



## **Living with Parkinson's Meetup**

### **July 2023: Relationships**

Davis Phinney Foundation

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

Chris Krueger (Program Manager- Content, Davis Phinney Foundation):

Here we go, everybody. Hi, everybody. Thanks for joining us today for The Living with Parkinson's Meetup. I'm Chris Krueger, and I'm the program manager for educational content with the Davis Phinney Foundation. And I'm here with a great group of our panelists for the meetup today. So why don't I let the panelists here go ahead and invite introduce themselves? And why don't you say, you know, since some of us were able to go to WPC recently, and some of us weren't, I'd just like to see if anybody has anything they want to share about something they learned new about Parkinson's recently. So maybe that's from WPC, or maybe it's not. But go ahead and introduce yourselves and why don't we start with Kevin?

Kevin Kwok (Board of Directors, Davis Phinney Foundation):

Hi everyone. Kevin here patching and from Boulder, Colorado. I was one of the fortunate ones to attend WPC, and I could tell you what I came away with is the theme for today's meetup is community. You know, the one thing that I got from, from attending, from the moment I landed in Barcelona, people would come up to me and say, you're the guy in the face that's in the Zoom calls all the time, and now I get to meet you in person. Those are the kind of interactions that I really took home and took to heart because it meant a lot to finally connect with these people in real life. But the flip side is there were a number of people that didn't make it. You know, Doug and Heather, I know you had issues with travel, and I think the community goes beyond the people that were just part of WPC. Some of you may know, one of our friends, Jerry Boster, passed away right after he returned home. I just remember talking with him, laughing with him, chatting at the reception, and all thinking, you know, this is really special, right? To be with someone and to have him fly home and pass away. And finding out about it really gave me the sense of productivism that I have for our community. So, we'll talk more about relationships as we progress, but that's what I took home from Barcelona.

Chris Krueger:

Great. Thanks, Kevin. Why don't we Doug, why don't you go ahead and introduce yourself and give us a sense of what's going on for you?

Doug Reid (Ambassador, Davis Phinney Foundation):



Hi, everyone. I'm Doug Reid. Zooming in from Lafayette, Colorado. I was diagnosed with young onset Parkinson's about 13 and a half years ago. Had DBS about three and a half years ago, and I'm doing my best to live well. I was supposed to go to the WPC but injured my leg, broke my leg in late March, and was still rehabbing, so I couldn't go. I've kind of realized recently, this is my I realized that Parkinson's has kind, kind of given me a purpose, a purpose in life. So that's my take on something that I learned recently about Parkinson's.

Chris Krueger:

Yeah, that's interesting. I've heard, I heard a lot of people say things like that and related to that at the, at the Congress, so that I'd be interested to hear more about what that has meant to you relative to the topic for today. But we'll get to that in a, in a couple minutes after we hear from why don't we go to Sree, please? I want to introduce myself if you don't mind.

Sree Sripathy (Ambassador, Davis Phinney Foundation):

Sure. So, my name is Sree. I have young onset Parkinson's Disease, and I did go to WPC. The one thing, the couple things I learned is, number one, and this is purely anecdotal based upon just a handful of people that I've spoken with, is that being around people who have Parkinson's disease, who are good friends, who've become family, is a healing environment to be in your medic. My medication lasted longer. My off, my off symptoms were not as severe. It was just a beautiful experience. The other thing I noticed, which is scientific, is that more people came up to me and said, oh, you're the girl who did the dopamine dunk versus from Davis Phinney. So, my dopamine dunk has gone viral, meaning like five people came up to me and notice me from that. So, I'm going to have to be very careful the next time I do anything with my friend Rochelle, who's the dopamine dunk legend because she'll video and photograph every moment.

Chris Krueger:

Yeah, you have to watch out for those people with cameras.

Sree Sripathy:

It's a, you have to watch out for the people with cameras.

Chris Krueger:

And how about Heather, if you don't mind saying hello and saying where you're calling in from and all that good stuff?

Heather Kennedy (Panelist, Davis Phinney Foundation):



So, hey, it's nice to be at the hospital. I had a special guest there who's with me on the screen, driving all the way in to say hi. She even attended my physical therapy and my occupational therapy sessions. So that was pretty cool. I'm just really happy to be here, and it's because of friends and immediate family that I'm here without the advocacy that they provided, I could be even paralyzed. So, I'm really glad, I mean, to be here for this, this means a lot to be here. Thanks.

Chris Krueger:

Thanks, Heather. We're glad you're here with us. And Brian, you're up.

Brian Reedy (Ambassador, Davis Phinney Foundation):

Well, hello. And I'm actually, I'm going to share this real quick. This is my best friend's mom from high school. So, she's been my adopted mom since high school. And she put up with me this is Edie, but it's interesting. I think the WPC was fantastic on so many levels. But I think what I got out of it the most was the people, the people that I met, and the things that I was able to be a part of. And I met Cherri when I was out shooting this spiritual festival. It was very colorful down the streets, and I was taking pictures and she pops up with her camera, and she's taking pictures too. And it was just great getting to meet a lot of us that are in this. And then I knew Heather had an interest in the video that she had been in that was up.

