



**The Victory Summit® Virtual Event: Care Partners  
Mood and Mental Health Strategies For Care Partners**

Recorded on November 13, 2021

Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

I am going to introduce our first speaker. I am thrilled to welcome Jessica Shurer to our virtual stage. Hi, Jessica. Jessica is the director of patient and care partner advocacy for the cure Parkinson's or excuse me, Cure PSP, whose mission and services are dedicated to the awareness, education, care, and cure of atypical Parkinsonism diseases. Prior to joining Cure PSP, Jessica served as a center coordinator and the clinical social worker of the movement disorder centers at the University of North Carolina Chapel Hill. And she was in that role since 2012. So, Jessica, welcome. I'm going to go off my screen here and turn it over to you. Thank you for being here today.

Jessica Shurer, MSW, LCSW (Director of Patient and Care Partner Advocacy, CurePSP):

Oh my gosh. It's my pleasure. Thanks everybody. So, yeah, I've only been in my new role for just over a month now. So I'm mostly working with folks with a progressive supranuclear palsy, corticobasal degeneration and multiple system atrophy now, but I spent nine and a half years primarily working with people with Parkinson's disease. And that will always be, I mean, y'all will always be and still are just did incredible you know, so close to my heart, this, I never want to fully leave the Parkinson's community. So it's really special to still be connected to everybody. I also had the honor of being part of actually I have a copy here too next to me, I just got it in the mail the other day of being one of the authors for your Every Victory Counts manual. And anyway, I just think Davis Phinney Foundation is a wonderful, so it is great to be here.

So let me share my screen. It's always the fun part of the whole zoom thing is doing the whole screen share thing. So yeah. Hi everybody. I'm Jessica. Happy Saturday. I am wanting to talk about the importance of addressing mood and mental health for care partners. I think that in the caregiving world and the Parkinson's world, we very often talk about the importance of self-care for care partners. But sometimes we don't always break that down into more specifics about what that can really look like or mean, but attending to mood and mental health is really a huge part of that. So that's really what I want to focus on today.

I have to acknowledge this is the tip of a very large iceberg. Mental health is extremely complex, right? It's dynamic. And it's also a very subjective topic. We could spend many hours, way longer than 50 minutes talking about this topic, but I do want to use this as an opportunity

for reflection and to really have a conversation. I'm going to try to save as much time as I can at the end for conversation and questions. I really wanted to start a conversation around mood and mental health of Parkinson's care partners. I think it's really important for us to normalize this as part of the human experience. And to think through ways to be more intentional about addressing this. Now, of course, I also want to recognize this is very personal and everybody defines mood and mental health very differently. And so thinking through how you define that for yourself is a part of this process.

Okay. So what is it, what is mental wellbeing, mood, mental health? I mean, these are all really big and sometimes broad, in general terms. Like I said, everybody defines this differently, but very generally what we're talking about is the emotional, psychological, and social health aspects of our health. But again, thinking through what this really means for you, and you all know, I mean, in that poll, we saw that many of you have been living with Parkinson's in your lives for many, many years. We know that in Parkinson's historically there has been so much attention to the physical health of Parkinson's. We call it a movement disorder. We focus on you know, on exercise and on pharmacological treatment and on your mobility. And of course, all of that is extremely important, but we also know it's equally as important to attend to the non-motor symptoms of Parkinson's disease.

But this goes for everybody as well, we talk about the importance of exercise and of going to the doctor and everything, but are we really talking about our mood and our mental health enough? So I think a lot of times care partners, just like we get real used to as care partners attending to the physical aspects of Parkinson's. You know, that's, we're seeing the same things with how care partners are taking care of their health. Parkinson's disease brings up a very complex emotional journey. This changes over the course of Parkinson's and I'm sure many of you can think back to when Parkinson's first came into your lives and how you and your partner reacted to that. How you felt about it, the fears, the questions, the considerations that that brought up for you, how you coped, how you've been coping with it, whether diagnosis was two months ago or 20 years ago, Parkinson's disease can bring up what we call anticipatory grief.

