



Living with Parkinson's Meetup:
The Value of Community, Purpose, and Meaning
Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello and welcome everybody to the Living with Parkinson's Meetup, formerly the YOPD Council. I'm Melani Dizon, the director of education at the Davis Phinney Foundation. And I'm really thrilled to have you all here today. For those of you who have been here for a while and have been on our monthly meetup, you might not know Bradley McDaniels but he's on the screen today. And we brought him back because he had joined our Council about a year ago, maybe two years ago, I, time is, don't know. And we were really excited that when we did this new sort of new name and everything to bring him back and get us kicked off. And so, Bradley, thank you so much for being with us today. Can you tell our listeners a little bit about yourself and then how did you get connected with the Parkinson's community?

Bradley McDaniels, PhD, CRC (Assistant Professor, University of North Texas, Department of Rehabilitation and Health Sciences):

Yeah, yeah. Thanks Mel for having me back, it's fun to get to see some faces that I haven't seen in a little while. So, this is exciting for me. So, just so you guys know, I got my degree in rehabilitation psychology and really went back to school late in life when my mom was diagnosed with Parkinson's. I had spent nearly 20 years in the pharma industry, and she was diagnosed, and I thought, what in the world can I do to help her? And I said, at 41, 2, I'm too old for medical school. I don't really want to spend the next 15 years to be a neurologist. And this PhD thing just kind of fell in my lap and I realized I loved school as an older adult and loved doing research and loved searching for these things and how can I make someone's life a little bit better?

And so I went back to school, got that, spent a couple of years at Virginia Commonwealth working in the School of Medicine there in physical medicine and rehabilitation, and ended up with a job in Texas, University of North Texas. And since I've been here, I've been so fortunate to get connected with so many people and I've done a lot of work with Indu Subramanian. She has been a wonderful mentor to me, and we have just had a blast looking at all of these things, these areas of life that make a difference and the places that sometimes we don't spend enough time talking about, which is one of the things I think we're going to talk about today. So, I'm excited to be here and just be able to offer my perspective on some of the work that that we've done. And just kind of hear the questions that come up. Those are always fascinating to me.

Melani Dizon:

Great. Thank you so much, Brad. Really great to have you here. For the new folks, I'd love for everybody to kind of just give a quick introduction of who you are, how long you've been living with Parkinson's. If you want to say how old you were, that's fine too. And maybe tell us, tell



everybody a little bit about why you love being a part of this group. I'm going to get started with somebody who's off mute. I'm going to go Robynn.

Robynn Moraites (Living with Parkinson's Panelist, Davis Phinney Foundation):

Oh, well, hey everybody. I'm Robynn Moriates from North Carolina. I got diagnosed in 2015. Excuse me. Wait, did I? Hold on. I'm having a moment. Yes. I got diagnosed in 2015 at the age of 48, but I've had symptoms for a couple of years. What I'm sorry, you caught me off guard. What else did you want us to share?

Melani Dizon:

Oh, just you know, why you like being part of this group? What do people have to look forward to?

Robynn Moraites:

I started stalking this group pretty soon after it formed, and I started finding people's emails and just emailing them and talking about what I really appreciated about this group was the candor. And I felt like some, there was such an understanding of like my state of mind, where I was coming from in terms of the research that I had done and the ways that I thought I could beat this disease and then got humbled by it in the process and all of that. So, I just really appreciated the candor and transparency that everyone talked about. Not only with their symptomology, but the emotional state that we have behind the scenes and all of that and as life unfolds.

Melani Dizon:

Thanks so much Robynn. Sree?

Sree Sripathy (Ambassador, Living with Parkinson's Panelist, Davis Phinney Foundation):

My name is Sree, I'm from the San Francisco Bay Area. I work full time as a visual journalist. I got diagnosed in 2015 and that was what seven, eight years ago, something like that. So, I've had symptoms two years before that, subtle symptoms, but I knew something was up and about 20 years before that I figured something was going on with my body due to various other non-motor type of symptoms. And the reason I joined this group is because I just want to hang out with Kat more, that's all, who's the panelist right there in the sleeveless magenta shirt. And then I wanted to take a look at Heather and say hi to Kevin and just be friends with everybody. So that's really why I'm here.

Melani Dizon:

Awesome. Alright, I'm going to move to Kat on that one.

Kat Hill (Ambassador, Living with Parkinson's Panelist, Davis Phinney Foundation):

Oh, hi everybody. I'm Kat Hill and I am usually from Portland, Oregon, but we're hitting the road in an Airstream, and I'm headed to Sree and Heather actually, in my Airstream. So anyway, I



love being part of this group. I just feel like these are my people and we get each other and many of these folks I haven't met in person. I'm honored that I have met a few in person, so I just feel like, it feels like coming home every time we log in. So, I just appreciate everybody here a lot and I learn something every time I log on. So, thanks everybody for coming out today.

Melani Dizon:

Thanks, Kat. Tom.

Tom Palizzi (Ambassador, Living with Parkinson's Panelist, Davis Phinney Foundation):

Hi everybody. I'm Tom Palizzi. I'm from Denver, Colorado, not too far away from the corporate offices for Davis Phinney Foundation. I was diagnosed in 2008 at the age of 48. And so, I think I'm the senior of the group these days. I'm looking around thinking I have way more gray hair than anybody else. I like being -

Melani Dizon:

Hair! You have hair. Look at Kevin.

