



Living with Parkinson's Meetup

August 2023: Vulnerability

Davis Phinney Foundation

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

Chris Krueger (Content Manager, Davis Phinney Foundation):

Okay. Hello everybody. Welcome to this month's Living with Parkinson's Meetup. I'm Chris Krueger, program manager for educational content with the Davis Phinney Foundation, and like our panelists, I also live with Parkinson's, having been diagnosed in March of 2020. And I'm just really excited to be here with the panelists and everybody that's viewing this webinar today for another meetup. So, before we get started with our topic for today, I just want to ask our panel to introduce themselves and maybe share something about the last time their experience with Parkinson's surprised them somehow. It could be that there are a lot of surprises that could, that could include. So why don't we start with Kat?

Kat Hill (Ambassador, Davis Phinney Foundation):

Hi, everybody. It's so nice to see everybody. I skipped a month, and I missed everybody terribly. Let's see. I am calling in from Lyle, Washington, which is where our property is, where we have dragged the Airstream to, and where we are camped out. And I was diagnosed eight, nine; I can't do the math. A few years ago, at the age of 48. And let's see, my Parkinson's last surprised me. You know, we're clearing a bunch of debris from our property, and I keep forgetting that these middle fingers, because of the Botox, don't work well. And I've jammed my finger a bit. Yeah. So, it drags, and I was surprised that even with my gloves on hauling a tree, I was able to jam it pretty well. So, I have to keep it in my brain that my hands don't work the same way even though I want them to. So, that's my last being on the spot there.

Chris Krueger:

Yeah. Sorry. Sorry to put you on the spot. I should say, too, I should chime in on this one. My mind is my hands too. I was trimming a tree branch, and I was like, I, all of a sudden, I'm in the middle of cutting this branch, and my arm and I stopped my arm. Just doesn't want to do that. Pulling motion where, so I had to switch positions on the ladder. It was lessons learned, you know, always make sure somebody's holding their ladder. Yeah. So Heather, how about you introduce yourself next, please?

Heather Kennedy (Panelist, Davis Phinney Foundation):

Heather Kennedy coming in from Walnut Creek, California, at this time, wanted to say that it's hard to be a human, although I don't even think to compare it to that I know of. And the last



time Parkinson's really surprised me was when I had, I was slowed down on purpose by Parkinson's, and I really was mad. I was stumbling around, and I needed to move, and I needed to move fast, and I couldn't. So, I walked up and down the street very, very slowly, gingerly, looking like Tim came from the car show. And I met the coolest people. You would not believe what happens when you are slowed down. I would never have done this voluntarily. Folks, I like to do things fast. I like to multitask. I'm from New York; I want to go. Yeah, yeah. Like right now, I'm on my meds. I was off my meds. This was a four-hour ordeal. Supposed to be a three-hour tour, but luckily, I had a friend who's here now, and she helped me by making a beat. Do you know what her beat was? It was staying alive by the Bee Gees; you can do. And so, it helped me get going again. It only took three hours, and she got really tired of singing this summer, but she's a great beatboxer now. So that was my big surprise with Parkinson's.

Chris Krueger:

Your friend is a beatboxer. That's a great surprise.

Heather Kennedy:

You got it.

Chris Krueger:

Okay, Kristi, you're up.

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

Hi, I'm Kristi LaMonica. I am from, I'm in, I live in upstate New York. I'm originally from Connecticut. I was diagnosed in 2020. This and what really surprises me, so this one's positive, I'm really surprised when medicine works, how well it works, you know, so when your meds kick in, how you can go from being like a slow zombie to like alive and functioning and moving really quickly. I've never I'm always amazed every day that works. If it works, when it works,

Chris Krueger:

It's a great surprise too. Okay, Robynn, you're up, please.

Robynn Moraites (Panelist, Davis Phinney Foundation):

Robynn Moraites from Charlotte, North Carolina. Diagnosed in late 2015 at the age of 46. But looking back on symptoms as early as 2003, 2004 in my early thirties, aside from all the unexpected rando that goes wrong with my body, my latest surprise was I was really nervous about my vacation when I went to the world Parkinson's Congress. because We were spending a month in Europe, and I even talked to my movement disorder specialist about it. I was like, God, I just, I'm really worried about my endurance and my and fatigue. I did not have a



problem. I loved every minute of it, I think, because it was so different. All the dopamine I had was charging through my brain like two days back. I'm so debilitated. I'm like, I'd have no motivation. I can't walk. My back is thrown. So that's my random surprise.