So a lot of feelings around what is this going to mean for me in the future? And you know, what's going to happen next? What should I expect? There's a lot of unpredictability with Parkinson's disease and it can be really hard when you don't get those answers from your providers about what to expect. And so it's sitting with that uncertainty. Again, I mention this because all of this is part of the complexity of what mental wellbeing means. I recently had this as a topic in one of my Parkinson's support groups or really, you know, an open discussion topic. And it was around this point, when we were talking about the emotional journey that one of the Parkinson's care partners called it a two-way street. She said that how I'm doing as a care

partner mentally and emotionally has an impact ultimately on her partner with Parkinson's disease.

And she said how her partner with Parkinson's disease is doing mentally and emotionally impacts her. And so it was really you know, it was really this two-way street between the two of them. And I thought that was just such a good point. Also, when we talk about mental health and mood, and this could be its own whole topic by itself, but wrapped into that is the care partner identity. You're, just like when someone gets diagnosed with Parkinson's disease and they have to live with that label, like now I am a person with Parkinson's or a patient. And what does that mean for my sense of self? We see that with care partners too being labeled as a care partner or a care giver and what does that mean for yourself incorporating that role and adjusting to that role into your sense of self into your lifestyle and your routine.

We also see when we talk, and this is important when we talk about self-care, but we see a lot of care partners, not having these conversations around mental health and mood or self-care because they share, they feel like they have to stay strong all the time for their person with Parkinson's disease. They have to keep, one of my support group members recently called this, they have to keep an even keel. So that means not really showing a lot of emotion about the journey. And that also means not showing vulnerability themselves because so much of that energy is centered around how the person with Parkinson's is doing. They don't want to bring that focus on themselves and feeling vulnerable. Of course, we also have to recognize the intersection of mood and mental health with Parkinson's disease, with other life challenges. Parkinson's disease does not happen in a void. There are other factors and situations in your life that are going to bring up difficult emotions or positive emotions. And how does that intersect with your life with Parkinson's disease?

Our mental health can also be reflected in how we talk about ourselves, how we talk to ourselves, are we very self-criticizing? Are we recognizing our own strengths or really just focused on what we could be doing better? Are we being nice to ourselves? We ask for others to be nice to us, but we're not always super nice to ourselves. And I'm sharing that from my own personal experience as well. But I hear that a lot from care partners, I'm not patient enough. I wish that I could do this better. When I brought this up in my support group recently, someone very pointedly shared that when they're asked the question of how are you, it's a very loaded question. And I think that even outside of Parkinson's and the care partner role, we see this too. I know from personal experience. You can have a lot going on and you run into someone, and they go, how are you?

And there's this very quick thought process of like, how much should I share? And you know, how much do I want to disclose, do I want to be honest with them? I just had this hard thing happen. And then you end up being like, I'm fine. How are you? Or, and this came up in my

support group recently, you end up saying something that might be very true and a little bit difficult of like, oh, you know, we've had this and this going on and then kind of dismissing it very quickly with, but, you know, I can't complain. Often, you know, I just think that this brings up the example of, are we really being honest with ourselves? Do we want to be honest with ourselves? Do we want to be honest with other people? Oftentimes the Parkinson's journey, the care partner journey is an experience that other people can't see outside of you and the other person with Parkinson's or sometimes your family or the people in the immediate, your immediate circle and network of support with Parkinson's. And we're kind of keeping that close to ourselves. I know that I'm talking about some very existential stuff at this point, and I will move forward now I promise, but I'm just, my point is mental health is very complex. But in our society, we're not really talking about this enough, or are we talking about this enough? And especially are doctors talking about this enough? Is it really coming up in healthcare to the extent that it should?

A lot of this is wrapped up in stigma as well. Stigma is very complicated in itself, but just to define it for y'all, it's a very complex construct that shapes a negative attitude towards something, it's impacted by self, cultural, and structural components. We can have self-stigma, we can have stigma towards others. It shows up with generalizations and stereotypes and behaviors. Mental health stigma by itself is embedded in the historical treatment of mentally ill and also of women, you know, around historical views of hysterics and emotions and how much we're allowed and not allowed to share our feelings. This can become internalized for us. So, you know, I, you know, when you have a feeling and then kind of shutting it down with, that's not normal, I shouldn't be feeling this. This can be a major barrier to participation in mental health services.