Tom Palizzi:

Got you, Kev. I like being a part of this group because it gives me a chance to share the things that I've experienced over the 14 or so years that I've had Parkinson's or have been diagnosed and also spend some time with this really cool group of people where we have a lot of fun. We finish each other's sentences, all that stuff. It's just a good time.

Melani Dizon:

Great. Thanks Tom. Kevin.

Kevin Kwok:

Hi everyone. This is Kevin. I say I'm recent transplant to Boulder, but it's now been three years. Originally, I'm from the Bay Area. I've been living with Parkinson's now for about 13 years and I would say it's 13 years strong and it's because of people like this Brady Bunch video that I feel like I'm part of, I feel like every time we dial in, this is an episode of the Brady Bunch. But I just -

Melani Dizon:

Much more irreverent, which we're good with.

Kevin Kwok:

Well, because we're not prime time. So that's, we're like for HBO. Right?

Melani Dizon:

Right.

Kevin Kwok:



But I just love the fact that this group can be honest and candid and frankly, every time we dial in, I feel like I'm learning from all of you. And you know, I have to say that the theme of today's session is community. You guys are my community.

Melani Dizon:

Thanks, Kevin. Heather, last but not least.

Heather Kennedy (Living with Parkinson's Panelist, Davis Phinney Foundation):

Try not to cry. Instead of talking a little bit about myself, cause I've done plenty of that, I just want to mention today we're with one of the foremost scholars, in my opinion, on Viktor Frankl, who wrote as, you know, *Man's Search for Meaning*, and when we don't feel the purpose or meaning in our groups, we tend to get thinking about other things or we tend to be depressive or aggressive or distracted or any number of things, addictive, whatever it is. So, this important work helps us give purpose and meaning. And part of that is because we have a community, it helps us find our purpose and continue that and feel useful. And what do we need when we have a degenerative disease? To be needed ourselves, we want to be part of this. So, thank you so much for this hosting today, Mel, and thank you for everyone for being here. I just love you guys.

Melani Dizon:

Thanks. Yeah. So, everybody sorts of touched on the fact that part of this is community, right? Part of this is finding purpose and meaning in what you're doing, how you're living with Parkinson's, how you're impacting other people who are affected by Parkinson's. And so again, one of the big reasons we're having Brad here today. So, Brad, I'd love to get started a little bit, if you could tell us a little bit about, I mean, it's a big question, but some of the research that you have been doing and that you're most excited about as it relates to purpose and meaning and this kind of community.

Bradley McDaniels:

Yeah. So, it is a broad question, Mel, and that's, this could go on for a while. I'll try to narrow it down a little bit because I get quite excited when I talk about this stuff, because I'm fascinated by it. And you know, one of the areas that I became interested in really early on was apathy, right? And I think everybody who's on this call understands what role apathy plays in PD. And you know, as I've looked at loneliness, social isolation, community connection and meaning and purpose, all of those things contribute to whether or not someone's apathetic. And I've got some research right now that's being reviewed in a journal that looked at, do people who have meaning in life have less apathy? And they do, clearly. And the evidence is really strong for what meaning in life does for us in general, any outcome you look at, across the board, is better for people who have meaning in life.

And so that's fascinating. Even mortality is less for people who have meaning in life. So, I don't have to sell anybody on the value of it. The broader question is how do we get it? Right? We

spend a lot of time in the medical world, I believe, doing a lot of descriptive research. We say X is related to Y, we publish it, and we move on. And people go, that's great. But what does that mean for me as the end user, as the patient? And that's what we're looking at. And community is one way that's been shown to increase meaning and purpose in someone's life. When we altruistically work with other people and get out of ourselves, we then begin to find meaning and purpose. And so, there's all of this stuff is so interchangeable. And the challenge that you guys get and that we all see from a community perspective is what happened during COVID, right?

So, we had all of, things were going fairly smoothly. Jan, you know, March 2020 hits, the world stops, everything goes virtual. And I view it as a physics problem, right? It's inertia. Objects in motion, stay in motion, objects at rest, stay at rest. And we got used to being at rest, doing everything virtually, staying home, being on the couch. I don't have to go anywhere. And we saw this problem with loneliness and social isolation. The data was staggering. Indu and I wrote a chapter talking about what happened during COVID and the effects of loneliness are shown to be greater than obesity, alcoholism, and diabetes combined. I say that again, combine the effects of all of those, loneliness is a more important issue and that's where we found ourselves, right? So, we get to the place where now we're done and we're saying, all right, guys, let's get back in.

And we're trying to figure out what that looks like. And I think that's the struggle that all of us can relate to. And how do we get over that hump? And you know, one of the things Roy Baumeister is a social psychologist who's been around for years and years and he talks about that this fundamental need for social connection and interpersonal relationship is essential to flourishing, meaning it's essential to our quality of life. And that's what is so exciting about what we're talking about here today and you guys talking about, those on the panel, what have you done to make sure that you stay connected? Right? Because exercise is extremely important. We could debate, is it the exercise that's the important piece or is it the social connection piece that's the important piece, right?