And so, I started videotaping the awards thing just in case her video won, and it won. And I was able to send her the video and she heard how everybody applauded for her when her name was mentioned. And that made me feel so good that I was able to send that to her. because She was in the hospital recovering from this surgery. So, to me, it's like everything that happened kind of had more purpose than I originally thought. It was just things at first, but the people I met and the things I experienced really opened doors. And I think the most profound was when I met Harington who got one of the Robin Elliott Awards along with Rochelle, who, by the way, I then went to Dublin and did a dunk with her and met a bunch of others in Dublin for the week I was there.

But Harington is a gentleman from Uganda whom Parkinson's looked at as witchcraft, and his mother died from it 17 years ago. And he and I were talking before I knew who he was or anything. And then Eli introduced us, and, after talking with him more, I said, I'm going to bring laughter yoga to Uganda for you. So that's this seed that got planted from WPC. I think that's the beauty of WPC. We sometimes don't find it right away, but we find things in us that we wouldn't think are in us because of the inspiration from the people we meet there.

Chris Krueger:

Yeah. Thanks, Brian. I agree. It was great to meet so many people and to, from all different parts of the world. So that was really a great part of WPC. I just wanted to make a quick note

that we are having some issues with the chat. I think that it, they're being resolved as, as I'm speaking, but, you know, bear with us and we'll get it all going very soon. I think it should be working now. But we'll move on to the topic that we wanted to talk about today, which is related to some of what was just already said, which is you know, relationships generally how they change through Parkinson's, or maybe sometimes because of Parkinson's. And this could be relationships with friends or family or, or partners or your dog or, you know, whatever relationships in your life have really dramatically changed. And maybe, I think, I think Kevin said that he would maybe lead us through this conversation. So, I'll hand it over to Kevin and see, see where we go with this topic about relationships and how they might change, and how to navigate the changes that come.

Kevin Kwok:

Thanks, Chris. So, I was thinking a lot about relationships, and I was thinking about this last week where I was reflecting on, I'm bachelor in it this week. My wife, Jen, went home to Michigan. And so, I was telling them, some of you on this panel, I I'm spending this week binge-watching TV and eating chips on the couch. All, all good stuff. It's some things that I don't always get allowed to do, but I binge-watched a movie the other night, which was all about relationships. I don't know if any of you have seen, I Love You, Man, with Paul Rudd, with the premise behind it, I won't give it all away, is about a guy who's engaged to get married, and he can't find the best man because most of his friends are not other men.

And so, he goes on this whole adventure. And it is very humorous and convoluted, but it got me into thinking about relationships and how mine have changed. I know that before I had Parkinson's I lived for relationships, you know, I was a professional networker but because I was an executive headhunter in healthcare, and so I made it my job to know as many people pretty much as I could. But I realized that over time things have changed. I mean, instead of being the social connector, I've become a little bit more reclusive. Part of that speech, part of it that is fatigue the process of not working anymore has changed a lot. And so, I guess with that, I'd like to open it up to our smaller panel today, but hopefully that we can go into more depth as to how relationships have changed, either personally in your family, with your colleagues, or anyone in our universe as, as we progress day to day. So, I'll open it up to my fellow panel members here to chime in. Go ahead.

Sree Sripathy:

I think for me, pre-diagnosis, I was more self-isolating in many ways. Ways I was not comfortable putting myself out there in a public sphere or doing as much networking as I would have wanted to or would've needed to post-diagnosis. When, you know, I'm not at the best stage of my life, that's actually when I find myself putting myself out there more, connecting more with people, which is very strange for me. because I used to be the person that shied away from any selfies, any photos, any group things, even at weddings, family weddings. I'd never do that. And now I'm doing more and more of that because I see how I was missing in

certain areas of my life. And the Parkinson's diagnosis made me aware of the beauty of the life that I had, and I still have. So, I think my relationships with many people have become stronger in many ways, and some have fallen away, but that's not because of the Parkinson's, that's just because of time and distance. But I do feel that my relationships in many areas have gotten stronger.

Kevin Kwok:

Thanks. Sree I would agree with you. Many of my relationships, especially with people like this on our panel, have definitely gotten stronger. Brian, what, what, what? You had your hand up for a sec.

Doug Reid:

I did. Yeah, go ahead, Doug.

Kevin Kwok:

It's hard, Doug, go ahead.

Doug Reid:

I've found that I haven't lost relationships with any of my close friends, but friends of friends I've lost contact with. And I think it's largely because of apathy on my part just not reaching out to people, letting people reach out to me. And there's people that I wouldn't see too often, I've just kind of lost contact with

Kevin Kwok:

Ha has that happened? I know that apathy definitely plays a role. But I've also noticed that sometimes if what we are making in our lives is, we live with Parkinson's every day, every minute of the day. And oftentimes I think the people that we count on, they're, they're fatigued by all of that. Mm-Hmm. <Affirmative> and so they, they sometimes there's an avoidance issue that I've discovered in there. Heather, you had your hand up. I know you had a lot of issues. With sort of the changing universe of our circle.