And it's also a barrier to people recognizing their own mental health challenges and to sharing it with providers and to providers asking about mental health. And of course, we also have Parkinson's stigma layered on top of that, Parkinson's stigma is very much related to ageism and ableism in our society. There's many misconceptions around what Parkinson's disease is and looks like. And this very much leads to people not, some people not sharing the diagnosis or trying to hide the diagnosis or not talking honestly about it. This leads to marginalization and isolation of not only people with Parkinson's disease, of care partners, but of people who are struggling with mental health challenges. It also leads us as a society to pathologizing what is really a normal part of the human experience. Parkinson's disease, other health conditions, mental health emotions, all of that. Now, I don't know about all of y'all robots out there, but most of us are human and these things happen, but we're abnormalizing them.

I don't know if abnormalizing is a word, but there you go. We're making them seem abnormal. And because of this, there's under recognition and under addressing under treatment of mental health challenges. But, and, you know, I will say I have seen more awareness around this,

especially in recent years, but still I find that mood and mental health seems to be a bit of an afterthought sometimes in healthcare. Especially when you compare it to physical health, we see this in health care sometimes we call it the hand on the door phenomenon that you go to your appointment with your neurologist or your primary care doctor. And you talk about, you know, the symptoms that have come up since you saw them six months ago with your walking or your voice or your medications, or whatever's going on. And that's really what the doctor is asking about.

And then your 30 minutes with the doctor's over, and you're literally leaving the room and you have your hand on the doorknob, and then that's when you turn and you go, oh, by the way, he's been struggling with depression recently and the appointment is over and that's something, that's a conversation that we don't want to rush. And you don't want to rush, but it's, again, it's almost like an afterthought. Another little phenomenon that we tend to see that has come up recently and I'm glad that it's coming up more recently is what I once heard a doctor called the tissue dance. So you come in for your appointment, whatever doctor's appointment and you're having conversations around what's been coming up and your questions and your concerns and all of that. And that can be very emotional, and someone might tear up, the person with Parkinson's, the care partner.

It brings up some, you know, some fears or some emotions, and they start tearing up and the doctor, there's this whole tissue dance of like, oh, they're crying now. I need tissues. Let me, where did I put the tissues, here they are. And so it's almost, instead of just being kind of prepared with tissues are here, this is a safe space to talk about some hard stuff. But a really cool thing is that we, all of us, we have the power to change this. So again, why I'm wanting to talk about this today. I want to empower ourselves, empower you all to know that we can change and normalize conversations around stigma, around mental health and mood. It's important to know the signs of what is, I don't want to call it not normal, because again, this is a normal part of the human experience, but know the signs of when, of depression, of anxiety, of caregiver burnout.

When it's time to really address this, that this is not sustainable, that something needs, something's not good here. And we need to manage this a little bit better. So with depression, we can see this with frequent crying just general sadness, maybe not finding joy in the same way that you used to, a big sign for us is when you're experiencing decreased pleasure in previously enjoyed activities. Of course, we always have to look out for thoughts of hurting yourself or hurting somebody else. Hopelessness and worthlessness is a big part of this as well, because we want you to still feel worth and value and productivity in your life. We want you to still find hope, even if that means reframing what hope means for you. So looking for those signs of depression in yourself, or in somebody else. With anxiety, I mean, everyone

experiences depression and anxiety sometimes, but what we're really looking for is very much preoccupation and worrying or negative thoughts.

Maybe they're causing you're causing sleeplessness. You can't even relax at night because there's just like this mental chewing gum, this rumination of all the things that you have to do, or that's worrying you. And it's hard to move past that. Of course, looking for situations where you have this sense of panic and that can show up very physically for a lot of people, are you avoiding certain situations or settings because they caused this anxiety or panic or increased stress, and then just general sense of fear all of the time. All of that is not good. It's not normal. You know, if these are signs that we really need to do something differently here so that you can, you can relax that you can find joy. Also knowing the signs for, you know, you care partners out there of caregiver, care partner, burnout, or a burden to the point where, you know, all these situations are going to have difficult feelings.

