



Living With Parkinson's Meetup: September 2023

Disability and Changes of Ability in Parkinson's

Davis Phinney Foundation

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

Chris Krueger (Manager of Educational Content, Davis Phinney Foundation):

Hello, everyone, and welcome to this month's Living with Parkinson's meetup. I'm Chris Krueger, program manager for educational content with the Davis Phinney Foundation. Like our panelists, I, too, live with Parkinson's. I was diagnosed in 2020, and I'm really excited to be here before we get started today because we're going to be talking about changes in ability that come with Parkinson's. Because we might talk about some things that we on the panel no longer do. I thought I'd ask our panelists today when they introduce themselves to do something that might be a little uncomfortable, and I hope they don't mind and say something that they think they're good at or maybe that their family thinks they're good at. Maybe even something like a superpower. I asked my partner what mine was, and she said that I could travel plan like the best of them. So, she thinks I'm a great researcher for that. I think I might agree. So, I guess we're going to, we're going to start off with some introductions and a little bit of superpower talk. Maybe I'll ask Kristi if she can start us off.

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

Hey everyone. I'm Kristi Lamonica. I live in Troy, New York. I've been diagnosed since I was 40. So, I have had Parkinson's for four years, but I know it was much longer. When I look at the symptoms, I think that my superpower is that I have the ability to remember crazy details. I don't know how, but I can always remember details, and I can always remember faces, except for today, I can't remember to take my meds on time. So, but whatever, but details,

Chris Krueger:

Okay. Kat, how about you? You go next, please.

Kat Hill (Ambassador, Davis Phinney Foundation):

I just want to say I'm really grateful for Kristi's superpower because I call on it often. Let's see. What is my superpower? I would say that I'm patient. That I'm patient. I think I would. I waited on a lot of babies to get here in my career, so I've gotten good at just sitting and being so.

Kristi LaMonica:



I rely on you to sop over interactions and other meetings with your patients because I'm not patient.

Kat Hill:

Fair enough. Well, thanks, Kristi.

Chris Krueger:

All right. Kevin, you're next on my screen. So, what about you?

Kevin Kwok (Board Member, Davis Phinney Foundation):

Well, this discussion of superpowers makes me think about a 1980 show where there were these superheroes. This is a superhero I want to be for Handyman. Handyman. Handyman, that's right. I won't be a handyman when I grow up. His weakness was Cripple Night. It's the most ident show in the world. So, but a handyman is.

Tom Palizzi (Ambassador, Davis Phinney Foundation):

That we all

Kevin Kwok:

Talk about it in the gym when we're working out. So, my superpower, besides being a handyman, is that I developed a good sense of empathy and active listening. People get really annoyed with me because I listen, and then I tend to ask really probing questions. Awesome. They say it's very disarming.

Kat Hill:

Weller.

Kevin Kwok:

I'm sorry,

Kat Hill:

I said that. Your good looks are a little disturbing. Aw,

Chris Krueger:

Breaking. Okay, So, Robynn, how about, how about you're up, please?



Robynn Moraites (Panelist, Davis Phinney Foundation):

Okay. I don't know. I'm freezing for some reason. My superpower is I have the ability to kind of because of my job. I have the ability to see through what's happening with someone and kind of get right to the heart of it. I know what to bring empathetically to a situation to help someone move to whatever the next level is, almost like a really good therapist.

Chris Krueger:

Great. Thanks for sharing.

Kevin Kwok:

Or bartender.

Robynn Moraites:

Or bartender. That too.

Chris Krueger:

Amber, how about you? You go next, please.

Amber Hesford (Panelist, Davis Phinney Foundation):

So, I asked my friends, and they said my wit or ability to use dark humor to cope.

Brian Reedy (Ambassador, Davis Phinney Foundation):

With Yes.

Chris Krueger:

Great. Doug, you're next on my screen. How about you?

Doug Reid (Ambassador, Davis Phinney Foundation):

Doug Reid. Calling in from Lafayette, Colorado, diagnosed in 2010. One of my best friends, I've known him for over 30 years, calls me the master of the side comment. So, I guess that means I have a quick wit and it's a good sense of humor.

Chris Krueger:

All right. Tom, you're next on my screen. How about you?



Tom Palizzi:

I'm, I'm, first of all, I'm glad to be back. It's been a crazy yay. Back on, back on all four feet. I think I'm doing okay. That said, my name's Tom Palizzi. I'm from Arvada, Colorado, just outside of Louisville, or between Louisville and Denver. I think my superpower is I can pretty much fix anything. I don't know why. I just had this uncanny knack for fixing stuff. In fact, when Covid was going on, I'd fixed everything that was broken. I had to start breaking things, So, I'd have something to do. So, it's good to be back.

Kat Hill:

We'd love to have you visit up our way. You need to.

Robynn Moraites:

It's good to have you back, Tom.

Kat Hill:

Yeah, Tom, great to see you. Yeah.

Chris Krueger:

Okay. Brian, how about you? What's your superpower?

Brian Reedy (Ambassador, Davis Phinney Foundation):

At my best, my superpower has been my optimism. Recently, I've been getting much better. Being back at that. I was told that I might have to have back surgery. The back surgeons, all three of them said, you'll never be a hundred percent again. So, I wrote my friends and said, this is super cool. I'm going to be like 120%. It's going to get better and better. So, that's my crazy optimism.