I think the answer's yes, to which one's more important, right? And I know that I've heard Tom talk about the riding and the groups and, you know, I think that having that connection is so critical and I believe it makes people want to show up to those exercise classes when they've already got that connection, right? So that's kind of a little spiel about where I've been and what I've done and you know, I'm, on the panel, I'm preaching to the choir because you guys are all on board with this stuff. Right?

Melani Dizon:

Yeah. But I think it would be helpful for the people listening for you guys to share, you know, I'm sure there have been times when you felt less connected or maybe it started early when you got your diagnosis, and you pulled back. So, let's share a little bit about that. Sree, I'd love for you to hop in.

Sree Sripathy:

I'm going to talk while my voice is still with me. So, I lost my job in 2020 right after COVID and I decided, okay, work was so stressful, I'm going to take some time off and I'm going to be a full-time freelance photographer and pursue my dream. And I found that that was very hard for me. I didn't really get out of bed. I just got, I don't know if I was depressed, if it was apathy, I don't know what it was, but I realized in my entire life, like in 25, well, at that time it was 46 years of living, 45, whatever it was, I'd never not been around people. I'd always been in school, with family, and all of a sudden, I had no one around me, my family, half my family was stuck in India. They couldn't come back to the US because of COVID.

I was on my own. And even when they came back, I didn't get to see friends. I didn't get to see coworkers and not being able to see coworkers or interact with them, even with anything, was tough. And I did not know how much I relied on that day-to-day to keep me going. If I have a meeting at 8:00 AM, if I have something at 9:00 AM, it really prompted me to get up and get out of the house. So, my solution, because I'm like, I will not work well on my own. This is just like too much. So, I went back and found another tech job. And then after I got that tech job, I left tech to become a visual journalist just a few months ago. And that was something that was a lot more interactive because even the tech job was lonely as well.

And so, then I said, I need to pursue my passion in another way. And so now I get to go out into the world and talk to people. But if it wasn't for COVID, I would not have realized how important the value of people and connection was. Not that I'm saying, you know, it was a good thing that COVID happened, not at all, but that really brought home a lot of truths to me about how important it is to keep in touch with friends. And you might think you're a great loner or you're an introvert and maybe you are, but you still need a cat, a dog, a something, someone to talk to, to relate to otherwise I would never have gotten out of bed. Probably.

Melani Dizon:

Thank you. Yeah, Kevin.

Kevin Kwok:

Yeah. You know, like Sree, I went through a series of personal things, which kind of all collided at the same time. You know, I ended up getting divorced and moving to a new town here in Boulder and my timing was good in one sense but sucked in another because it was right when COVID hit. So, all these newfound friends that I was hoping to make, all of a sudden weren't there for us and all the friends that I, the close network that I developed back in San Francisco were now gone. And then on top of it, like Sree, I also was laid off. And so, all of a sudden, you have this double isolation, no friends and not your professional world either. And so, the combination of both was devastating, you know, but you just realize that we have to find our own way of finding that connection with other people. I've just been lucky. You know, my girlfriend was here, which is a great help, but on top of that, it started off with the virtual



relationships, with all of you, which has just grown to face to face now that we're hopefully coming out of this COVID phase, but we're not out yet. Anyway, that's my 2 cents on my experience.

Melani Dizon:
Thanks Kevin, Tom.

Tom Palizzi:

Thanks, Kevin. That was good. I can empathize with you. I think you and I were a lot in the same place at the same time over the last 14 years. In my case, as work was sort of dwindling down for me in the sense that I was heading, I could tell I was heading that direction, unable to do the things I used to do. I could feel that door closing. And when I, that door started to close, I looked to find other doors or windows that might be opening up. And that did happen for me quite well. And I kind of made that world, the transition from my professional career to what I call now, my twilight career and after retirement, I think that fit really well.

And that's just to be, I've been involved as a volunteer, and an ambassador for the Phinney Foundation primarily, and some other organizations, but also getting, combining the exercise program from the Pedaling for Parkinson's with almost a social type of environment or a support group, if you will, has been a great deal. And that's been worked out really well for me personally, as well as the people that attend the class that I run on three days a week nationwide. So, but again, I think referring back to what Kevin said, and the others, there is a, the onus is on you to try to figure out which way you need to go. And we're certainly here to help bounce ideas off or whatever, or give you our experiences again, if that helps. So.

Melani Dizon:

Yeah. Thanks, Tom. Yeah. I wanted to put a note on that as well. All three of you, you know, you, like Sree, you said you wanted to change, you went to another job and then you're like, nope, this isn't it. I'm going to tech. Nope, nope. This isn't it. And you just kept moving. And I think that's really important is like, it might not work. You might try something else. If it doesn't work, you can still keep going. Even, even Brad said, you know, hey, I was in one place, 41 years old, I changed everything, and I went somewhere else and look where he is now. So, whether you have Parkinson's or don't have Parkinson's, there is, you know, agency is critical. It not only feels good, but it actually gets you somewhere that you want to go. So, Robynn, yeah, you have your hand raised.

Robynn Moraites:
Yep, Heather had her hand raised before me.

Melani Dizon:
Oh, I didn't see it. It was so light. Heather.

