowing, which is basically like you're watching someone kind of walking in slow motion, they're like moving through jello that just, everything seems slower. So, there's both sort of the mood component of depression.

You know, someone being able to say, I feel sad, I feel depressed, right? And it's not just, it's here for a fleeting moment, and then it goes away. It's there. And that's kind of where they're living, right? If that's going on, please, please, please reach out for help. Reach out to your healthcare providers. Call your primary care doctor. Call a therapist, right? A psychiatrist. I think that's really important because these can absolutely go hand in hand. And then, you know, if someone has grief, if they've lost a loved one, there's this idea of complicated grief or complicated bereavement. And for whatever reason, and I cannot tell you why this is, people ask me this all the time, and I'm like, I simply do not know the DSM. So, the diagnostic manual,

which is what psychiatrists use, it gives us like the terms that we use for psychiatric illnesses. So, the DSM defines bereavement, the normal process of grieving, as lasting for a year after a loved one has passed.

I am unaware of anything that magically happens on day 366, where you're like, okay, now I'm good. Right? And it's not what, you know, this is trying to say, but grief that is prolonged where the person really is, you know, having a hard time reintegrating with life, you know, with their social connections, you know, and it's been past that year mark, or people who are, you know, still within that acute grief, you know, within that year, but are, you know, having trouble getting up out of bed, having trouble, you know, not eating or not sleeping or oversleeping, you know, things like this. Or are, you know, it's not uncommon for people to think that they saw their loved one out of the corner of their eye or think that they saw their loved one in a crowd, you know, if someone has passed on, right?

Or to have dreams about them. But when it's happening a lot, when the person is having a hard time distinguishing what's real, those can be symptoms of complex or complicated grief. And those we want to make sure that we're treating people. So, telehealth care providers, get help, and talk with a therapist. There are things that people can do. And, you know, [...] if someone has a very sudden unexpected loss, like there, that can increase the chance of complicated grief. So, those are just kind of things to know about. But if you're going through those feelings, you are not alone. And there's help for that.

Polly Dawkins:

Betsy asks an interesting question. She said, I have felt anti anticipatory grief for years. Often when I see our former pictures. Well, having felt all this grief preempt the significant grief of losing my person to death.

Jori Fleisher:

It's such a great question, and I certainly don't have the answer. I think I've had some people, some care partners, tell me that they did feel as much as they never would've wanted any of this to happen, right? That losing their loved one in this kind of slower way, right? Not all of a sudden kind of seeing the changes slowly they felt did make things a little bit easier at the end. But I've had other people where it didn't seem, you know, it's not a savings plan where if you pay enough upfront, there's less to pay at the end, right? I think there's just this bank of grief that's different for everyone. And so, I don't know. I think being able to recognize feeling that anticipatory grief is normal and, you know, very normal in the setting of Parkinson's and other related diagnoses and balancing that with the gratitude and the mindfulness of here's what we can do. You know, here's what we do have, here's what we are able to do together, right? And here's what quality of life looks like now.

Right? It's not what we thought it would look like before, right? And we know this from a lot of research is if we ask people in the context of like, advanced care planning, if you ask a 20 something year old person, you know, what happens if tomorrow you're in a car accident and

you become paraplegic and you're in a wheelchair for the rest of your life, right? Many people would say, I would never want to live like that if that's what happens. Don't let me survive like that. If you ask someone who's in a wheelchair and say, this is not what you had hoped for, right? But do you have a quality of life? Absolutely. I have my family, I have this, I can do this, I can do this, I can do this. Right? And so, as, as life evolves and as you know, diagnoses change and progress, what we thought quality of life would look like and what would be enough for us changes over time, right? And that's resilience, right? And so, I think being able to say, you know, yeah, it says in Paris, right? But it's Holland. And you can still mourn in Paris, right?

Polly Dawkins:

Yeah. Dan and Nick say, I think the care partner needs a care partner for themselves, too. In my case, my person as my care partner makes for a great relationship and helps us both through our journey with Parkinson's.