Chris Krueger:

Yeah. So that's another great surprise. All right. So, so Kevin, let's, let's get you on the horn here.

Kevin Kwok (Ambassador, Davis Phinney Foundation):

Hi everyone. This is Kevin, dialing in from Boulder. I'm wearing my Barbie in Ken jacket today because I thought it was such a good movie in so many lessons. So, I've been living with Parkinson's now for about 14 years. And through those 14 years, like all of you, I have had all the sort of the circling in and out of different symptoms. One of the pleasant surprises, and Chris, you know, this, I've mentioned this to you in a previous broadcast I've been really sort of suffering from really disabling disfiguring dystonia. And in the past, my hand was almost always locked in this position, which made things like rock-steady boxing, riding a bike, and holding a ski pole really challenging. But my most pleasant surprise is that I've been working on playing the ukulele for the last month as a form of that hand therapy. And I'm getting a little bit of movement back. I'm not going to be doing any concerts real soon, but this.

Kristi LaMonica:

That was my next question.

Kevin Kwok:

No, I'm not playing Red Rocks anytime in the near future, but that forced just fine motor skill is starting to make it so I can make a fist again, which I love. So anyway, I'm working on the song Creep by Radiohead. It's not coming along very well, but hopefully, in the future I'll play it for y'all.

Chris Krueger:

Oh, that'd be great. Yeah. So, Kevin, you've inspired me a little bit. I picked up my guitar again, and you can maybe see it behind me if it if you can see that. But it was kind of because of you I started to play it again, and it's really actually been helpful for me too. So, thanks for, thanks for helping me in that way. Brian goes ahead and tell us where you're at. And you're on; it looks sunny where you are. I think you might be muted.

Brian Reedy (Ambassador, Davis Phinney Foundation):



Sorry. Got me now. Yep. So, I'm in Carson City, Nevada. I've just been moving slowly. I actually got in here about 10 o'clock last night, and everything's in boxes. So, it was a rush equipment for this. But I've been diagnosed I think, 13, 14 years now. I think a really cool thing that happened unexpectedly. I did this No Barriers Warriors thing in Colorado two weeks ago. And they got us up to we climbed a, a 20-foot tower and with a belay, and then we get at the edge of the tower, and we leap off for this bar. And I get up there, and my tremor is just going mad. It's just like, this is crazy insane in the whole tower. You're on a telephone pole at 20 feet. It's wobbling back and forth. I'm just, ah, a deep breath. And I just focused, and I locked my muscles as best I could, and I got a standstill. It worked. And all of a sudden, then I just bent, oh, took the leap. I didn't make it, but I made the leap, and it was awesome. It really surprised me, and everybody was so encouraging. So, it was really a cool thing.

Chris Krueger:

That's amazing. Well, we are talking about vulnerability, which is our topic today. Yeah. It was a pretty vulnerable position to be in, I guess.

Kristi LaMonica:

Brian, you're amazing. That's like, I, that I don't have a tremor, but I feel like I'm going to get one just hearing that.

Brian Reedy:

Yeah.

Kristi LaMonica:

Me too. Like, no thanks.

Brian Reedy:

Well, the whole purpose of this No Barriers Warriors it's taking people with disabilities, and this time it's veterans and putting us in a challenging situation. So, it worked.

Chris Krueger:

Yeah, it was great. It's very challenging. It's, I'd love to see a video of that, if there was one. That sounds awesome. You're, you're a hero. Today, our topic is vulnerability. And you know, I guess I want to say a couple of words at the start about that. I think, you know, vulnerability can, can be a lot of things, and it can mean a lot of different things for different people, but I think generally it's about being susceptible to risks or, you know, potentially some injury. And living with Parkinson's, we are susceptible to that in a variety of ways. Physically, new symptoms, changing, symptoms emotionally, fear, anxiety, and socially you know, we can feel isolated or

be isolated, and there's all these different ways that we can be vulnerable. And you know, I thought that that made this a good topic to sort of talk about.