Heather Kennedy:

Hi, thank you Robynn. And thank you for being here, Brad, and thanks for hosting this, Mel. I was thinking about the many facets that we have to think about once we talk about purpose and meaning, like the quality of our relationships. It's easy to be lonely in a crowd, especially if we feel that we are disabled or different or somehow judged, or maybe we have, I don't know, imposter syndrome because they don't see us crawling. They don't see our downside. They see us when our meds are ON because I don't usually leave my house when I can't walk with my walking stick, you know. The adaptation that we have to have, it's all about adapting to circumstances. We must always. And also, I was thinking about we all need to be seen and heard, you know, that's really all we're asking. It's not, you know, we're living in a world that makes it very clear that it's not going to adapt to us, as Pema Chödrön says, we can put leather on the whole world, or we can put a little piece of leather around our foot to walk along. And that just got me thinking about staying curious and involved and present, all of these things we do together here. So, I feel like this might be a series, Mel. Anyway, thank you.

Melani Dizon:

It definitely is. I mean, I haven't told Brad this yet, but it is, it is a series.

Bradley McDaniels:

Looking forward to it. This is fun.

Melani Dizon:

Yeah. Okay, Robynn.

Robynn Moraites:

Sure. Thanks Heather. Thanks everybody for what you've shared. I was thinking about the quest for meaning is so individual, some people are kind of putting in the chat, do you know of a class I can take to find meaning in my life? And I would encourage people, you have what you need inside. It's only there that you're going to find the resource for what brings meaning to you. And it's so individual that, you know, all of us on this panel have very individual things that bring meaning to us. And I do agree that for me, my job has been very meaningful and kept me involved when maybe I otherwise wouldn't have been.

I just want to mention, I've mentioned it on this panel before, but it goes right to the heart of what Brad was saying about the obesity, diabetes and alcoholism combined. Laurie Mischley out of Washington State has a study on alternative medicine and she's trying to study everything under the sun that affects people with Parkinson's. And I found it really interesting that the one single factor that she found improved progression or slowed progression was how people answered the question, "I feel lonely, true or false." And I just think that that is just fascinating, but you, if you think about the kinds of interests that you have, for example I started using Meetup as a tool where I could find people in my community who are interested in the same kind of arts or the same kind of theater or things like that, the same kinds of

exercise. There's a meetup group for just about anything under the sun. You know, you have a parakeet named Bruno, there's a meetup for it. So, there are tools and resources available. But just kind of look inside yourself a little bit for what do you like, what are you drawn to and then find some other people that are drawn to that as well.

Melani Dizon:

Yeah, absolutely. Sree?

Sree Sripathy:

I think a couple of people have asked further on for more information. And the one thing I can say is it's difficult to tell somebody what might work for them or not. And I was definitely seeking those answers when I was first diagnosed. I asked in seminars and doctors, okay, you're telling me to exercise, for example. Well, just tell me what exercise to do. I'll do it. And the response I'd get was, well, you need to find something you like. And I said, I don't want to find something I like, I want you to tell me exactly what I need to do. So, is it tango? Is it cha-cha? Is it, you know, running? What do I need to do? And not a single medical professional would tell me the answer. And so, I had to figure out for myself, which is really one of the most irritating things ever.

But honestly, it's the only thing because they're not going to know what I like. So, once I tell them, okay, I'm going to do tango, I'm going to do tai chi. Then they could say, okay, this is actually good. That's safe for you to do. If I want to do, like, the long jump, they might say, maybe not. Maybe don't try that, but it's a process. It's a really long process. And the one thing I think that helped me was figuring out what brought me joy as a kid. What did I really love doing as a kid that I might have given up as an adult? You know, I love dancing. I love singing. I love doing lots of different things. So, I kind of went back to that and figured out what I could still do as an adult that would bring me that joy that resembled what I did as a kid. So that might be something people can look into to combat loneliness. Like maybe if you liked watching old movies, movie nights with friends or something like that. That's all I got.

Melani Dizon:

That's great. Yeah. It's sort of the meaning question-

Tom Palizzi:

Pedaling for Parkinson's.

Melani Dizon:

What was that?

Tom Palizzi:

I said Pedaling for Parkinson's, my little sign.



Melani Dizon:

That's right. I'm going to put up your link, Tom, so that everybody on this thing can join your classes.

Tom Palizzi:

Sree, you'll have to join the class. We ride three days a week.

Melani Dizon:

It reminds me of sort of the passion question. Like people will say like, what's my passion? I need to find my passion. Like it's out there at like a store. You can pick it up or something and they'll take classes, and they'll do a million things. And the reality is, you don't find your passion, like by taking a quiz or something, you work into it, you do stuff, you get out there and do things. And then you discover what you love, what, you know, what makes you in the zone, all of those things. But I am really curious, Brad, if you could speak to this a little bit about this idea of meaning and giving back, like I, right like, has anybody ever found meaning focusing on themselves?

Bradley McDaniels:

No.

Melani Dizon:

No.

Bradley McDaniels:

No.

Melani Dizon:

Right?

Bradley Michaels:

Right. That that's the short answer.

Melani Dizon:

So, first place to start is getting out, getting out of your head and like, what can you do? What can you like, think about what do you bring to the table? Little thing. It can be a tiny little thing, but it's amazing how fast it happens. So, can you talk a little bit about that?