Heather Kennedy:

I would say that there is no relationship that remains unchanged by Parkinson's. My dog, for example, I can't let my dog out. He'll be sitting by the door, and he is like, what is up with you lady? Like, I need to go. It's time to go. You know? Or where's my treat eater? You know, my cat is terrified of me alone. Everybody else who comes in here, I, that's fine, but I can't get down on the floor. I'm in the b l t stage of recovering from spinal surgery with my new hardware for that as well. So, there's always some comorbidity or something else going on. You know, none of

this happens in a vacuum. Our friends have their own lives, and friendship is voluntary family. We tend to expect all more from family. But that's a slippery slope too. Until I had Parkinson's, I did not understand the depth of this chaos.

Heather Kennedy:

So, I'm very careful with what I expect from others, but that also includes myself. I had to take it down a notch, you know, maybe a couple, because I was going full bore thinking that I could still be involved in all these social activities. But the truth is, I can. So, after bowing out of so many things, people just get tired of asking, probably. And then I ask them to come by, and then they're stuck here doing my laundry for me. So, of course, you know, my friendships have changed. I've become fairly dependent on some of my friends. I have, I have a best friend who's, who's probably got some you know, compassion fatigue. So yeah, it's hard. It's really hard on families, children, I would just say, you know, have compassion for yourself and others. It's tough, it's tough.

Kevin Kwok:

It's tough, tough, Brian.

Brian Reedy:

Well, I agree with what Heather's saying on so many different levels. But like you, she had mentioned about family and how it changes completely. And you know, mine has changed completely. But I think what I've come to understand Covid was no friend to the isolation issues with Parkinson's. But at the same time, I think it drew us more, it drew me more inside myself, and I was going through PTSD issues at the same time. But what I feel the benefit from this is I've learned to stop expecting things, especially from family. I've learned to start expecting more from myself and to be more aware of myself and mainly to listen to others better. And that's, I've been talking with Edie today, and I was just telling her about all the stories I've heard in the time that I've been getting outside more and getting with people in Barcelona, especially the stories I heard from people were just absolutely incredible.

And I think that's the part I was saying something to somebody about how Parkinson's is, I see it as a gift. I don't see it as a gift in itself. I see it as; I'm not going to curse it. I'm going to sit there and I'm going to look at the blessings I have with it. And to me, the blessings I have with it are the ability to get outside of myself and understand the world a little better and choose to be with people that don't, I don't feel judged or that I put that stuff on. So, it's drawn me to a whole new circle of people. Yeah.

Chris Krueger:

Brian, that's really interesting because I think that one thing that can be easy to, and I think Heather said something about this too, not, it's not really self-advocacy, but it's sort of standing up for yourself, being present and being clear about what you, what you need for yourself, and what situation you're experiencing, I think is really important. It can be really, really hard. And I guess I should say, because I want to draw attention to some things that are happening in the chat. And I think one of the things I want to say about that makes it relevant for me to add something that I didn't say in the beginning, which is that I also live with Parkinson's. So, I have, I have a certain perspective on this, but it's just mine. And Jen in the chat asked how do, how do you find people in similar situations?

And that can be and noted that can be hard. I think Jen said she's in Phoenix. And I just, from my perspective, the way I found people to connect with was being open about what was going on for me. Yeah. And I, that may be not okay for everybody. So, I don't want to suggest that that's the best path for every person, but for me, it was only when I started to really open up about the fact that I had been diagnosed with Parkinson's that I started to connect. So anyway, I wanted to ask if anybody had any other tips about that. So, what, what do you think? Does anybody have any other avenues to ask? Sree, go ahead.

Sree Sripathy:

So, well, while the way that I met people was originally through the first World Parkinson Congress, which I went to, in 2016, I found another group of people through kind of sharing my story more online, not necessarily through Davis Phinney, but with the work I do with the women's Parkinson's project, but also just TikTok and Instagram, and sharing things that I would normally never, never think of sharing. And I think we each have boundaries, not even, I think, I know we each have our own boundaries, and so not everyone is going to be comfortable sharing everything, but it's, if you're comfortable with social media and technology and putting yourself out there a little bit, there's a big community of people on TikTok, on Twitter, on Instagram. You don't necessarily need to use your real name or real location. You can come up with an anonymous account and find a community.

And when your comfortable kind of sharing your identity or your situation as much as you want to, you can do that. You'll find that there are so many people who are in similar situations that are willing to connect, not only people with Parkinson's disease, but people with fibromyalgia, people with dystonia, people with multiple sclerosis that experience similar things that we are all going through and that are willing to connect and share, and just share the love and support online. So, for people who live in remote areas that don't have a chance to go to a support group or something like that, there are options. And I'm happy to talk with anyone one-on-one who needs some guidance in that. Not that I'm a super guide, but if you don't know what to do, I'm happy to help.

Chris Krueger:



But you're not alone.

Kevin Kwok:

Sree, I'm curious how you and others on the panel were with support groups. Initially, I tended to avoid them because in the very onset, because I was thinking that that's them, it's not me.