Chris Krueger:

I also wanted to draw attention to the way that it can be a superpower too, and that learning to sort of lean into it can be really helpful too, sometimes. And maybe we'll hear all those perspectives from the panel today. And maybe we'll just focus on one or the other, but we'll see where we go. To start us out, I wanted to see if we could maybe talk a little bit about the last time, we felt particularly vulnerable or were particularly vulnerable because of Parkinson's. And maybe I'll ask Robynn, if you might start us out just when, sometime recently or not recently, you felt particularly vulnerable because of Parkinson's.

Robynn Moraites:

Sure. I have so many examples, some big ones, some little ones. So, I'll start with little ones. But before we do that, I want to give a shout out to Chris from Rocky Gap, Virginia. I see Rocky Gaff, Virginia, every month on the chat. And I'm like, Rocky Gab. I pass your exit on the turnpike twice a month. I drive between here and Ohio. And whenever I pass the Rocky Gap xo, I think someone lives here who has Parkinson's. So I want to talk about something that recently happened that was kind of scary. We did a bike trip from the Norman Coast to Paris along the same river. And we had an outfitter that was not very concerned with participant safety, which I've never experienced before. I've never had a tour operator that really didn't care about people's safety and didn't give important ride updates and information.

And so, part of this route took us across the bridge, which is a really tall bridge, and my partner's terrified of height. So, he wasn't doing the bridge; he was taking the bus to the destination in this last sort of 12-mile stretch. But I'm not afraid of heights. I am, however, afraid of riding on I 95. And this bike lane was as wide as my handlebars, and semi-trucks were passing within six inches of me. And I was being buffeted by the wind, and it was just, I was using every mindfulness skill, every mountain bike handling technique I could, like momentum is your friend. And, but I was shaking so hard. I started shaking. All four of my limbs started trembling, and I was afraid that I was going to lose control of my bike, particularly on the downhill, because I mean, and these trucks, the speed limit was 90 kilometers per hour.

And these, I'm trembling just talking about this; it's ruined me for bridges forever. But these trucks were screeching by. And I'm not exaggerating how close it was. One of the people was one of the riders on a tandem bike, and she rode in the back, and she took a picture over her shoulder, and she was able to get a picture of a rider with the semi just right there. And it's a trucking lane. And the outfitter didn't tell us that. But as I was coming down on the downhill, I was trying to feather my brakes. But the more that I kind of feathered the brakes and grip the handlebars, the more my bike was shaking because my body was shaking so badly. I'm just so

grateful. I got to I got to the other side of the bridge, and there was a little parking lot off to the side.

And, you know, it's always sort of a measured decision-making process, whether I'm going to inform people that I have Parkinson's, because I don't want to be identified only as Parkinson's, you know, which can happen. It's just I never really know what to do. Well, there was no denying it. My whole body was shaking so bad, and these two other writers named Dave and Jenny pulled in behind me and asked if I was okay. And I clearly wasn't. And I was like; I don't know what I'm going to do. I don't know how I'm going to go on. And I went on, we finished the ride, but the out there we're one and done with that outfitter. We will never book that outfit again. There were other examples too, where he just, didn't care about safety, he didn't care about food planning, he didn't care about ride info on the route. But that was one time that was really scary for me, physically. I think it would've been scary to anyone, but it was hard to control my bike.

Chris Krueger:

Yeah, that sounds like a really challenging moment where, you know, you don't want to necessarily, you're in this tough spot. Do you want to say something about having Parkinson's? Do you not? And then, you know, maybe it's a, yeah, that's really challenging. I'm sorry you got to go through that. That sounds really tough.

Heather Kennedy:

That's horrifying. I lost a very, very close friend.

Robynn Moraites:

Riding, riding a bike.

Heather Kennedy:

Yeah. So, the thank you for sharing that. That is terrifying.