Bradley McDaniels:

Yeah. You know, I want to draw a comparison for anybody on here who has been exposed to the world of recovery and the 12 steps, right? The way that the recovery world works is by someone taking time to help someone else, but in reality, I'm helping myself by doing that. Right? It's that counterintuitive thing. And that's truly where meaning's found. And you know, I

didn't talk a whole lot at the beginning about meaning I didn't want to necessarily, because that's an area I love, and I could talk about meaning forever. But you know, what I've heard on here is so good because you can go and you can have counseling and have someone help you find meaning if you want to pay for X number of sessions, go eight to 12 mindfulness-based stress reduction therapy from John Kabat-Zinn or whoever it is, right?

You can do CBT. You can do acceptance and commitment therapy. Any, those things all work, but I don't believe they're necessary. I believe what it is, and anytime I give a talk specifically about meaning, I talk about that. I say, where do you find your Zen? Right? Maybe it's in nature. Maybe you just like going for walks on a trail. Maybe you like cycling. It really doesn't matter. But the important component is it needs to be something that purpose is kind of an underneath component of meaning. And purpose is that thing that says, this gives me something, a goal to aim for. And we need that. We need that thing that's further out that we're seeking and maybe it's stronger relationships with my friends. Maybe it's becoming more physically fit, maybe, right, fill in the blank.

There are a thousand things we could fill that in with. And so, it, you can find it anywhere. And I think Sree was right that, and Mel, you were right. You don't have to go read a book to learn how to find meaning. I mean, Viktor Frankl, if you want to read a book about meaning, read *Man's Search for Meaning*, because Viktor Frankl lays it out very nicely and he wasn't looking for it. It came to him while he was in a concentration camp and he goes, ah, this is it. And it's that thing that you are living for that's out there. And you're right, Mel, that it's, it never works when I'm that thing I'm living for. Right? It's always more valuable, think about the times in your life that were the most meaningful. They're always involving other people. It's not that you just were sitting at home, and you read this book and all of a sudden, now you feel brilliant because you read Victor Frankl.

Right? It's these interactions that we have. It's the phone conversations we have with someone else that we just connect. It's going to the group and feeling like someone is pushing you or pulling you along in that group. And you're learning, wow, this is what it's like to have a group of people around me with a common goal. And we're all aiming for it. And something magical happens when we do that. And I wish I could describe it. I probably could describe it from the way that the brain works, but that really doesn't matter. The fact is it just works. And I am such a believer in meaning. Heather and I have had this conversation ad nauseum about the importance of this and Gavin and I have done the same thing. And we just see that as people start connecting, they seem to get better.

And I'm not saying that everything in your, the problems in your life disappear when you find meaning, right? Life shows up. The difference is how I deal with the problems in my life now, right? Viktor Frankl talks about that. He says, you can take everything away from a person except their ability to choose their attitude in any situation. Something is different when our attitude is positive. Right? And I see that from the people on the panel, right? I mean, you see

the smiling faces, you see the excitement to be here, you see that they want to connect, and it makes a difference.

Melani Dizon:

Yeah. And I think it's interesting the makeup of this group. You know, we have some that are still very much in the work world and very much working and then some that are not, and, you know, there are, there's a lot of work out there for, you know, many older age people that when they stop working, they sort of really go downhill. And so, you know, it's, many of you are in really difficult situations. You might really want to work. You know, you might be young enough and really want to keep working and you can't do the work that you used to do. And I know for Kat, she must have lost her connection, but for those of you who don't know, she was a midwife, nurse midwife for many, many years, delivered a thousand babies. And she could no longer work. And that was, you know, a huge part of her life. It brought a lot of meaning to her. And one of the ways that she found it was giving back to the Parkinson's community. And everybody obviously on this panel is doing that. And they've had access to do that. But I would encourage anybody who's kind of struggling with that to reach out, just maybe ask somebody on this panel.

What could you do? You know, if you're stuck, because I know it's really easy to be like, hey, ABC, do the things but some of you are stuck and that is a really tough place to be. And so, it is tiny. Clean your refrigerator, I don't know, clean your refrigerator today and then see where that goes. It's just sort of that inertia that Brad talked about earlier is start moving, start doing something. You have no idea where it's going to lead. And hopefully it's connecting with other people in the process. Kevin, your hand, I don't know if your hand is up, newly up, or was up before.

Kevin Kwok:

No, this is a fresh one.

Melani Dizon:

Let's do it.

Kevin Kwok:

So, you know like Brad, I'm also from the pharmaceutical industry and for 30 years, you know, before my diagnosis, I always was in admiration of the patients that came before me in whatever field I happen to be working in. And I remember asking my neurologist when I was diagnosed, how can I get more involved with my disease? It's my turn to give back now. And she had no answer, like what Sree was saying. But so, what I realized was we're all left for ourselves and our own efforts to go find that meaning. And it can come in so many different places. I mean, I'll call out Tom with accolades. Tom, threw an event this past weekend, which those of you don't know, was a bike tour, you know, for the Davis Phinney Foundation, which brought people from all over the country here.