Chris Krueger:

All right, Heather, tell me, how about you? You have a superpower for us.

Heather Kennedy (Panelist, Davis Phinney Foundation):

Brian also has humor because he sent me a message that said I could see his labs, which was a picture of a couple of dogs.

Kat Hill:

Pretty good



Heather Kennedy:

My superpowers are cattle today because I can never find the link in time. So, I'm really lucky to be patient once in my life because patience is not my forte. I think one of my superpowers is just making goofy situations happen. Like, I'm excellent at sight gags. If you ever need some comic relief, like, you know, the wingman who falls all over everybody and then disappears from the scene, I'm your girl, let's do it.

Kat Hill:

So, just know in the chat that it may be from me, or it may be from Heather. So, that's my disclaimer for all the

Heather Kennedy:

Keeping them on their toes today.

Kristi LaMonica:

You guys are out of control already.

Chris Krueger:

Okay. So, I want to get us started on our topic for today, but I also want to invite you, the audience, please. If you have a superpower, you know, let us know in the chat, like fill it in there. Today, we're going to talk about changes in ability that are brought on by Parkinson's, including the ways that Parkinson's might be overtly disabling. Parkinson's can change abilities in a lot of different ways. It can affect our ability to exercise or drive or our ability to walk or move at all. It can affect our ability to access things and places we want to go. It can affect our ability to talk and write and change our ability to communicate in a lot of ways. I'm going to pass this off to Kristi to get us started talking about what changes in ability the panelists have faced and how they're navigating these changes or how they've navigated them in the past. You know, please, please don't forget that we welcome your questions in the chat. So, let us know if there's anything we can address that you're wondering about. So, Kristi, can you take us off?

Kristi LaMonica:

So, I want to kind of start off by talking about imposter syndrome and disability. So, I was thinking about this when I use my p tag, my handicap ping tag. I don't know if anyone else feels like this, but when I use my pang tag, I always feel guilty when parking in the handicap spot. If I can walk normally, I don't know why I feel like people are judging me and looking at me, and that is because I can walk at that point in time, but I can't guarantee that I can walk normally in about 10 or 15 minutes. So, does anyone have any other examples to share of how they navigate those types of situations? Kevin? Yeah,



Kevin Kwok:

Chris, I'm with you on that. It's been a bit of a journey for me on it. Really, the admission of disability in general. You know, when you're early on in your disease, you tend to say, I can get through this. I'm all right; I'm okay. I'm not; I'm doing fine. Right? What you find over time is that the efforts that we have to do things become more challenging. I want to talk about an example; I got together with a group of 3 360 disabled people the other day up in Breckenridge at this conference called No Barriers, no Barriers is an event that brings people with huge disabilities. It was founded by a climber who climbed Mount Everest blind 20 years ago. He holds this conference where he brings people together. There were so many people in that conference that were hugely obvious.

Kevin Kwok:

I mean, they had shrapnel, you know, from bomb blasts, or we had people that were blind or, or very obvious individuals. But a group of us were together where our disabilities were a little more invisible. We talked a lot about imposter syndrome. These individuals were all people who had PTSD or things like diseases where you couldn't see all the things that were happening. What was really nice about this weekend was it was not a competition to say whose disability was greater, but it was really celebrating the fact that we all had something that was challenging us, and we all lifted each other up through that event. So, first of all, I didn't use my disability placard when I was at this event because some people really needed the parking spots. But what I would say is that we are all ambassadors of both Parkinson's and this disability that we have. If you get out of your car and someone questions, you're representing all of our population tribe here. So, I've gone from the embarrassment of using the placard to almost wearing it as a symbol of pride somehow. So, that's my 2 cents on the imposter syndrome. I'd be curious to hear what other people say.

Kristi LaMonica:

Me too. That's a great perspective, Robynn.

Robynn Moraites:

I talk about cycling all the time, but I cycle with groups of people who go fast, and I wasn't able to keep up with them anymore, even at a most basic pace. So, I use an electric assist bike, and it looks like, I mean, I just almost feel the need to explain myself every single time I'm on a group ride, and it's like outing myself. But, you know, if I didn't have an electric assist bike, my average speed would be eight miles an hour. So, that's just one of those things where I always feel the need to explain myself.

Tom Palizzi:



Yeah, it can; it certainly is an uncomfortable feeling sometimes. Because people will look at you, you know, they are making comments, I'm sure in their heads that that guy doesn't look disabled to me. But again, you know, I never know how I may enter a building walking, and I may walk out of the building or crawl out of the building on my way out. So, you never know what's going to happen. That's why I don't, I really don't let it, I don't really worry about it. So, I haven't ever given it much thought.

Heather Kennedy:

The only time it becomes really dangerous is if you're heading into an emergency department and they don't think that you're disabled, or they don't realize your specific health needs because of how you initially appear in terms of being really dangerous for us anyway. But I have found in parking places, there's an awful lot of people who have an awful lot of opinions. I used to be one of them; that's the thing we don't know until we know. So, can't get too mad at them because they just don't know yet. Maybe they'll never know. I hope they don't. But

Kevin Kwok:

I never had I never had a handicap pal. You've struggled a lot lately on this topic of finding yourself in a situation and having to explain yourself. To me, that's one of the hardest things when we're going through this sort of survival. I just want to get through this and try to teach someone with alert teaching experience; sometimes, we don't have the patience to do that.