Sree Sripathy:

I'll speak really quickly to that and then open it up or not open it up, give anybody other people a chance to talk. So, the first thing I did after diagnosis was attend some support groups that were for YOPD. And I was, when I went to those support groups, I found that the people who are in those groups were much older than I was by about 30-plus years. And they were YOPD, but their YOPD was diagnosed like 30 or 40 years ago. And I saw the stage of their Parkinson's, and it truly, it frightened me because I was just newly diagnosed. So that didn't work for me at that time. Now I'm very comfortable in that space, more so. But when I found a support group specific to people around my age range. And Kevin, you were part of that support group where we met in San Francisco like almost a decade ago. So that, I'd say, if you're newly diagnosed, you know, just be aware that you're going to meet people in all sorts of different stages of Parkinson's disease. And not everyone is going to be similar to you know?

Kevin Kwok:

Yeah. I get these calls like, Kevin, can you talk to my husband, wife, boyfriend, whatever. And they, I sense a lot of resistance on their part. Mm-Hmm. They're not ready yet to make the connection. And you can't force yourself onto people like that. Have others experienced that too? Brian? Are you raising your hand?

Brian Reedy:

Yeah. Lily and I had started a support group halfway. So, I was diagnosed in 2010, so about 2016 during the Portland WPC, we were learning stuff to start a support group. And at first, we were getting a lot of just the older people, and I was thinking, gosh, this isn't really what I want. I need to be around younger people. But I found so many blessings in there and so much strength and courage that once I got past that, you know, I don't want to look like that kind of thing. I was just blown away by these people. And so, I think that was part of my journey. And I think a lot of people that I've talked to who are Young-Onset say, yeah, I can't go to the meetings because I see all these older folks.

And there may be a nugget in there and there may not be. But I think just to start and just to try and not be afraid and open the door and see what happens. But since we ran the group, I just met so many different people and so many more experiences that, I think the best thing I found was there are so many online avenues that are really good. You know, like the Davis Phinney,





like the people in Phoenix that teach for support groups that I can't remember right now, one of, you know and avenues like that, that are on a national level, that are reputable that can help you talk about or learn things. And even the Fox Foundation has some stuff out there that helps on an individual basis. So that's another avenue to go to learn when you're trying to find that circle of people.

Doug Reid:

Heather is that your hand raised?

Heather Kennedy:

Yeah. I just want to speak to a few things in the chat, but did you want to, anyone else want to comment on the topic of hand? First?

Doug Reid:

I would just recommend checking with regional Parkinson's associations for the various types of support groups that they have. In Colorado, we have Parkinson's Association of the Rockies, which covers many states. Not Arizona, I don't believe, but I would imagine there's some Parkinson's Association of Arizona or something similar.

Heather Kennedy:

So, I just wanted to talk about what's in the chat. Someone said that they were terrified of becoming a burden and that they tend to hide a little surprise. I'll be the last one to ask for help. By the time I ask for help, I'm already in a crisis, which is then harder for the people to catch up to help us. It is so hard to know the words. Sometimes we don't even know what we need. Think about it. We're lacking dopamine, which means pleasure, award, and movement. So let me get this clear. I'm trapped in quicksand and or quickly drying cement, and I'm miserable, anxious, and depressive. Why on earth would I be losing friends? You know, after a while you're like, they're coming to take me away. You know, I mean, no wonder people get suspicious too. The medications were on. I had to titrate up and off meds, and up and off meds again.

And then when the surgery was done on my back, and I realized that my problems were not based on DBS by the way, or Parkinson's that had slipped discs and cysts and everything else, I was absolutely thrilled. Everyone's like, how could you be thrilled? You're in the hospital since June. You've been in the hospital for two weeks at least so far, and you're, you're happy. I was crying, tears of joy. The nurses would come in at night and they'd say, what's wrong? I'm like, nothing. I can walk again. It's a miracle. I mean, I could have been with a preacher up on the stage, getting out of the wheelchair, I was so happy. But let's just talk about a few more things that are in here. Memory difficulties, sleeping difficulties. Oh yeah. Hey, you're not losing your

mind. You're just exhausted. And just one more thing that I saw that was really important to mention too.

There are so many people asking for, like, remedies for micrographia. Good luck. Let me know if you find one. Here, here's the exact quote, I'm terrified to be seen as dependent or needy. My world is shrinking. I just, that's what I want to speak to. The world's shrinking. You do feel like the kid behind the glass, watching it with the people playing. You do start to get a little too sensitive sometimes. And when I say you, I mean, I've never met a park since a patient who hasn't at some point. But it's not about us. It's about us sharing the message so that others don't feel so isolated. That's why we're all here. We all have the same, you know, like from, you know, Brian and Kevin, straight, Doug, Chris, everyone here wants to make you see that you can do this. I'm here coming straight out of the hospital going, hey, look at us. Look at us. We, we can do this. If I can. Anybody can. And that's the bottom line. If you feel alone, reach out to one of us. I'll talk to you. I feel alone a lot.

Kevin Kwok:

Heather, you're coming off of a particularly challenging illustrated situation where you were in the emergency room. Any words of wisdom from that experience?