And I was thinking, you know, as someone else was saying, sometimes you're a stranger in your own group. I couldn't participate because of, you know, functionality with my hands, couldn't shift, couldn't brake. You don't want me on the road on a bike with you if you can't break. So instead, I was feeling sort of lost. And so, I volunteered, I worked at the event and then I decided, well, why don't we have a little party, a little reception for those that were out of state. And I thought maybe two or three people would come. Well, on Sunday, we had a full house here of like almost 20 different caregivers and Parkinson's people. People who came back hours after going home came back and we all said afterwards, this was magic. There's something about this attraction that Parkinson's people and our tribe have for each other. It's very hard to describe, but it's like, I'm with my people, they know what I'm going through. And I encourage us now that we're starting to come out of this isolation, just throw that party, right? Reach out and do because good things happen when you do it.

Melani Dizon:

Thanks, Kevin. Yeah. Tom, what an event that was. It was so, so good. And I said this week, it was one of my top five moments at DPF of the whole four and a half years I've been here. It was just the most fun. And yeah. So, when you get those chances, take them because they matter a lot. Robynn.

Tom Palizzi:

Thanks, Mel.

Melani Dizon:

Yeah.

Robynn Moraites:

It sounds great. Kevin, it made me think about, and I want to ask Brad a question. I spent a fair amount of time in my job, educating people about mirror neurons in the context of mental health and wellbeing. And it occurs to me so much this idea of community. I'm also in long term recovery, but this idea of community and when Kevin was talking about the party and the people, what role do mirror neurons play in our sense of community and wellbeing that's reflected back to us? I mean, I think that's one of the reasons we have such a successful panel is because we're with, we are with our tribe, people are talking about their tribe. So, what do you have to say about that?

Bradley McDaniels:

Yeah. Well, I think your point's very well taken and I get it. And what I'll add to that is the research is very clear that loneliness is the single most robust predictor of psychological distress in people with chronic illness. That's a pretty impressive stat, right? Out of everything that we experience. And so, what that says, right, if you read into that, is that if I have, in your words, my tribe, and I have these people whom I'm interacting with, who I have social connection with,

whom I share something important with, my psychological distress will be less, right? And so, I think it makes total sense that this is what's happening. And yeah, there are ways that we can look at the chemicals in the brain and we can see what happens with people who are lonely versus those who aren't or people who are socially connected versus those that aren't, there are significant changes.

They can see it under MRI and CT scan with some of these changes in the brain. And it's fascinating stuff. And I wrote a little bit about it in the chapter that we did. I am not a neuroscientist. So, I always refrain from getting too deep into the weeds, talking about neurobiochemicals and all of the things that could make changes. But what I know is what you said to be true. And I know that there are explanations for it, which are fascinating and higher, you know, it's related to cortisol, too. That's another issue. People who are lonely have higher cortisol levels, people who are lonely have poor immune response and get sick more. They have more depression, they have more anxiety. All of which people with PD already have issues with, right, up to 50% of people with PD have anxiety and depression issues to begin with, up to 70% have apathy, depending on which study you look at.

So now you add loneliness to that, and it compounds, right? And the challenge with it is, and Mel, you kind of hit on this, what is the treatment for depression and apathy? The real treatment is to get engaged. The problem is they don't want to get engaged because they're apathetic, right? So, we're on this merry-go-round that we're going, trying to get, and so, it's such a challenge to just get them into the game, right? Invite them into your tribe, to where they can experience that. And something happens when that takes place and they begin to feel a part of, and you know, on a little bit of a different topic, one of the other things we just wrote about, we were talking about demoralization. We spend a lot of time talking about depression, apathy, the mental health issues, but nobody talks about what is this thing that happens when you're diagnosed with PD, right?

And I think we call it, it's a demoralization. It's kind of hard to put a word on it, but everything in your life changes in that moment. And these reactions that we have are sometimes, "I'm just going to give up, you know, I can't do anything that I used to do. I'm a very different person. I'm not going to be the guy or a gal that I was before. So, why even try?" And that's a really tough one to deal with. And unfortunately, those of you who are seeing movement disorder specialists, many times, they don't know what to do with that. They just don't. Davis Phinney's got a ton of great materials that they hand out to every doctor, and you find out patients leave, and they don't have it. What's the problem, right? We're telling you everything you need to know in this little pamphlet. And I think, you know, docs are, I think they realize at some point they're just not sure what to do and -

Melani Dizon:

Yeah. I think, you know, apathy, depression, those are not quick fixes. They're not something like, "Cool. We have five more minutes. I'm going to tell you; we're going to fix it all up. Have

you out of the door, right?" These are bigger deals. And so, a couple of things I want to point out, we did a, I found this super interesting, we did a call a couple years, or I don't know, with Dr. Gregory Pontone, we talked a lot about apathy. And the funny thing is about apathy. They don't care. So, they're not going to like, they're not going to listen. They're probably also not on this call for the most part, right? Because this takes initiative, this takes a thing to like to log on and care about it. That said we can go in and out of apathy. Right?

So, one of the really great things to do that a lot of our community members have done is when you see somebody who's feeling, you're like, "Oh, this, they don't want to do anything. They used to come to the class. They don't come to the class anymore." Get them on your schedule. A lot of times, you know, he made like sort of a joke about it. It was just like, "If you get them on the schedule, they don't care enough not to be there on the schedule." Right? So, if you can say, "We're going to do this class, I'm going to pick you up every day, 11:45. We're going to go to boxing at 12," and you just keep showing up and pretty soon something will change in them. So, we're going to put the link for that. It's a really, really great session on apathy.