Heather Kennedy:

I have a funny story, though,

Kevin Kwok:

Please

Heather Kennedy:

On that note, Kristi, not to change the subject completely from parking, but it does have to do with transportation.

Kevin Kwok:

An okay. Please share.

Heather Kennedy:

I found another; my superpowers happen to be the quadrant roundabouts you go through in an airport where, picture this, we're moving as a school of fish where if the person stops abruptly



right in front of you will fall. The access doors are all locked on either side. So, I had to go through the turns, and the revolving door froze for at least a minute. Everybody hits the glass, and they were like, man, down terminal three ells, oh, an elderly couple down. It's ma'am, security to terminal three. Get over to the quadrant immediately. You could hear this on the loudspeaker: they're calling security. It was a pile-up. Who caused it? Me. So, I'm sitting there getting the side eye; everybody's looking at me. I'm going, I can't. They're like, why didn't you just move out of the way? I go, huh, I don't know, IRO. I completely froze. Pretty soon, everyone is just livid with me. I got Parkinson's, the only word I could get out. That actually happened. Anyway, security knows me now. We're like this.

Tom Palizzi:

He's back.

Amber Hesford:

Hey, Doug.

Doug Reid:

The only time I've experienced imposter syndrome was pretty recently when I was on vacation and in the airport, and I got a wheelchair. I loved the wheelchair experience to the point that I think I'm going to request a wheelchair every time I fly. For those of you who are regular attendees to this meeting, you probably know I broke my leg in March and had bunion surgery last month. So, I've been having a tough time of it. But I decided when people are looking at me, this relatively young guy riding in a chair, I'm going to wear my Davis Phinney t-shirts when I travel. There you go. Just advertise that I have Parkinson's. Beautiful. When I meet new people, it's one of the first things out of my mouth after I've shaken hands or had greetings. I just want people to know I've been living with this disease for over 13 years now, and I almost have a sense of pride about it.

Kristi LaMonica:

So, when we went to WPC, I got a wheelchair myself, too, for when we landed in Chicago on our layover there. Did you how did you feel being in the wheelchair? Did you feel invisible, like going through the airport? Or did you feel that people saw you? I felt very invisible.

Doug Reid:

I felt like people were looking at me.

Amber Hesford:



I agree with Doug. I got the wheelchair on my first trip to WPC on the way over there. I used it to get onto the plane to Barcelona. But on the way back, I had to use it for all of them. I felt like, yeah, people are definitely starting to see somebody young in a wheelchair. It looks like I'm completely able, and I was not.

Tom Palizzi:

It is, it's difficult. I find when I, when we're traveling, and I use a wheelchair almost exclusively these days. Especially if we're traveling at odd hours, like early in the morning or late in the evening and it helps I don't feel like people, I don't feel invisible. I have to laugh at the guys who are pushing the wheelchair, kind of make a lot of noise or ring the bell or whatever to signal that we're coming and that kind of thing. But it's definitely, definitely worthwhile. I am going to say I don't really mind if people see me. I think it's a good thing. I've never, no one's ever asked or made a comment to me at all so far. So, I did have one instance when I froze, putting my bag up in the bin, and I just couldn't move. This guy's looking at me thinking I was staring at him, and I'm like, no, I'm not staring at you. Then he got up and said, can I help you? I said, yeah, I have Parkinson's. I can't, I can't move. He took my bag, and he put it up there for me. So, again, I think the guys that have all mentioned this, far, all of you folks have mentioned it. So far, about being a teaching o opportunity, that's how I look at it. It works pretty well.

Kristi LaMonica:

Yep. Karen?

Brian Reedy:

I, yeah, and I agree with everybody about getting the wheelchair. I did bar to Barcelona when it was suggested, and the standing that we would've had to have done in the lines going through to get in the country would've been insane. So, yeah, I can walk, you know, a mile without too many problems. Sometimes I'll look funny. But the whole idea is we have to take care of ourselves for the long run. If we walk and we hurt ourselves, we're, we're not helping that goal. One thing when you said imposter syndrome, and this is about Parkinson's, and it addresses our times when we're bad and when we're not. But when I was still teaching, and I had Parkinson's, I'd go through the school, and I was just like hunched over, and I had a cane, and I just had all the stress on me.

And then I was out shopping at Costco with Lily, and a teacher commented to her kids one day that I think Mr. Reed's faking it. He just walks around here like this, and then he is at Costco, and he is fine. It's like, you know, there's the pressure and the stress, it's overwhelming. Then you get home, and you're with the gorgeous woman you love; of course, you're going to start to feel better, and you're going to relax, and then you go out, and you're just getting a few things. So, I had to kind of explain that to her. But that's the thing with Parkinson's: we don't know when we're going to need it. Sometimes, we're just wrapped out; other times, we're



amazing. Yeah, explaining that to people isn't that easy, but it gets comments in other ways. I thought that people who work there might have some of that to address.