Heather Kennedy:

Oh, guys, I don't want to hog this time, but I will say I have a whole kit that I'm preparing. It's not like the Aware and Care kit. It's like, sort of like a series of videos to prepare you for emergency and crisis situations. The emergency room does not understand Parkinson's. Don't expect them to, I was treated like a pain-seeking person. I was treated like a person struggling with addiction. There's nothing in my chart about any of that. I don't know why they thought that three times in a row. They kept saying she was just here in April. She was just here, and they let me sit for eight hours, you know, and without any help whatsoever. And it was really it was stunning that this could happen. It was really a look-up trauma center. It's a piece on YouTube that I did. But I will say this, the bottom line is this. We're all people. It includes everyone in the medical system, training and education are everything. And here we are. Use our voices. All of us, everyone here, all these, we have 130 participants here. Let's do this thing. We got this.

Kevin Kwok:

Thanks, Heather. I know I listened to one of your pieces and was blown away. You've expressed sort of your views on being isolated, but your, this particular piece really hit home that it could happen to anybody who turns up in an emergency room for with need. And no one should have to go through that.

Brian Reedy:

I listened to that piece too, Kevin. I agree. And she really, Heather, you really spelled it out really well. But we need to help our ERs and hospitals be aware of this, and Heather does it very well with great respect for the healthcare industry. She's, she's not going to rip them apart, but she's kind of going at the people that treated her so horribly. But it brings a lot to head that, you know, people don't understand when we come in some of our symptoms. And the Aware and Care kit helps a little bit, but there's a lot more. And so, Heather raised a lot of really interesting points if you have a chance to listen to that presentation.

Kevin Kwok:

Awareness of PD is universal. We have so many levels of playing a role where we educate someone out there at WPC, I went on the last day to a film that was presented with a reporter who had Parkinson's, who went to Kenya and took himself off medication so he could relate to the people there who didn't have, who couldn't afford just regular cinema. And it showed this world, I know Brian, you were alluding to it, where people are treated with Parkinson's, they're stigmatized and told that they're possessed. And this is witchcraft. And this video was just brilliant on pointing this out. I mean, even priests and part of their family were saying, just pray it'll go away. So, the levels of understanding go from something basic like this in a developing country to California ERs, you know, there are so many levels of misunderstanding out there. It's a place where we can all play a role.

Brian Reedy:

And it's universally true with any disabilities or any chronic issues where we don't understand things. But I think one of the things I was talking about people at the Parkinson's Congress is, I think the reason when we all gather together and we have such a wonderful time, is all the pretenses are gone. There's no and pardon the language, but there's, there's no. Sorry, Edie. No. It's okay. It's, everybody is just as they are. And you get right to the thick of things, you know, I saw Carl and Chris Robber on here, and I met them, and they're two of the most amazing people I met there. And it's that opportunity to meet people that are in this with us. And you just get right to the thing of it, you know? And the biggest thing, I think the second thing I would add is humor.

Humor, humor. You know, laugh along with it. Try not to take it too seriously. Try to find a way to help it be light in your heart, so it doesn't hurt you. And it makes others I find comfortable today. My tremor was really bad, and Edie has never seen it. And I just said, you know, I've always been a mover and a shaker. It just shows now, you know, something stupid like that, but it breaks the ice. You know, like, why is he trembling so much? You know? Things like that help.

Chris Krueger:

So anyway, so, I want to, I want to loop in on something that's been sort of, we're circling around to something that I think needs to be, or if we can talk about it. Maybe we should. I

think, you know, obviously the people on this call are willing to step into this sort of role of helping under explain some of the situations that people with Parkinson's live with. And obviously, you've all made that choice. But for some people, that's not a comfortable choice. Some people don't want to be in that role. There was a person in the chat who mentioned that, you know, they, they have a place where people come to stay with them to visit, and then they get to see what their, what life with Parkinson's is like. But maybe not everybody feels comfortable with that. So, I'm wondering if anybody on the panel has any perspective about, you know, maybe how to respond if you're put in a position where you are kind of asked to educate about Parkinson's. Just be through somebody's not understanding. They may not ask explicitly, but they may just clearly misunderstand what's being before them from you know, a person with Parkinson's. And I'm wondering if anybody has any tips for how to deal with that moment if you don't want to be the educator, how do you navigate that? Yeah, go ahead.

Sree Sripathy:

I really never planned on being an educator. And I still don't consider myself to be one. Yeah, just a person with Parkinson's. But I get comments from friends and family who I think would know what I go through with the disease. because I've sent them like an audio link, a video link, a podcast link that asked me, why are you shaking like that? Why is your head moving like that? What's wrong with you? All these sorts of questions. And it gets tiring to have to explain it again and again. So, I just continue to send them to those podcasts and to those videos and to the Davis Phinney Foundation and send those links. But I guarantee you 95%, and it is a fact, 95% of them will not watch, read, or listen to any of that. So, I don't really have a solution for that. I mean, sometimes you're just like, it's Parkinson's and you just move along because you don't have the energy to explain what the disease is while you're struggling with the disease. You know? And maybe you can have an advocate with you, like a friend who is able to explain it better than you can, or hand out a card, you know, like I thought of creating a little card that I just hand out to people. These are my symptoms. This is what they are. Don't be scared. I'm a completely normal human being.