We're going to have stress involved. But when you hit this point of just significant exhaustion, not being able to enjoy yourself, I have a lot of care partners share that when they're, they become very short tempered with other people, and that's not normally in their nature, that can be a sign that they're hitting that burnout kind of wall. Of course not attending to your own physical health. Like when your life can seem to revolve around Parkinson's and somebody else's need to exercise and take their medications on time and go to appointments. Are you doing that for yourself too? Thinking back to like, when's the last time I saw my doctor or am I missing my medications, or have I been having some physical challenges that I'm really not attending to right now? Anger and resentment, all of these feelings are normal, but when you're feeling a lot of resentment of like, that's so focused on someone that it's hurting your relationship with them or your feeling towards them, that's again, that's not, that's not great. And that's something that is a sign of, we need to change the situation or maybe get a little bit more support or step away from this role so that you can attend to your mental wellbeing through the experience of caring for someone with Parkinson's disease.

All of this takes an incredible amount of intention and self-awareness, and checking in with yourself just as you would be checking in with somebody else. So you can ask yourself questions, like, how am I feeling, but not on a surface level? Like, how am I really feeling? And what does that mean for me? What are my triggers and how can I better manage those triggers or maybe step away from those situations that are triggering for me, thinking through and knowing it's okay to think through what is the most stressful aspect of caring for and about somebody with Parkinson's disease, but also knowing that you can ask yourself sort of the flip side of that, of what's the most rewarding aspect and knowing it's okay to hold space for those seemingly opposite feelings and perspectives about the Parkinson's experience, ask yourself what are the three things or more than three things, but in a minimum three things that bring me the most joy, or are there things that used to bring me joy that maybe I need to get back to

a little bit. Also asking yourself a part of my mental well wellbeing that I need to pay more attention to is what, fill in the blank there.

And once you answer that, what do I need in order to make that happen? And maybe that just means one small change in my life that I can make in order to make that happen. It doesn't have to be huge or earth shattering. It could just be one small change that I make. But when you ask yourself these questions really listen to yourself and really be honest with yourself in these answers. Make a plan for yourself for how you can be more intentional about addressing your mood and mental wellbeing, gather support through that journey, through that process, just as you're checking in with yourself, ask somebody else if they can check in with you too. I have, this actually just came up in a conversation yesterday. I have a patient and her husband who tell me that they, I think it's every Friday, it's once a week, they have a special sit-down time where there's no screens, there's no TV, it's just focused on each other.

And they told me they always make eye contact during this conversation where they ask each other, how are you doing? And what are you needing right now? And I thought, that's so smart, building into your routine time for you to check in with yourself and for somebody else to check in with you and for you to check in with them, find ways to manage your stress. I know that's kind of a loaded thought and it could mean whatever it means for you. A lot of people have been sharing with me, especially recently this means getting outside, having a change of scenery, stepping away from Parkinson's and from that role and from your house and these four walls for just a little bit, so you can kind of recharge and come back to it, make sure that you're connecting with other people. This has been, this has looked differently, this has been a little bit harder over the last almost two years, right?

A lot of people shared, they feel isolated. So, you know, finding ways that you can still connect with people and maybe do that safely and doing that in ways that you're comfortable with. Support groups are really great way to connect with other people who can perhaps relate to your experience, or at least to some extent where they can validate a little bit about what you're going through, tell your healthcare provider if you're having mood and mental wellbeing challenges, especially if they don't ask you, if it's something that is priority for you and it's not coming up naturally, you have the power to reach out to them to say, hey, this is something that I'm struggling with, that I'd really like your help with. And that also means seeking professional help.

Again, a lot of this is wrapped up in stigma of if I have to talk to somebody about my feelings, it means that something's wrong with me, but that's not true. Sometimes it's just really helpful to process an experience with an unbiased person. I have so many people who tell me I don't need that because I have my sister or my best friend or whoever to talk to. And that's great. I'm glad that they're part of your support network, but this is different from that. It's different from



having a friendly sounding board at someone who's trained in mental health, who can really break down that experience and give unbiased insight and focus on coping strategies around that. When you look into mental health providers, and I did put a resource up here, which is called psychology today, on that website, but just generally, it's hard to find someone who is specially trained in Parkinson's disease.

That is something a lot of my folks want to look for, but they're kind of few and far between. So my recommendation is to look for providers who say they specialize in things like coping with chronic illness, coping with medical diagnosis, caregiving, aging, grief, anxiety, and depression, because at the themes that we see across all of those are you know, going to be despite Parkinson's disease or a different diagnosis. But if that's what they're specialized in, all of those things I just mentioned, chronic illness, caregiving. They should be able to process what's at the heart of what you're needing to talk to with them.