Kevin Kwok:

You know, I know the purpose of this talk today is not really to discuss some of the more technical issues of what disability means, but one thing that brought me great pleasure in 2016 was when the Parkinson's Action Network lobbied to make non-motor symptoms recognized by Social Security. That was a big deal for all of us. I think what's happening is there's still catch-up patients themselves, employers, and the whole environment are catching up with the recognition that the non-motor symptoms are, in fact, a disability.

Kat Hill:

Yeah, Kevin, I would really echo that because, in terms of quality of life, I don't know about all of you, but it's often the non-motor symptoms that are the most impactful for me. Some of the more the, what's the word we're using? The IM is invisible to many people, including my wonderful, loving husband. Many of you know him. He's, he's a wonderful, empathetic, great man. He still sometimes will say, I'll say, honey, I really want us to park in the handicap mainly because I'm tired. It's the same thing. Then you have to go in and now, especially Costco, I don't, I think it's because the parking lots are huge, and then you get inside, and there's So, much stimulation and so, many choices. So, it's, yeah, it's almost always, and I walk in usually looking pretty okay and feeling pretty okay, but I know by the time I leave, I'm not going to be, and then to navigate a busy parking lot, it's complicated.

Kat Hill:

And so, I've, he's, I've had to say to him, Ken, I don't really want to explain every time I, but I'd love for you to ask, and I'd love for you just to assume that if I'm with you at Costco, that I'm going to want to part in the handicap. If I have to explain to somebody who sees me day in and day out, you can imagine what the rest of the world is like. Who doesn't have Parkinson's? So, I think it's I think it's interesting, and it's reinforcing that nobody else is in our bodies or in our brains. Even when we think we are presenting symptomatically, I loved the quote Pam wrote in the chat over here: what other people think of us is none of our business. Exactly. I try to go to this place like, who am I to think that anybody's trying to figure me out?

You know, who I'm not So, special, right? I try to think about not having so much of an ego because often, we're all looking at each other from our own places. So, I try to remember that even though I feel self-conscious or whatever, everybody's carrying their own load. It's really none of my business what people are thinking. Frankly, if I can't figure out my husband, who I love and have lived with for 35 years, I'm often wrong trying to guess what he's thinking. I certainly can't figure out the whole world in a parking lot or Costco. Right. So, or an airport or, anyway, for what it's worth, Robynn.

Robynn Moraites:

Well, sort of cutting back the other direction, you know, one of the things my mom has got diagnosed with Parkinson's after I did. I feel like on this panel, most of our panelists were really good about talking about adjusting expectations, and you know, last month, we were talking about, you know, me being a maverick and having to sort of downscale certain activities, but I have had interactions with my mom, and she's having a hard time accepting that the outside version of her does not match the version that she has in her head. She has put herself in very dangerous situations, such as not riding on an expressway, but that resulted in a fall and a broken bone, which could be the first domino to tip in a slow-motion catastrophe. There is this sort of, my brother and I had to come to Jesus moment with her because we're like, you have got to stop minimizing our suggestions and rolling your eyes and sort of saying, I'm fine, I'm fine.

I'm going to do what I always could do. I, you know, I don't want to be different. She ended up having an experience. I'll email it to the panelists so that it can't go public, but I'll email it to the panelists. She wrote a story about it where she decided, you know, she was going to go to the dentist without any help at all, and she had an eye-opening experience with it. So, on the reverse side, there's this idea about what we talked about last month, sort of really adjusting our expectations of ourselves based on the physical realities versus having an overblown idea of what we have in our head. That, you know, my mom isn't her 35-year-old self. It's interesting for me to be interacting with someone; I mean, in some ways, I feel like I accept my Parkinson's more than my mom accepts hers. That creates a very different safety situation and very different Parkinson's practical considerations.

Chris Krueger:

Yeah. Robynn, you're pointing to something interesting to me that I think we've kind of circled around but haven't really dialed in on, which is, you know, we've talked about some practical difficulties that are significant, obviously, but there's also kind of deeper emotional and familial issues that arise out of, out of changes in ability that have to be navigated. So, I'm wondering if anybody has any perspective on, I mean, Kat's talked about it a little bit, and Doug maybe has talked about a little bit, but just the emotional side, you know, how do we deal with these things internally? Somebody was talking about patience as their superpower, and I would just wonder how we create that. How do we find that inner strength? Does anybody have any thoughts about the emotional side and how we find strength?

Brian Reedy:

Well, it's kind of the denial and the acceptance thing. I know when I first got it, I was in denial for a long time. When I used to do presentations, I realized I had been in denial. I put up a picture of the Nile River, and I say, not that Nile; I'm in denial. Denial. But it's something that I think we all kind of inherit in the sense that we're young and vital, and we have this thing that



we can't see. So, we have like, oh no, I can still do this. Oh, I can do that. Oh, that was a catastrophe. I'm still having to re-navigate. Well, now living alone, it's tougher because I don't have somebody say, Hey, that's stupid for you. Or, you know, something, but guidance. But it is truly the biggest challenge I think we have because we want to remain vital. I think it's an ongoing thing, at least in my end. It's something where I have to get humbled sometimes to get it in.

Kat Hill:

Yeah. Kevin's been great.