Doug Reid:

I'm always happy to educate people. I'm happy to talk about the disease. I was at the wound care clinic recently, and my nurse was talking to me about Parkinson's, and she had a lot of questions, and I was happy to answer them. And then we started talking about DBS, and she was fascinated, and I was happy to keep talking.

Sree Sripathy:

So, Doug, can I refer my people over to you?

Doug Reid:

Sure. Give me something to do.

Chris Krueger:

So, another thing that I was thinking about on this, this subject of relationships, and this came out of my experience at WPC, just meeting so many people with such wide-ranging experiences, was, you know, what about the changes with your relationship to yourself? And I know we've talked about this in the past couple of weeks too, but I just was thinking about it and in the context of, you know the fear or the shame, which we talked about in the past couple of months, is not the only way that your identity can be affected. And, you know, things that you might have tried to do before might change. You might not be able to do them as well. So, for me, it's, I don't play soccer anymore. And I know there are other things that people have maybe changed about what they, the activities they engage in. So, I'm wondering if anybody has any thoughts about the changes that they've experienced to their sense of their relationship with who they are. I realize that's a deeply personal issue, but,

Doug Reid:

Well, I can talk about that a little bit. I found recently, and I've been taking mindfulness co-study courses, and I've found that when I feel myself getting depressed, I can catch it and remind myself, as Brian was mentioning, don't sweat the small stuff and approach everything with a sense of humor. And I'm able to tell myself, now it's just Parkinson's. It's not going to get me down. I'm not going to let it,

Heather Kennedy:

What is this mindfulness thing? Is that like that word, they keep saying patience.

Doug Reid:

Mine is kind of meditation based, and I just have found that I can stop myself when I'm starting to get down about something.

Kevin Kwok:

Well, it's interesting. My therapist was presenting a paper at WPC a poster on mind using mindfulness, still overcoming anxiety and depression. And I participated in her study. And so, to hear her present, you know, live and show, you know, the data collectively from a number of people I thought was very interesting. The issue of mindfulness is different for different people. Some people meditate very well, and other people just say, my mind is too fleeting. I think that it's, it is not that we become Tibetan monks, you know, and there, but everyone who's walking, who's breathing can just be aware of how they're feeling in the moment. And to me, that's what mindfulness is in a broader application. My biggest thing is getting over the fact that you



can't do things that you used to be able to do. Yeah, we all have that where we can do something and we lament, but you have to get out of that trap because you get into the self-pity party then where it spirals you down. And I just find that, again, if I turn to community, if I call one of you on the phone or text you and just ask how are you doing? I actually find that that sort of helps to get me out of the funk.

Sree Sripathy:

The one thing I found that I can still do that I'm so thankful for is pull out my chin hair with tweezers. And when that ability goes away, I will be very, very devastated. I love you. I'll be devastated.

Kevin Kwok:

I'll come over with my tweezers.

Sree Sripathy:

Thank you, Kevin. I appreciate that.

Doug Reid:

Somebody put in the chat, they wanted to know what purpose I see that I've gained through having Parkinson's. And it's the role of the Davis Phinney ambassador, helping people with Parkinson's to live well, talking to newly diagnosed people, and letting them know it's not a death sentence. You can live well with this disease. Just speak carefully.

Heather Kennedy:

This is where I would like to say something about the Davis Phinney organization in particular. It's about living well now. You know, there are plenty of organizations that are doing tremendous work, raising money for research that will personally Yes. Live well today. Right? Sorry, I misquoted. I always do that. I'm great at misquoting. Like rumors of my death have been greatly exaggerated. I think that was Twain, right? But, but, but back to, you know, being here right now and working on this now, you know, some of those things will not, will not help us, because you won't see that in our lifetime. That doesn't mean that we don't participate. I just mentioned Kevin's been in this study about mindfulness. Right? And maybe you could talk a little bit about that, Kevin, I'm sure people want to hear a little bit about the study that you did.

Kevin Kwok:

Well, you know, Heather, this study happened right at a time where I felt like my world was caving in. You know, I had just lost my brother to cancer, just got laid off, and just turned 60 all within the same month as this happened. And so, this study came about looking for people to

get involved in meditation study. It would be a two-month program where you would do once a week gathering with other people in a group Zoom, and then the other, every day you would practice a different form or different technique of mindfulness. And I mean, it really got me through a really challenging time. Any one of those things would've done many people in. But the combination of all those, like I was taking body punches and getting hit from left and right. And I still feel like I managed to come out in a pretty good voice. Go ahead, Brian.

Brian Reedy:

I was going to echo something straight, put in the chat that I just saw, but it was about journaling. And I'm in this group called No Barriers Warriors, and it's for people with disabilities that are also disabled vets and PTSD. And so, they've had us go through these learning things online, and you're having to identify things like what, what do you see as like the people on your rope that help you? because It's based on Kevin, help me with his name. I'm going.

Kevin Kwok:

Eric Meyer.