I told you all, this was a topic in my support group recently, and I took notes as they were sharing about what mental health means for them. And here's what they shared with me. They, one person very flat out was like medications and therapy. This person has struggled with anxiety for a very long time. And she said, and I quoted her you know, I wrote down what she said, "people with Parkinson's don't understand what it's like to live with Parkinson's, people without anxiety, don't understand what it's like to live with anxiety and what she needs for that is a combination of mental health therapy and pharmacological treatment, just as people with Parkinson's need physical therapy and carbidopa levodopa," she addresses her anxiety from that same approach. And I think that can go for care partners as well. I also had someone in that support group share, "it means finding time away from Parkinson's, from not talking about Parkinson's or not thinking about Parkinson's for just a little bit."

I brought up how a lot of people have been sharing how they need to get out of the house. They need to connect with nature. They need to take walks. That definitely came up in my support group. I had someone in my group say it means learning how to breathe. And I really liked that. I mean, being intentional about connecting with your body and taking a moment and kind of grounding yourself and breathing in some fresh air. Chatting with a friend was something that a care partner shared. And then someone else shared and this led to a very rich conversation, having a safe space, to talk about it, to talk about Parkinson's, to talk about mood and mental wellbeing, instead of trying to fix it. A lot of people want to try to fix it when you talk to them about tough things. And that brings me to a little video, just three minutes that I want to share with you all. And I'll kind of talk about it after, and hopefully this works. Everyone cross your fingers.

Hopefully you can hear it.

So what is empathy and why is it very different than sympathy? Empathy fuels connection, sympathy drives disconnection. Empathy. It's very interesting. Theresa Wiseman is a nursing scholar who studied professions, very diverse professions, where empathy is relevant and came up with four qualities of empathy, perspective taking, the ability to take the perspective of another person or recognize their perspective as their truth. Staying out of judgment, not easy when you enjoy it as much as most of us do, recognizing emotion in other people and then communicating that. Empathy is feeling with people. And to me, I always think of empathy as this kind of sacred space when someone's kind of in a deep hole and they shout out from the bottom and they say, I'm stuck, it's dark, I'm overwhelmed. And then we look, and we say, hey, and you climb down, I know what it's like down here. And you're not alone.

Sympathy is, Ooh, it's bad. Unh huh. No, you want a sandwich? Empathy is a choice and it's a vulnerable choice because in order to connect with you, I have to connect with something in myself that knows that feeling. Rarely, if ever does an empathic response begin with, at least. Yeah. And we do it all the time because you know what? Someone just shared something with us that's incredibly painful and we're trying to silver lining it. I don't think that's a verb, but I'm using it as one. We're trying to put the silver lining around it. So I had a miscarriage, oh, at least, you know, you can get pregnant. I think my marriage is falling apart. At least you have a marriage, John's getting kicked out of school. At least Sarah is an A student. But one of the things we do sometimes in the face of very difficult conversations is we try to make things better. If I share something with you that's very difficult. I'd rather you say, I don't even know what to say right now. I'm just so glad you told me because the truth is rarely can a response make something better. What makes something better is connection.

I'm going to try to make sure that doesn't start again. So I share that video, which is by Brené Brown, by the way, she is a social, she has her PhD in social work and she's in Texas. And she focuses most of her research around vulnerability and shame and finding strength through vulnerability. And I share that about empathy because I find that many people don't talk about hard stuff. And aren't honest with themselves and others, like when they're asked, how are you? Because they're afraid of making somebody else uncomfortable or feeling, fearing the reaction that they're going to be pitied or seeming ungrateful for the good things that they have or getting a reaction like someone trying to fix it or make it okay. And I share that because I want us to recognize it's okay to ask for empathy. It's different than asking for sympathy. Empathy takes practice. It's meeting other people where they are and it's meeting ourselves where we are.

I think all of this, what we're talking about today takes, like I said, self-awareness, but it also takes self-advocacy. So again, defining what mental wellbeing means for you. It's trying to change conversations around mood and mental health. It's allowing yourself the permission to describe your needs and also your boundaries. So saying here's how you can help support me.