Jori Fleisher:

Yes. And I'll say, I can't remember if we've talked about this before, but connect with other, you know, care partner people with Parkinson's pairs. I know a crew that they were four couples, and they were meeting and doing dinner on Zoom all throughout the pandemic. And the care partners, you know, could, they didn't have to explain, they didn't have to excuse anything, right? If someone dropped a fork or if someone spilled something, right? There was no because they were all in this, you know, in this boat together, right? Even though everyone's Parkinson's and everyone's loved one was different, and all the care partners were different, right? You sort of lowered the threshold of like; you took away the stigma. You could just be, and those care partners, I've seen them be unbelievable care partners now for each other.

Polly Dawkins:

Beautiful.

Jori Fleisher:

It's really beautiful. And especially among, you know, some who've lost their loved ones and just the relationships that have formed between the care partners and the way that they have learned to advocate and the way that, you know, this process has made them stronger and has developed friendships. So, you know, no one ever, I tell folks when I make the diagnosis you know, no one ever asked to be part of this community, but you're here and it's the most amazing community you'll ever be part of. So, there are plenty of people in your pre-diagnosis life who just won't get it. But there are plenty of people here who do. So, find the helpers, right? Find the people who get it, where you don't have to explain, and you don't have to excuse, and you don't have to ask permission. You can just be, right? And you can know that they're just being, and you can talk about it.

Polly Dawkins:

We have some care partners connected to the Davis Phinney Foundation who have lost their, their person, their loved one, and continue to work in this community and continue to be mentors and help others through. And some of them say, you know, this was the best work of my life. and I don't, I don't want anybody else to have to go through that alone. I'm going to help them through that and continue to give back because all that experience is really useful.

Jori Fleisher:

It's invaluable. And I think, you know, thinking about self-efficacy, I've had some of our folks who've been mentors in, you know, prior studies and hearing from them, I mean, they've said things like, you know, I'd never realized that I knew this much.

I didn't think, you know, Jori, their loved one may be gone. And they were just sort of left with like, what did I do with those years? And to realize that there's so much lived wisdom, right? And just practical experience and that that is absolute, that's gold for someone else. I mean if you think about, you know, here's what I know now about Parkinson's. Here's how we manage now, right? With Parkinson's, and did I know any of this five years ago or 10 years ago? Could, you know, could I do this then? It's not the skillset you might have hoped that you would glean in the last however many years, but it is a skillset, right? It's an emotional skillset, it's a knowledge skillset. You have so much by virtue, just by virtue of living with Parkinson's. But you're here, right? And this is not, I would guess for most people, this is not the first time you are engaging with, let me learn something more about this condition, right? So, it's all in there. It may not feel like it's in there at, you know, four in the morning or in one of those moments where you want to go and scream into a pillow. That's okay, but your brain remembers it's all in there.

Polly Dawkins:

I think we're getting close to wrap up for today, a little early for today, unless others have others have questions about these topics, I think we're going to come to a close a little bit early, give you all a few minutes back in your day. And joy, you can help on a plane. Any other questions or comments?

Jori Fleisher:

She said she remembers someone saying, we're not to worry. Our personality will return after this journey with Parkinson's. I think that's the other thing to remember is, you know, and this is true with any journey, right? Is that how their will be life after caregiving for a lot of people. And for some people, that is a really bittersweet thing to remember, but you are still you, right? Just the way that despite being a caregiver, you are still you despite your loved one having a diagnosis, they are still them, right? And hold on, remember those things that bring you joy, that you are good at, that teach you self-efficacy because you can go back to those, right? You'll have those again in the future. So, yeah, I would say people's homework is you get like 40 free minutes back in your day that someone else might think that you're supposed to be doing



something. Breathe, bike, go scream into a pillow, go do something. Right? You get 43 minutes, do something with it. Take care of yourself, right?

Polly Dawkins:

What you're grateful for.

Jori Fleisher:

Yes.

Polly Dawkins:

Yeah. Jori, audience members, thank you so much. Bye-Bye. Thanks, everybody. Bye-Bye.

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