Robynn Moraites:

I mean, I, he, he was sort of downplaying the whole thing. Oh, tons of people ride over the bridge. We've never had anything catastrophic happen. I mean, I got back, and I told my partner; I said, I can't believe nobody's ever been killed. I mean, I really can't. I just the only reason nobody has been killed is because it's France and it's a cycling-centric culture there. So even the semi-truck drivers are sort of, if it was in America, no way. No way. I'm shaking.

Heather Kennedy:



Think about it. Like, I started shaking while you were talking.

Kristi LaMonica:

How was up until the bridge, was it, how was, was it that terrifying up until the bridge?

Robynn Moraites:

What's No, in fact, you know, when France is so cycling centric that it was such a pleasure riding for ten days there. And our outfitter said, don't worry everyone who passes you in a car, they all ride bikes. Their elderly parents ride bikes; their small children ride bikes. That was true. I mean, they were so welcoming and so accommodating. So, I was not at all afraid about going over the bridge. I'm not afraid of heights. And I was the one who asked, he said, are there any questions? I said, is there a designated bike lane? Because it had been so wonderful up to that point that I thought, okay, well, you know, they'd been going around, and it was fine. It was not fine there. He said, oh yeah, there's a designated bike lane. It was about as wide as my handlebars.

Heather Kennedy:

Fine,

Kevin Kwok:

Robynn. I think this topic behooves us to go deeper because there is a fine line between pushing the limits beyond what you're comfortable doing to get over your vulnerability and going to a place which could endanger yourself.

Robynn Moraites:

Interesting. That's interesting. We've

Kevin Kwok:

All we've all been there, right? We all sort of, as ma Mavericks of our world, want to push the limits to the next level.

Robynn Moraites:

In my defense, had he said, it's like riding your bike on I 95, I would not have gone, I would've gotten on the bus, but he didn't. So, I didn't know. I just thought, okay, I'm not afraid of heights, I'll ride this bridge.

Kevin Kwok:

Yeah.

Robynn Moraites:

So, I'm saying that in my defense, but to your point, Kevin, you're totally right because I do that.

Kevin Kwok:

Yeah. You know, I think part of living well with Parkinson's, for me personally, is pushing the limits. You know, setting, setting something, which I know will be a push goal, right? And to me, that's the joy that I get. But when I hear a story like that, or a story of the kid in Boulder here that recently got run down on Diagonal Highway, it says to me that maybe we can't live in fear, but at the same time we have to be exercise caution when necessary.

Kat Hill:

Yeah. I'd love to piggyback that a little bit. So, so I'm a risk taker in many ways, but I'm not really a physical risk taker. And I've learned that I pre-Parkinson's with Parkinson's, I'm just not. And so, while I agree and push ourselves some and having goals, I also think that we aren't invincible. None of us here are invincible. And so, for me, getting on a bicycle on, while I love the idea of cycling stationary or inside, I really am fearful about traffic and those kinds of things. So even pre-Parkinson's is not something that I would do. And so, I just, the idea of it makes me feel hugely vulnerable. And but I do think it's an interesting distinction because we're all really encouraged to get out and get moving and do the exercise we're comfortable with. And just by doing that though, it can put us in a vulnerable situation. Just getting out and taking a walk some days can put us in a vulnerable situation. You know, Heather, your story about, you know, not kind of getting stuck and being frozen and how beautiful that you were able to take that time, which I'm sure felt super vulnerable to say, huh, this is really not very comfortable. But gosh, there is some silver lining to that and yeah.

Kevin Kwok:

And everybody's staring.

Brian Reedy:

Yeah,

Kat Hill:

Everybody's staring at that social vulnerability of nothing like feeling different in the moment. Nothing like, yeah. Yeah. Anyway, I just really wanted to acknowledge that. And Robynn, I am so glad you're safe. I would, you're crazy, but I'm so glad you're staying here.



Robynn Moraites:

Brian Reedy:

Yeah. That the harrowing tale, Robynn, and as I was listening to it, I was just thinking, just because when I get nervous, my tremor goes worse. And that would make it even more challenging. And that you got through that, I think speaks a lot to how committed you are to the goal.

Robynn Moraites:

Well, and Brian, I was going to speak on something else, and Chris had emailed me because I had to leave the call early. So, Chris had emailed me to say, can I, can I lead with you and ask you this question? So, I thought, and thought and thought about it, and I had a different example. But when you talked about getting up on that pole and shaking so bad, I was like, oh my God, how could I not talk about this?