Or when someone reacts with something or offers a certain kind of help, saying, you know, that's actually really not what I'm needing right now. Here's what I'm needing right now. So a lot of this takes courage. It takes permission to feel all the feelings that's going to come up during the Parkinson's journey, whether that's feeling overwhelmed or sad or anxious or annoyed or angry, existential, but also permission to feel hopeful, to feel joyful, to feel grateful, to feel opposing emotions at the same time, knowing that it's okay to feel vulnerable and to reframe that vulnerability, finding strength through that vulnerability. Recognizing your own capacity through this, each of us has capacity for change, for growth, for empowerment, and also showing up for yourself just as you're showing up for your person with Parkinson's disease, it's important to show up for ourselves.

I was, I have a three-year-old son and I was recently reading him. I know this is a little bit a little bit different, but I was recently reading him the book, "Oh The Places You'll Go," by Dr. Seuss. And I was reading this part of it. And I was like, this is a really good analogy for Parkinson's disease and for the care partner experience. So I'm going to read that to you now. I'm afraid that sometimes you'll play lonely games, too. Games you can't win because you'll play against you. All alone, whether you like it or not alone will be something you'll be quite a lot. And when you're alone, there's a very good chance you'll meet things that scare you right out of your pants. There are some down the road between hither and Yon that can scare you so much you won't want to go on, but on, you will go, though the weather be foul. On you will go though your enemies prowl. On you will go though the hacking cracks howl (hacking cracks are Parkinson's disease), onward up many a frightening creek though your arms may get sore and your sneakers are weak, on you will hike and I know you'll hike far and face up to your problems, whatever they are. You'll get mixed up of course, as you already know, you'll get mixed up with many strange birds as you go. So be sure when you step, step with great care and great tact, and remember that life's a great balancing act. Just never forget to be dexterous and deft and never mix up your right foot with your left. And will you succeed? Yes, you will succeed. 98 and three quarters percent guaranteed. You'll move mountains. So be your name Boxbum or Bixby or Bray or Mordecai Ali van Allen O'shea. You're off to great places. Today is your day. Your mountain is waiting. So get on your way. Thank you all so much. I think we have a little bit of time for some discussion and questions. I'll stop sharing my screen.

Polly Dawkins:

Jessica. I'm smiling so much. That was tremendous. We do have some questions from the audience. Some of them are pretty hard and we may not be able to dive into them with the time we have left, but let me start with one question that somebody asks. She says, I'm a really private person and I will not normally share my trials with others. How could a support group helped me?

Jessica Shurer:

Oh, that is a good question. And I think so many of us are sort of taught very early on that we don't share the tough stuff or that we're, you know, to keep a lot of that close to us and to be private. And I think that's fine. Everyone is just so different in how they approach this, but you know, support groups, I always recommend trying one or two. You don't have to go into it sharing your whole life story. I have a lot of people who will just say to me, is it okay if I'm just kind of a quiet observer or listener for this first time? And yes, you know, you can go in just to hear the kinds of things that other people are sharing and checking in with yourself. Is this something that I, that is resonating with me that's helpful for me?

Do I feel safe or want to share? There's no obligation when you go into a support group to share. I think that just knowing that you're not alone in this experience, that there are other people out there in the world who might be able to relate to you or share sometimes very tangible pieces of advice is just very validating for a lot of people. Now, of course, if every single person went into a support group being just a listener, then nobody would end up sharing in it. But it's, you know, there are people who share a whole lot and there are people who kind of just sit back and listen and all of that's okay.

Polly Dawkins:

Is your support group today virtual or is it in person?

Jessica Shurer:

It's been virtual since March, 2020. And with having left UNC, I am also continuing to run my local support group until my replacement starts next month. But you know, eventually we'd like to go back to at least somewhat in person, whatever that means. But I think that it's a good point to talk about that too, because with virtual support groups, there can be a lot, it's a lot easier to practice anonymity in that, you know, you don't have to have your video on, you don't have to share your full name in that. It's a little bit, you're sharing space with others, but not in the same physical space so you can, it's a little bit easier to just be like, I'm gonna just sit back and listen right now.

Polly Dawkins:

Somebody asks if your support group is open to anybody in this video here?