Kevin Kwok:

Can I ask the panel here? Have any of you ever taken a functional capabilities exam? My disability lawyer recommended that I do it. I went to work with this occupational therapist for four hours doing all kinds of tests, lifting fine motor skills, you name it. In the end, it was a very teary session where she said, you are definitely disabled according to my criteria. But she went on to say that just because you're disabled for something like a work evaluation, you're not disabled socially and living life. She says those are two separate disabilities that we're dealing with. So, I think it's really important to sort of disassociate what is your physical disability versus an emotional disability.

Kat Hill:

Yeah. Kevin, is it okay if I jump in? I don't want to take it.

Kevin Kwok:

Yeah, jump in.

Kat Hill:

I think that that; I've been talking to a lot of folks lately about the process of going through qualifying for Social Security disability, and it's quite a process. We're not experts here on this panel, but I'd like to talk about the mixed feelings when you're awarded Social Security disability; part of you wants to jump up and down and say, thank goodness that is over. Thank goodness I have some promise of at least some income for the rest of my life. I may have been giving up my job, but it's also a really hard thing to say that people have dubbed you or granted you disability because it can be a real catch-22 in your own head. The story that we tell ourselves is the most important story we're ever going to tell. I think that, while I think it's important to grieve the losses that we have physically, things become more and more challenging, and that's really important.

Kat Hill:

And I think it's important that we can look at ourselves honestly in the mirror and not put ourselves at risk. I think those are hard, hard things. I think that we undervalue how hard it is to shift and not put ourselves in a box, even though we can use the handicap placard. I think that the trap is saying that when we are disabled or dubbed disabled or awarded disability, that can take away our vitality and all of our abilities. So, I think it's really difficult. I agree with you, Kevin, that Kevin just commented that, for me, it was harder. The day that I was awarded Social Security disability was one of the hardest days of my entire life.

Heather Kennedy:

Mine, too.

Kat Hill:

It was, oh, I'm going to choke up. It was validating in some ways, but it was also such a huge loss because I loved my work, and I knew that it was safer for me not to practice midwifery anymore for a whole host of reasons. But it was such a huge loss for me. I really thought that, professionally and intellectually, it would; my life was over in many ways. I'm so grateful that it isn't that I've been able to go on and redefine myself, but I get how hard that is. I don't want us to downplay that because I think it is the single hardest part about living with a disability and also being diagnosed at a time when you're not ready to leave your professional life. Economically, it has significant impacts. Impacts. Sorry.

Heather Kennedy:

That is so powerful, Kat. Now you're helping a lot of other people. You're helping so many of us. You've helped me basically birth something. Look at you. You're just, you don't stop helping. So, thanks.

Kat Hill:

Well, thank you. Sorry to be a mush pot.

Heather Kennedy:

Don't be sorry. No, Ken.

Robynn Moraites:

Well, Kat and you bring up such an important point because I think particularly for this panel, we're all of the personality types that we identify a lot with our jobs, our careers, and what we do. It forces, it's forcing me that you talked about finding vitality other ways, redefining ourselves. It's sort of like a spiritual journey of unlatching your identity from the externals and finding, you know, joy just in relating to people or in our hobbies or whatever it may be. That's



not an easy task. That's not an easy journey. I think Kat, So, often on these webinars, you always talk about this as a human experience. I do think that we all have these spiritual journeys of, you know, growth, and this is one of them.

Tom Palizzi:

And there's the grieving process. I've, I've heard people talk about that all the time, especially in this environment, about grieving the loss of your job or your career, whatever. I mean, that's, that's certainly a real thing by all means. I know I felt very similar to Kat. My job wasn't anywhere near as glorious as yours, but it was definitely a costly thing for me mentally. I think what helps on the other side of the coin, though, is it's quiet, a business-like decision that you make. There it is. For me, it was assuring myself that I had affordable insurance for the rest of a long period of time. That was really the big reason I sought Social Security disability. Plus, there's pressure from me, a private insurer that supplies the bulk of my disability, to get that that alleviates some money that they have to kick in. But the money aside, it was really more about having the security of having some decent insurance at a regional cost. So, there are some good business things that, if you focus on those that, might help the process of sharing that label of being disabled.

Kevin Kwok:

Has anyone on this panel been denied insurance because they didn't file properly for their disability?

Kristi LaMonica:

Well, Amber had a comment first. So, she had her hand up for a while.

Amber Hesford:

Oh, sorry. Then I, we'll come back. I was just going to echo what Kat was saying. I recently attended a Social Security administration seminar, and you know, I'm still working full time. I'm a single mom, so I have to think about monetarily being able to provide for the kids and, you know, insurance and all of that. But I have basically a full-down breakdown thinking about not going to work. I feel like that is my identity, and that's the escape from my house. Because I don't have a partner here at home, that's really how I get out and socialize. What would that do if I didn't have that? Like, So, can I just work forever?

Kristi LaMonica:

We'll keep you busy here. Amber and my job just changed. So, I can work forever, though, because.

Amber Hesford:

Yes, yes.

Kristi LaMonica:

Kind of like on this, on the other hand, it's thinking about having to go to work and teach; how long can I actually physically do this? Sorry, Heather, I'll follow you for a second. Like, how long can I physically do this before I'm going to have to apply?