Brian Reedy:

Eric Weihenmayer, who was the first blind man to hike Everest. But he, he kind of uses that as ways, like, one of the things is, you know, what is your vision? And, but I'm finding myself journaling these things and when you journal, you have to think deeper. Well, you don't have to. I do because of the question, and I choose to get into that. But to me, that was really insightful to start doing that. And I used to be a big journaler. I've kind of stopped it. And so, when I saw Cherri put that in there, it's like, yeah, that is a really good thing. And great gratitude journals are a thing I heard a lot at WPC. People focus on that because I think we can follow that trap. Like Kevin said, you know, I used to, you know, and somebody said a long time ago, you really have to avoid that trap.

Because that's just, that's a landmine that's just going to blow up if you know, I used to, I used to it's more important to start to find the newness and yeah, that's hard. And there's a letting go phase in probably the stages of mourning and all that. But it's a matter of finding the gifts that you have now with if you want to look at it, a curse or whatever it is that we have that makes going forward a lot easier. And there are gifts within, and it's being aware of that. And so maybe a journal gets you there, maybe a gratitude journal or something. But, sorry, I jumped on that because I saw s do that. I, they thought it was a great comment.

Sree Sripathy:

Just a quick comment on that I was responding to something Gabriel in the chat had said that I think they find that journaling and writing is more helpful for them than other methods. And



the one thing I struggle with journaling, and someone mentioned this regarding Micrographia, is that the journals are so small, even the big journals are small. And I find that I need a big swath of paper. Mm-Hmm. <affirmative>. Yeah, exactly right, Chris. So, if you have micrographia or even stiff movement or rigid movement, those things do not help. So, I bought a bunch of what is it called? That kind of paper that you find in kindergarten classrooms, like the brown paper, craft paper roll, A roll of craft paper that I would write on. And it's not quite journaling, but it gets my arm to move in really big movements because, you know, think big. And that helps me write more fluidly because I can't do any type of journaling in the normal-sized journals anymore. They just don't work for me. So, well,

Brian Reedy:

I do mine audio, I do them on the recorder app. And then there are apps that will translate it. Now. So, because I'm like you, I can't even type well anymore.

Doug Reid:

Somebody had put in the chat something about not being able to meditate and can't shut off her brain. And I have that problem too.

Heather Kennedy:

You can shut off your brain.

Doug Reid:

What's that?

Heather Kennedy:

You can shut off your brain. Call me. you're alive and you shut. You can stop your thoughts. I want to talk to you.

Sree Sripathy:

And the thing about meditation is what I've found out from when I was younger in my twenties to what I've discovered it is you're not meant to shut off your brain. That's not what meditation is. From everything I've studied in all the classes I've taken; it's about just being in the moment. And so, when your brain is going crazy, you just bring it back to your breath or bring it back to a certain phrase that you focus on. So, the brain is always going to be the brain. It's always going to think and jump and leap and do all sorts of things, but you just kind of keep bringing it back. It's like when you have a toddler that's going everywhere, wants to run around, and you have to keep bringing the toddler back to yourself. So, it's, you know, in a safe space. I mean, that's not maybe the best analogy, but,

Brian Reedy:

But what you're saying about breath helps. because That's what I started to do when I was learning about breath with laughter yoga. But now when I swim, I sit there, and I just put my arms up and I do the deep in and then down. And I just noticed by slowing my breath down, I slow my thoughts down.

Sree Sripathy:

The other thing I do is meditate by watching Bridgerton season one because there are some good-looking Bridgerton, season 1.

Heather Kennedy:

I was going to go, like, is it vendors Wings of Desire, wings, angels on the streets of Berlin? Yeah. Here's Eric's book. It's really fascinating. You get a chance. Sorry. Thank you.

Brian Reedy:

He, he's incredibly insightful about living with challenges and finding the spirit within. And he was actually one of the, he went blind when he was entering high school just two weeks before he started his freshman year. And he said one of the last things he could see was this guy, Terry Fox, who had cancer and was losing his leg, had lost his leg to cancer. And what he was doing was walking across the country to bring attention to cancer raising cancer awareness. And so, Eric's describing, like, he just had a vision with one eye, and he had to get up there really close, but he said he saw a light in Terry Fox's face that showed him this person who had this horrible thing happen to him. He made something beautiful out of it. And that's what inspired Eric along with his work. And I think that's what a lot of us are talking about, is we're trying to find that thing, or we're doing that thing without realizing it just by being here.

Kevin Kwok:

Yeah, his recent conference was, what is Your Everest is a great thing where we all have something that we're trying to overcome. And so, you know, I also want to bring this back a little bit to relationships. Talking about something that I saw with Connie presenting the keynote address at Barcelona. I thought she really hid it out of the park when she presented the role of the care provider and the importance of them in our lives. And I know many of us are still searching for that care provider for it. And I would say to this if you can, if you have a partner or can find a partner life, it is, it is so invaluable. I didn't ask for my care provider. I actually just chased my people away in my life.

Because I didn't want to be taken care of. And anybody who saw my weakness, I really pushed them out of the way, including my, my former wife and there, and that to me, one of, if I had a

high in life, it's to recognize that sooner and make sure that we own our relationships. And it's very easy to sort of shut people out. But if you find yourself more, more open, and vulnerable, and giving, I do think that your care provider is ready to step in there or someone in your life. I happen to be very lucky to have Jen in my life because she now has come into it as I've advanced. And she can sort of now read my mind if she sees my voice going, the fatigue coming in, she steps in front of me. And that's a very fortunate thing to have, which I in the past would've shunned away.