The other thing is we have, I think we have, I'm going to say this wrong, 80, like ambassadors. We have ambassadors all over the country and Canada, and they are here for you. And they, if you are on this call and you're watching this and you're saying gosh, where do I find this? I live here and I don't know anybody. Go onto our ambassador page. I promise we'll put that link in there. Again, you can search by location. You can search for them. You can fill out a form and reach out to them, their email and say, hey, I'm really struggling with A, B or C. And that is somebody you can connect with immediately. They're all very responsive and very open to helping you. So definitely check that out. That's a really important resource. Heather.

Heather Kennedy:

I also wanted to say that, unfortunately, the medications that we must use to move are inextricably interconnected with pleasure reward. This causes compulsive disorders. Occasionally it changes our personalities, occasionally, or we become people who have behaviors that are very difficult to deal with that we don't even understand. We may not even recognize they're happening until it's too late. So just as an added bonus, the medications we need can cause some shifts. So just be aware of that as well, that it's not the person. Please don't confuse the person with the disease side effects or the medical side effects.

Also, the demoralization that Brad mentioned is so important. I was at the doctor the other day and I was frozen. I couldn't really talk. And she leans in, she's like "Ma'am!" and she says to the person next to me, "Can she hear me?" I'm like, "Lord, help me. I'm going to kill this woman. I'm going to kill this young lady." And she, like, holds out my paperwork and announces to the whole room, "Here are your pelvic floor strengthening exercises!" And I'm thinking, "This girl, I don't look good in orange. She is so lucky because I have a cane in my hand. I'm going to cause her some cane pain, you know, I'm going to hit her, cause cane pain cane pain." So, you know, there are many things we can do to sort of joke about this so that we don't feel so demoralized

or talk to other people. It's really kind of sad that people don't understand it. Also, the comparative thinking, somebody else mentioned that. Don't compare yourself now to how you think you should be or how you used to be, or to the people on the internet. Those are highly curated personalities you're seeing. I can vouch for that. We show you our good side. We show you when we're well. Anyway, that's sort of what I wanted to get at is that we're all just humans. You know, look at what's happening in space. So, we're doing the best we can. It's all you can do.

Melani Dizon:

Thanks. Sree?

Sree Sripathy:

So, I wanted to share an experience I had with my parents who are older adults and retired, and they are struggling with finding purpose in life and meaning in life. So, it's not just people with Parkinson's disease, it could be anyone. And with Parkinson's, I think it's a little bit more extreme sometimes, as it is with many other neurological conditions. But they were really struggling, and they were retired, and you know, we're all grown up. The kids are grown up, we're all out of the house. Well, kind of, almost. And the grandkids are busy doing what grandkids do. And I would tell my parents, "Do not live for your grandkids." Some people might disagree with this, but I'm like, they're going to grow up. They're going to be teenagers. And then they're going to college and they're not going to want to hang out with you as much.

You know, they're just going to be busy partying and doing their stuff. So, find some other purpose and meaning in life. And so, my mom listened to me, and she came into my room and saw that I was reading a racy romance novel. So, she's like, "Oh, maybe I'll read one of these." And I'm like, "No, not a good idea, Mom, try something else, something else." So, in the end, they started volunteering at the local temple, which is quite close by. So, if you're part of a church, a congregation, maybe reach out to them. And then she joined a virtual book club, which has been really wonderful for them. You know, to read a book every day, you don't have to go out of the house. You can join in person if you want to, but it is virtual. And I think the other thing, they started calling their friends and just, you know, old college classmates, people they haven't talked to in a while, and I kept encouraging them, "if this was a great friend of yours from college, why don't you just call them?" College friends are college friends for life, you know? And then I encourage my dad to start writing his memoir. I'm thinking, "You have grandkids," or it doesn't matter. Don't write it for your grandkids, write it for yourself, go back and think about what your childhood was like. So slowly, I'm encouraging him to do that. And that has helped, but maybe those are just some suggestions somebody might find helpful, if you're not able to be mobile and get out and do something, you know?

Melani Dizon:

Yeah. That's great, Sree. And actually, I wanted to bring up what Jan said. I think it's a really great point. "Some of us introverts find meaning and connection from something small, like

participating in an online poetry jam or taking a creative class. It doesn't have to be a major commitment." I think that's important for a couple of reasons. One is, yes, it doesn't matter. There's no one way to do it. But the other thing is like, it doesn't have to be so big in your mind that it stops you from doing it. And I think that's great. So great advice, Jan, thanks for sharing that. And we've had a lot of great comments in the chat, so we'll share the ones that we can help with. Small towns can limit what resources are available without driving 45 minutes for a 30-minute class. Peggy. Yeah. That is a tough one. Does anybody have any...?

Robynn Moraites:

Well, that, I think that was in response to a chat that I put in there that some people earlier in the chat were asking about, "How can I find people in my community?" And when you were talking about the ambassadors, sometimes there's a back door approach where you can find a Pedaling for Parkinson's or a Rock Steady Boxing or a Tai Chi for Parkinson's. And you could find people that way that there might be a class nearby. And if you're in a small town, it's possible that I'm not, I don't know. You know, it's possible that there's someone else in the small town who has it too, that might be willing to drive you to that class. I don't know. You know, everybody's got different circumstances. I'm just trying to think out of the box about ways you can get connected to the PD community.