Amber Hesford:

And that's why I attended the meeting. Because I'm already thinking, like, I don't know how long I've gotten to continue doing this. You know, things are getting harder, things are progressing, and you know, but then at the other end of it, like, I don't know how I will not do this.

Brian Reedy:

If Heather wants to

Heather Kennedy:

I wanted to mention that sometimes, we can get very myopic. Like I'll be super focused on something I need to do, like a stick of butter and, you know, and then some bread and a carton of milk. I'm memorizing this as I walk into this UPS store to mail something. It was very important to some doctor's notes they had to get. Because I've been waiting for all my files to come in, I get all my medical records, and as I walk in, the woman's looking at me suspiciously, and I saw it in her eyes, the same look my dad used to have, same look my grandma had, same look my aunt had. She was very confused. She kept saying, why are you talking into your phone? What's going on? And I realized, oh, she has dementia starting or all summer and probably doesn't realize it.

And she had just kept going and going, and she was so awful to me. But she made me cry, but not for me, for her; her husband then got involved and kept apologizing to me, falling all over himself, and saying it was okay. I think we both are struggling. She couldn't hear me very well. She was confused. She's trying to work, and maybe she needs help too. I just left because I realized that I was so focused on myself, what I needed, and what I needed to come in with. So, I just want to talk about disability. So many things don't show that we all struggle with. Kat had mentioned that before. Sometimes we get, I get so egoistic, we get so egoistic and like, I'm going to get this done. It's about, you know, and then I realized, oh, everybody's got something, and now we can just see it a little better. I just wanted to add that into the mix. Thanks.

Brian Reedy:

And I wanted to mention, and I agree with Heather profoundly because I think when we were going through grief here when Lily was in dealing with her cancer, people would say, what couldn't we do? I told you the best thing you can do is smile at a person who's grumpy in line. Because You don't know what's been set upon them or what they're having to deal with. The last thing they need is somebody to pile on their grief. Just give them a nice smile. Just be kind. But what I wanted to say about the whole Social Security and the working thing that Kat mentioned is I remember we did interviews down at our Social Security board here in Nevada. I was painstaking because I was still teaching. I really didn't want this. So, much like Kat, I had the best career in the world.

I was a high school teacher. I had kids who were winning national and state awards. They were making videos and just a fantastic program. It waned down because I didn't have the energy, and letting go of that was something I was never going to do. But reality hit. That's the biggest thing is all of you who are saying you don't know when, you'll see when you will know when, and you'll address it then. But keep it as a conversation with those that are close to you that you can have. So, they can help you see when and then even if you don't, you know, do like Amber is doing now and start going to Social Security meetings and start understanding it. So, you can navigate it when you get there. Because it is a tough thing to navigate, but it is navigated, it can be done. So, that's my 2 cents.

Kevin Kwok:

It's really complicated to navigate; it's one of the more difficult topics. Social Security, Medicare, I mean, these things are really challenging, and you're sort of fraught with this, almost this grieving and loss of your life. Now, having to deal with all these issues is really challenging in my for, for, for me. As in this journey, dealing with the bureaucracy of disability plus physical, the head on the physical components is probably the most challenging thing that I've experienced in the 14 years that I've had. P's

Robynn Moraites:

Unfortunately, you're forced to deal with this really difficult, complicated navigation of, you know, meeting criteria and stuff at a time when you're sort of least able to do that, right?

Kevin Kwok:

Yes. To make a recommendation. You know, based on one of these conversations that we had a couple of years ago, one of the previous members directed me toward seeking professional counsel. This was Amy, who actually said, Kevin, you need to get a lawyer, right? And someone who can really guide you through this. I will tell you it's the best money I've ever spent. Because of all these things of filling out forms and trying to figure out this intensive maze when you're emotionally distraught, my lawyer really helps me just calm down and say that's just the way they are. We'll get through this.



Brian Reedy:

And you're right about seeing someone I forgot about that we did that. Because it's a process that is very difficult when we have to let go of something. So, the psychologist really helped me gain perspective, and I think that's a huge plus. Kevin, I love that you added that.

Doug Reid:

Yeah. I got kind of a funny story about getting approved for SSDI and Social Security disability this past April 6th. I was supposed to have a phone hearing in before a judge, and I was sweating it primarily because my long-term disability insurance provider wanted me to apply for Social Security disability income. Ever since I had DBS, I've been doing a lot better. I was worried the judge was going to reject me and that I was going to have a hard time dealing with my insurance provider. Then, on March 31st, I broke my leg. I'm sitting in the ski patrol's office, waiting for the shuttle to take me to the emergency department. My phone rings, and it's my disability lawyer who tells me we don't need to have the hearing. The judges approved your claim. So, it was kind of ironic that I'm worried about being flagged as non-disabled. I'm out skiing, and I get approved. All right. That's enough of that story.

Tom Palizzi:

But it's important to note that Social Security disability was put in place or came about long before there were computers and cell phones and that type of thing. So, it was designed around a workforce that was more manual labor, right? All

Robynn Moraites:

It doesn't make sense.