Sree Sripathy:

Yeah. I find it interesting for me that I, well, I've always prided myself on being strong and independent and, you know, being able to take care of myself. And I would have no problem back then asking people to open like a water bottle if I just didn't have the strength to do it. That never bothered me. But now that I can't open the water bottle because of Parkinson's disease, I have a lot of trouble asking people for help because it's because of Parkinson's. And I just was really surprised to find myself thinking that way. So, for me to ask people for help, I do it, but there's always, I mean, there's always this like, God, why can't I do this on my own? It used to be so easy, or I, you know, it used to be for different reasons, and that's something I still struggle with, and I have to constantly get over on a daily basis, you know, asking for help and putting it out there. So, there are just some things I can't do anymore. I just can't.

Kevin Kwok:

You know, what I found very refreshing about traveling abroad these last few weeks. I travel with a walking stick. The number of people on the subway and the metro and Barcelona and on buses who stood up to give me their seats when they saw me, who just touched my heart the respect that they have in other cultures for those that are not as well off as, as we are, is something that we have to get back to in this country. It speaks to what Heather went through and what all of us sometimes feel a little bit lost in the world when someone smiles and offers us a seat, that that's a really special moment.

Brian Reedy:

Well, and I was going to say about, you know, having the care partner and those who are single, and don't I think what, you know, and I lost my wife three years ago. So, I had a great care partner, but being without, I tried dating and it was horrible because there was negativity involved. But what I've found in my piece because I think Kevin even though the same thing before Jen, but it's like, you know, who would want to take on all of this stuff? So, I don't even look at that now. I'm so enjoying just meeting and listening to people and hearing their stories. And I was at a bus stop in Barcelona and waiting by this church and this woman came up and just started to talk to me about Charlie, my dog at first, but then she was talking about her travels, and I said, what's your favorite? And we just had this wonderful conversation. It's just

like, there, there's so much out there. If you're not looking for something and you're just open to what's there, it's a wonder.

Heather Kennedy:

You're going to be in the moment, right? Not having a gentle or an expectation is really hard. But I just wanted to also say it's anxious enough to look out into the world and see the world feels like it's falling apart. You know, everyone's saying, you know, it's getting more violent and it's this and that. I'm like, maybe it is getting more violent. But remember the lions and the gladiators, you know, there's always this sort of a way to sort of have to regain your perspective. And human neurosis has not changed in thousands of whatever years. So, we know that we're all fairly anxious, to begin with, add in lack of dopamine, and surprise. So of course, we're already sort of falling apart. We measure ourselves against them. We compare ourselves to others, and that's really not fair. We compare ourselves to how we used to be, and our friends feel this tension, and we make people feel uncomfortable because that's their relationship with disease and chaos, not because it's personal.

We're showing them a world of chaos. It's terrifying to them. Maybe they're afraid to be around it, not like in a place like Kevin, Brian, everyone's mentioned, where they think it's like leprosy, but more like, you know, those are negative people. Look out, they're sick. You know, there's this whole stigma that gives us some shame too. And that affects every relationship. So, let's go back to the part where we're whole, we're fine. We're not in the bargain bin. We are real. We're here and we're coming at you, and we can keep doing this. You know, we are not separate from the world. There's no duality here. We're, we're part of the world, and we can find a way to live in it. So, thanks for, you know, being here, everybody. Mm-Hmm.  
<Affirmative>. It's great. It helps me. You're helping me.

Chris Krueger:

Yeah. So, we're, we're just about to come up on the end of our, of our time here. And I think you know, I just wanted to draw attention to the way that you know, what Heather was just saying, sort of tied together a bunch of the things that we've talked about today about how to, how to navigate your own experience of the world, but and then make yourself open to the next, to the next things that might come, come to you. So you know, I just want to thank everybody for joining us and you know, mentioned that our next meetup will be on the 17th of August, and you'll get an email following up on the, you know, summarizing what we talked about today, and that'll have a link in there that you can share with anybody who you think might want to join us in the future. So, thanks again for joining us, everybody, and we look forward to seeing you next month. Yeah. Brian, you got something. One

Brian Reedy:

Quick note. Yeah. The, one of the most amazing things, and I think this is great for everybody to hear at the conference, was Paul McCartney let one of his songs be used for Rocky, the Raccoon for Parky the Raccoon. But he gave a testament afterward about his best friend, who he lost who had Parkinson's, and he's the one who introduced John and Paul and that he's got great empathy and compassion for people with Parkinson's. And it was so wonderful to hear that from somebody of such notoriety and with such a beautiful song.

Chris Krueger:

Yeah, I've seen the recording of the video that Paul McCartney recorded, and I haven't seen a video of the song that he was referencing yet. Oh, it was great. I'll try to put, I mean, I've seen the video, but I didn't, I haven't found a recording of it. In any case, I'll put those in the wrap-up in the recap that we email out so that everyone can see that it was, it was pretty, pretty interesting stuff for sure. All right, thanks, everybody. We'll see you next time. I'll still look. Bye.

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