Jessica Shurer:

You know, it's funny, I guess it technically is because it's virtual. I've had three people since the pandemic hit who moved out of state and two people in California and someone in Washington who keep, who are still coming because they can. So I guess it technically is, but it's also technically the Chapel Hill Parkinson's support group. So most people are in the area.

Polly Dawkins:

Yeah. Another question, somebody asked, if you could define from your slide, the phrase pathologizing the human experience. Could you explain that just a little bit more? What that means?

Jessica Shurer:

Sure. I mean, it's complicated, right? But so much of what we deal with on a day-to-day basis of getting a diagnosis of a physical condition or these emotions that can come up, all of that, you know, again, we're human, all of it's normal. It's normal to live, it's normal to die. I know that's a hard thing to talk about. Sometimes it's normal to get sick. It's normal to feel fear. All these things that sometimes we don't like to talk about because it's like, you know, that's too tough or that's abnormal. And you know, again, a lot of it's embedded in stigma. And so people don't like to, it's so complicated, I'm not explaining this well at all and I, but, when someone is struggling with something like depression or anxiety, or when a new diagnosis comes into our life, like Parkinson's disease, there's this fear of people are gonna look at me like something's wrong with me.

And then there's an internalization of that of something must be wrong with me because I have this diagnosis, or I'm having this experience when at the end of the day, you know, it'd be weird to go through your life just with nothing, with no vulnerability, with no health conditions with, it's okay to recognize that that's normal. We don't want to treat things that are part of the human experience as, ooh, my video just changed, what just has happened, I'm not explaining those well, it's not all, we just, we can't address things without first saying that this is okay. I did not explain that well. Did I?

Polly Dawkins:

I think that's all right. And for everybody who's listening in, if we can't get to your questions with Jessica, we will follow up in our follow-up email with some, a deeper dive into some of these topics. And so don't worry about not getting your questions answered here. And we have time for one more question. And do you have a recommendation for somebody who their person with Parkinson's has moderate dementia and the care partner is extremely depressed and isolated and needing help, needing counseling, needing to get away. Do you have like one recommendation of where that person can start?

Jessica Shurer:

Where that person can start? Yeah, well, I'm biased because I'm a social worker, but I think if you have a social worker at your clinic, or you can find one at like a local department on aging or something like that. It's real, they're really helpful at connecting you to resources. So whether that is bringing in a little bit of respite care so that you can step away and attend to your own needs or connecting you with mental health professionals in your community, who they know have been recommended by other people who might specialize in things like



caregiving and depression and coping with illness. Social workers are really good resources, but of course, you know, organizations like Davis Phinney Foundation, Parkinson's Foundation has a helpline too. I mean, calling these organizations that understand Parkinson's disease and seeing if they know resources in your community that they can connect you to, I think is really, really important. And of course your local support groups, it's really helpful to reach out to other people, like I said, who can relate, but where you can actually say, I'm struggling with this thing. Do you have any recommendations for a mental health professional or an in-home care company or something that's worked well for you that I can reach out to?

Polly Dawkins:

Thank you for that, Jessica. Thank you. Oh, go ahead. Do you have one more thing?

Jessica Shurer:

I was going to say, I didn't know you couldn't see the book when I was reading it.

Polly Dawkins:

I could see you, but you were a smaller screen.

Jessica Shurer:

I just want to show everybody, cause I kinda zoomed in on this. I said that the hack and cracks are my analogy for Parkinson's and I just want to make sure everyone can see it.

Polly Dawkins:

That's great.

Jessica Shurer:

Thank you for having me.

Polly Dawkins:

Yeah. For those of you. who would like to know more from Jessica, she's got a terrific article she's written in the Every Victory Counts for care partners manual. We gave information. We'll send information about how you can order a copy for yourself. Jessica, thank you so much for being here today. I'm going to say goodbye for now and welcome our next presenters to the stage. Thank you so much, Jessica.

Jessica Shurer:

Thank you for having me. Thank you all for showing up for yourselves today and I hope you have a great rest of your conference.



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Thank you to our Peak Partners, Amneal, Adamas, Sunovion, and Kyowa Kirin, for making it possible for us to print, distribute, and ship the Every Victory Counts manual.