Tom Palizzi:

Yeah. All the information that you have to put into that is kind of based on how much you can lift, how much you can carry, how long you can stand, that kind of stuff. Which few of us do in our jobs anymore. Most of the time. I wrote the, I wrote a computer keyboard. So, you know, those are the kinds of things that, are you disabled or are you not disabled? All by the old stoic viewpoint of SSDI, it was hard to look like you were disabled. But in the new world, today's new world, and I don't know if that's a new world or not, but in the world that we live in today, it's not necessarily based on all the manual things. That's where I think attorneys can really help a lot. Your doctors can really help when you're making those applications to those things.

Kristi LaMonica:

Yeah.



Kat Hill:

Yeah. I'd also like to say that I thank you, everybody, for your kind comments. First off, I try not to fall apart here, but I also want to say that for all that, the system is difficult. I do feel very lucky to live in this country and be able to have some resources. I'm so well aware that in many parts of the world, people don't have the kind of resources that we have. So, even though the system is not perfect, it is a system that allows us to have free speech. While a lot of us may feel stigmatized or marginalized, we, in general, have a world that we can be in without a lot of that. So, I don't want to minimize that people around the world, are suffering. I actually would love to hand it off to Kev because I think he and I have been working on some projects together, and I just want to share something, let him share something powerful about it, and that helped give me some perspective. Key

Kevin Kwok:

Kat, I thank you for teeing that one up. You know, I was thinking about this just last week when I was; they turned my DBS off so that I could get Botox. I felt like I was having trouble swallowing, blinking, even breathing. But I mean, at that point in time if you'd seen me, I was totally disabled. But what led me to think about how lucky I am, I mean, here I am getting state-of-the-art care. I mean, I drove to the hospital, parted the, to save a lot, getting the vest of DBS and vests of Botox and medical care and all, and realizing that there are people around the world that have nothing.

Kristi LaMonica:

Right. Pills, I have all these.

Kevin Kwok:

That's right. There's a project that several of us are working on in medication equity in developing countries like Africa. I mean, the stigmatization if you're in Africa is that you are possessed by the devil if you have Parkinson's.

Kat Hill:

In some parts of Africa.

Kevin Kwok:

That's true. Not in Colorado, too. Well, that's the point on here is that stigmatization is in different forms everywhere. We may not have it as extreme as in parts of Africa, where people are literally pulled out of their homes and killed. I mean, you, there's a documentary that just showed on BBC called Shaking Hands with the Devil. I would encourage everyone to watch this,



and we could come back and have a very different conversation here if people are willing and interested in doing it. But it really is sort of level sets and puts in perspective.

Kristi LaMonica:

It only minimizes all of our complaints. Right. It just makes us feel very humble.

Kevin Kwok:

That's right.

Kat Hill:

And we don't point out this documentary because we want you to feel bad about yourselves. After all, I think we all are a product of the cultures that we are born and raised in. I think what's been interesting doing this work with Kevin and a group of international advocates is that it's just enlightening because sometimes we sit, get to sit in our own homes and refill our prescriptions and drive to the markets when you realize that other people in the world don't have those privileges. I think that it's humbling to think that simply by being diagnosed with Parkinson's in some parts of the world, people put their lives at risk, letting that become public. So, it's a powerful it's a powerful watch. I think it's great awareness for anybody to watch, but we don't. We're not saying it or bringing it up to make you all feel humbled or bad, or we're more bringing it up as an awareness point. I think, for me, it's eye-opening. It's humbling. It's also a touchpoint for me to remember my own relative privilege.

Brian Reedy:

I want to veer back just a little bit because one aspect of disability that I know very well because I'm a veteran is veterans getting disability and getting Parkinson's in there. So, just a quick moment on that because it's very difficult. But now that they've done this recognition of the toxic exposure and the chemicals in all of that, they found two of the bases. My wife discovered that two of the bases I was at hand D c E Tetra Flora Ethylene.

Kat Hill:

Ethylene,

Brian Reedy:

Yeah. Yeah. In the, in the drinking water. But so, here's the trick, and this might even work with some of the stuff you're doing with Social Security. We found out that if we could get a doctorate or a researcher of Parkinson's to say that my exposure is as likely as not to have contributed to my Parkinson's, at least in the VA sense of the government as likely as not, they will go with, okay, that's good enough for us. So, as some of you are navigating disability, I can't



remember all the paperwork we did for that one with Social Security, but that's a very important phrase. To have a doctor give that to you, it's called a Nexus letter that can get you through. My wife was a genius. We did it in three years. We got a hundred percent disability in three years. Normally, that's like a 15-year process. But I just want to put that out there. Better

Kristi LaMonica:

Now that there's the PACT Act, they can look up and get help through the PACT Act, too. Yeah.

Kat Hill:

PACT.

Kristi LaMonica:

Yeah.

Brian Reedy:

PACT. Yeah. Okay. It's a really big thing for getting the veterans who've been exposed mainly during the recent wars, but it also works if you were at a basis that had this stuff. The other thing I wanted to mention as I've been listening to all of you is because we're talking about disabilities, we're talking about the sadness of it or hardness of it, but Kevin has mentioned No barriers, and I did No Barriers Warriors, which was the veteran's aspect of it. But what I loved without going just into no barriers was when you look at them and their website, and you start to see all these other links in all these other places that are doing things for people with disabilities like fly fishing or hiking. It's like, there's just a whole wide variety. When you get into that world, and you see people that have disabilities like you that don't really show, you know, I've met people who were crushed by cars, but they can walk again. But it's, you know, tricky and dicey, and they need the disability stuff. But when you're all together in this, and you're lifting each other up to climb these poles and do the ropes course and get through the hike or get through them, it's like disability isn't the end of it. Disability is just another avenue. That is, I want to open that avenue up as we're looking at the disability. I don't want to have it, just sadness. There's a whole lot of fun in the disability world. Still to be had.