Melani Dizon:

Yeah. In the small towns, you know, we've had a lot of stories of people that are, yeah, they're in small towns and if they do find one or two people, like, unfortunately Parkinson's, isn't super rare right now, you know, and they can find one or two people and sometimes that's all it takes. You know, it takes that one person who gets you, that you can meet for coffee with. And you don't have to explain yourself to them. And it feels like a great connection. So...

Tom Palizzi:

Yeah, that's true. I think the small-town thing is also, the virtual environment really works well for that. I know that's not optimal for everybody, but it really works well. We collect people from all over the country that, like, for example, ride with the Pedaling for Parkinson's classes.

Melani Dizon:

Yeah. And somebody said, trouble, they're not very technical or can't manage Zoom or, you know, how do they stay connected? And I'll tell you, if you have trouble with connection, just reach out to us at blog@dpf.org. Let's not make, we won't make that a thing that stops you. So, we'll figure out something and you know what, the old telephone is a really great thing, I use it a lot lately, it's an app that didn't get used much in my life, but now I'm using it. Yes, and your library is such a great place. Thank you, Mary, for saying that, yes, your public library, great resources and librarians are an insane wealth of information about their community. So, don't be afraid to ask them and say, hey, have you ever heard, have you heard anything about this? Do you know of any groups? Do you know anybody in the community? And maybe they can connect you.

Tom Palizzi:

And look, getting back to the virtual thing. My mom still can't use a cell phone, but she figured out how to do zoom. So, if she can do that, anybody can.

Melani Dizon:

That's great. Yeah. "Local hospitals, social workers have helped me find resources." That's another great place to go. Great place to go. Alright. Does anybody in the chat have, I mean, we have Brad, he is ready to talk about any of these things. Does anybody have any questions for him? One of the things that came, that I was just thinking of is what, this is like, this is such an important topic, right? People really care about it. They're constantly asking about it and we've given some ideas and we've talked to people about how to connect and do all of that kind of stuff. But I would love to hear from people of like, when, what do you do when it doesn't work? When you put yourself out there, when you try to connect and it's a negative experience. And then you're like, oh God, I can't do it. What do you do?

Bradley McDaniels:

Are you asking that to me? Or you leaving that open?

Melani Dizon:

I'm going to leave it up to anybody.

Bradley McDaniels:

Okay. Yeah.

Melani Dizon:

Kevin is that your hand raised or is that for-?

Kevin Kwok:

It was on a different topic, but to answer your question on there, you cannot force yourself on other people. That's been my one observation, you could put, you can cast a wide net, but if people don't come into the net, you're not going to be able to force that to happen. I don't know how others feel about that.

Melani Dizon:

Yeah. Interesting. Wait, okay. Research definition of loneliness in your research, Brad, how to define, to determine academic research and indices of degree of loneliness, or is it pretty much a personal definition?

Bradley McDaniels:

Well, you know, one of the challenges in any of the social sciences is typically we're relying on self-report measures and it's an individual perception. So, when we look at loneliness, Heather

hit it at the beginning. The difference between loneliness and social isolation comes down to the quality of the relationship and when, not the quantity. So, Heather's right. You can feel alone, right, when you're with a group of people and loneliness is really subjective. And it's a consequence frequently of social isolation and it's related to the quality of the contact rather than the quantity. So that's kind of a long answer to that, but there is a UCLA loneliness scale, which is the scale that's commonly used. And the research that we've done, we've used the three item UCLA loneliness scale, we're in the process of validating that in people with PD as we speak. So that that's something that can be used later, but yeah, it is, somebody's going to answer that question and say, yes, I feel lonely. And from a research perspective, I can't look at their answers and go, well, you're really not, you know, it doesn't look to me like you're lonely. So that always creates challenges with us. So, it's sometimes difficult to tease out the specifics about that.

Melani Dizon:

Yeah. Is there anything that anyone on the panel would like to end the day with, think about something great, a funny story, or let's see. Yeah, Tom.

Tom Palizzi:

This isn't necessarily a funny story, but it can be. Folks that are out there, you're always welcome to call us or reach out to us. And people do that all the time to me. And I know everyone on this council and that's what ambassadors do. Somebody asked earlier in the questions, what do ambassadors do? We do a lot of things, but that's probably the thing that gives us the most feeling of accomplishment or wholeness or whatever, but it's really a good experience for us to help you and that's what we're here for. So, again, you can find us on the internet, dpf.org, look under whatever, you can, I don't know. I think Mel's going to send the link to that, but I don't remember how to get there, but find ambassadors.

Melani Dizon:

Yeah. I will send all the links. Kevin.

Kevin Kwok:

Yeah. I just also want to stress that this is not like finding Nirvana, it's not a one-time find, and then you're saved. We're constantly going to be going through this journey of finding meaning as our disease progresses and what you're gonna do in your first two to four years of your diagnosis will change after 12 years, it will change after 20. And we just have to be able to continually ride it and adjust. So those are my words of wisdom.

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