Brian Reedy:

Well, you were awesome to get through that. That sounds, I was like, ugh, listening to its harrowing experience.

Kat Hill:

Yeah.

Chris Krueger:

I think to Kevin's point, you know, I think one important thing is, you know, one way in which we're vulnerable, at least I feel this way, I can't, I shouldn't speak for everybody, I have my own experience, obviously. But I often have to think very carefully about what I'm going to do and really map out the things that I'm going to do. And obviously, I don't mean to criticize you, Robynn, you know, you have to take the information you have, and that's all you can do. And you tried. But, you know, I just think that one way that we, you know, we have to be careful, or at least I feel I do, is just making sure that I understand, as best I can, the situation I'm getting into. And even then, you can only get so much information. So just kind of be willing to,

Kristi LaMonica:

Like the fact that you said you were on a ladder, whatever, cutting down something. To me, that's like, no, I have to like to check myself when I want to get on the ladder to do something around my house. I have to just be like, oh wait, no, I can wait for someone else to do that. I



don't have to be on the ladder because I'm the last person we want up on a ladder. Because it's not, it might not end well, it might, but it might not. So, I have to make that.

Kat Hill:

Yeah.

Kristi LaMonica:

The effort like to check myself on doing the stuff I want to.

Heather Kennedy:

What could possibly go wrong? A ladder, possibly I had to give up on my knife throwing and, you know, what could.

Kristi LaMonica:

It could go right with all that. You know,

Kat Hill:

Roller skates are definitely out for me.

Kristi LaMonica:

We need to have a week-long gathering of everything ridiculous that we can do as Parkies.

Heather Kennedy:

Out of the way away from our families for it safe.

Kat Hill:

Okay, so I wasn't diagnosed yet, you guys, this is okay, we're going to be a little off topic, but I was sort of, well, I was totally going midlife, kind of midlife crisis. And in college, I rode a scooter. Okay. And I loved my scooter, and I was thinking, what's fun? I could go to my deliveries, you know, zoom out of the house with my scooter on midwife on a scooter to the hospital, right? Super practical. So, I test-drove this Vespa, it was a friend of mine's Vespa. And it's one of the early examples of where my balance was really different. So, I test drove the Vespa and didn't speed up enough, tipped it over and crashed, and broke my collar bone. So that was my husband's like, I don't think you should buy the Vespa. I was like, yeah. Probably not a good idea. But that was a good example of feeling like that was a vulnerability. Right? And then, and it wiped me out for three months. I couldn't work for three months because I couldn't catch babies with one hand. They're slippery when they first come out.



Kristi LaMonica:

Before I was diagnosed, I tried to go roller skating, and I used to do speed skating when I was a kid. So, I was really good at roller skating. Yeah.

Kat Hill:

It brings joy, right? We wanted joy. Yeah.

Kristi LaMonica:

But I tried, and I was like, I need to hold onto a wall because I don't have balance. Of course, that was before I was diagnosed too. I was holding onto my friend's five-year-old at the time. Because I figured, you know, he, he'll bounce back and he falls down the slippery people, still.

Kat Hill:

But those, I actually, Kristi did similar things to you. So, I, that balance thing. So, I'm happy to get on a bike as long as it's stationary. I don't have to balance it. I'm, ladders, roller skates are out, and high heels.

Kristi LaMonica:

Yeah.

Heather Kennedy:

Forgettable.

Kristi LaMonica:

Postmark.

Kat Hill:

Yeah.

Heather Kennedy:

Kitten heels. No heels.

Kat Hill:

No heels. Not



Kristi LaMonica:

Even, not even like kitten ones that are two inches or an inch and a half too, too much. I'll fall over.

Robynn Moraites:

Well, related to what I was saying on the back end about telling people I have Parkinson's, going more into social vulnerability, someone in the chat it looks like maybe Gabe, or I don't have the full name, is going to a 40th high school reunion and is struggling to let people know that they've been diagnosed with PD. So, have any of you guys struggled with, should I tell, shouldn't I tell? Because sometimes nobody can tell based on my symptoms presentation externally. And that was a goal for me on this trip, is I really didn't want to tell. Because I just wanted to go and enjoy my bike. And I told not everybody, but a couple of people.