Kevin Kwok:

You know, Brian, there was no sadness on that weekend. Yeah. I mean, people were dancing to a deaf musician who could hear nothing, and we're all out there having a good time. I can't tell you how much joy comes from admission and trying to help each other out. I have one observation from WPC that I wanted to chat about, and that's the cultural treatment of people with disabilities. What I noticed was when we were in Barcelona, every time I was on a bus or a train, someone got up and gave me their seat. I can't tell you how moved I was by that. Then

they would offer Jen, my care provider, one because she was with me. So, I've tried to make it part of my world right now to do something that I can do one-on-one with people directly instead of getting on a bus and getting out my phone and starting to text to look around and see people that I can help. If you are just being a little aware and you teach your kids to do that, I mean, the world would be so much better if we treat our own disabled friends around us. Well,

Kat Hill:

Wouldn't the world be better if we all were just a little bit more aware and mindful about everything, right? Not just about who may need help, but maybe be more present with the people we love and the people we care about. I think that helps with gratitude, Doug. It's amazing. You know how I feel the same way if I'm feeling, you know, crummy. I do feel like, like, I can try to dial back and remember that that, you know, electricity and internet connection and red lipstick are privileges. That's why I put it on. I was feeling a little down.

Brian Reedy:

This is a difference.

Kristi LaMonica:

Having inpatients that because so, asked what you're saying So, that people give, give you, their seats. But if you look, if you look like you don't need it, are they more likely to do it? So, I think that being patient with people who might not display that they have issues or have a disability or need to be seen at that time, I think that people should practice patience too; it'd be a nicer world.

Chris Krueger:

Yeah. So, we're approaching the end of our time. I think that's a great sentiment to start to wrap up with because one thing that I think has permeated this conversation about how we move forward given changes that might occur in disabilities, we might experience, I think central to all those things that you have offered on the panel today is a kind of calmness and an open-heartedness about the circumstances that you see. I think that Kristi, you're spot on that I think it can be very helpful to have that for other people, too. Approach other people calmly, whether they're your family or your friends. Yeah, Brian, have you got something?

Brian Reedy:

And with a nice comment or a thought when I was at the No Barriers thing, and they were cheering me to go up the climbing wall, I was crying, thinking, I can't do this. This is too hard. They're all chanting, you've got this, you've got this. Brian, we're right there with you. You can



do this. A month ago, I got put in a wheelchair because of this problem with my back, and the first thing I heard was, you got this, Brian, we're with you. I have no sadness. I hardly talk about it in that sense. Now you got it; it's like a temporary thing. But that's a good thing we have with our groups is that we all lift each other.

Tom Palizzi:

You got this.

Brian Reedy:

, you got,

Kristi LaMonica:

We all got it. Yeah. It's all So hard. It's all So hard. So, I

Heather Kennedy:

Just went through the same thing, and I had surgery. I'm with you. It's going to be easy. You'll, you'll fly through it.

Kristi LaMonica:

That's

Brian Reedy:

We had, right?

Kristi LaMonica:

We're going to make everybody else's life easy, more difficult. Why not make it easier and just be kind and be nice to everybody

Brian Reedy:

And listen to their stories.

Kristi LaMonica:

Yes,

Brian Reedy:



Listen to other stories.

Kristi LaMonica:

Everybody has something to teach you If you just listen and

Tom Palizzi:

To those of you out there that if there's any way we can help you, I know on behalf of myself and all the, all the folks on the meet up here and the rest of the ambassadors, we're here to help. Feel free to reach out to us. You can usually find us on the webpage dpf.org. Look under resources.

Chris Krueger:

Yeah. On that note, we'll post the links to the ambassador search in the follow-up post that'll come out by the end of next week. You know, thanks so much for joining us today. We look forward to seeing everybody next week, or I'm sorry, next month's third Thursday. We meet, and we hope to see you then. Thanks for joining us, and thanks to the panelists for being here today. You rule, you got this. Brian

Brian Reedy:

You all are great. Thank you. Thanks.

Kristi LaMonica:

See you guys.

WANT MORE PRACTICAL ARTICLES LIKE THIS?

You can learn much more about living well with Parkinson's today through our *Every Victory Counts*® suite of resources. Each manual is packed with up-to-date information about everything Parkinson's. Click the link below to reserve your manual(s).

[Reserve Your Manual\(s\) Now](#)

Thank you to our 2023 Peak Partners, AbbVie Grants and Amneal, and for their ongoing support of these must-have manuals. Additionally, we'd like to thank *Barbara and Dale Ankenman, Abby and Ken Dawkins, Bonnie Gibbons, Gail Gitin in loving memory of Gene Gitin, Irwin Narter, and Lorraine and J Wilson for their generous donations that allow us to make these resources available and free to all.*