Heather Kennedy:

Well, if you can get away with it, why tell, I mean, I know I couldn't get away with it for very long, so I said pretty much everybody, you know so that they wouldn't be like, is she drunk? Is she? Did she have a stroke in the last five minutes? What happened to her? She just went in the bathroom. Now she can't walk. I

Kristi LaMonica:

I don't understand. My fluctuations like are so wild like that. So, I totally understand.

Heather Kennedy:

You were just walking. What happened to you? Did you fall and bump your head? I just got tired of explaining all the other scenarios that could come up. So, I just said, you know what, it's just Parkinson's folks, it's going to be okay. Ryan Grant has a funny story. He gets in an elevator, and he's all like, he's all like, ah, hi. You know, because he's like, he's super disc kinetic one time, and he's like, I scared a lot of people. I'm like, yeah, I scared people, and I got an elevator too, you know, he's six feet, you know, 12 almost. You know, he's just like, oh. He's like; it's okay. It's just Parkinson's because everyone's sort of, like, So good. So

Kat Hill:

Good. Kevin's been wanting to jump in. Kev, Kev. Kev. Yeah.

Kevin Kwok:

Robynn. My personal view on that is that if you do tell people at your reunion, you actually may find that it will open up channels of a stronger relationship that you might not have had, had

you had the veneer in front of you. So, I mean, listen to me for the first four years of work, I didn't say anything either, but I have found more benefits to being open. People will come up to you with encouragement and will open up channels for speaking engagements or other things because of that openness. And there, and you have to figure that people will figure it out anyway. We all have a quirkiness about us even when we were normally pre-diagnosed, but these quirkiness attributes come out so much more now, right? Mm-Hmm. <Affirmative>. Well, I, my 2 cents worth.

Brian Reedy:

I find if you handle things like, if you handle things with humor, so, you know, I debated whether to tell when I was a high school teacher, debated whether to share it with the staff or not. And when I did, I just made jokes about it. I just said, you guys know I've always been a mover and a shaker. Now it just shows more. And you just find ways to kind of be disarming, and then people are a lot more receptive, you know? I, to me, that that end has worked. I had another part to that, but I forgot it. So-

Kat Hill:

It's Parkinson's. Brian?

Chris Krueger:

I am putting together those two things that Kevin and Brian just noted. That's sort of what I was thinking about when I thought about the superpower of vulnerability. You know, being open with people can, can sort of be disarming to people who you might tell, and then it can open up possibilities like Kevin was describing. So, you know, that's, that's been my experience personally as well, that it has been helpful actually. And a lot of people turn around and tell me, oh, I've no, my grandmother or, you know, my friend Bob, or, you know, whomever, and that then opens up a new phase of a type of way to interact with that person, which has been good for me. Yeah.

Heather Kennedy:

Yeah, I agree.

Kat Hill:

So, I think even, even though Parkinson's may increase the opportunities for us to be vulnerable, maybe I'm being, I don't know what the word is, like, too positive about that. It, everybody is vulnerable sometimes. And I have found, like you, Chris, and Kevin, that people tend to be compassionate. But I, Robynn, I understand that, though, that feeling of not wanting to be othered or different or seen differently. And sometimes I'll handle that and say, listen, I



want you to know that I have Parkinson's. There may be some symptoms that come up, and I'm telling you, not because I want to be treated in it any differently, but because I want you to know in case, I'm symptomatic or in case if I ask for an accommodation or special help. And that's something that maybe for me, I might have shared with I forget what the guide or the person taking you so that they knew, but then you can tell them you wanted to choose to disclose or not disclose. I don't know. Yeah.

Robynn Moraites:

I did have to tell the outfitter, but yeah, my whole thing wasn't about being different or othered. It's more just that that's the continuous identity and I'm so much more than my Parkinson's.

Kat Hill:

Of course, you are.

Robynn Moraites:

And I don't want that to be the sole focus because I don't, I'm not too worried about worried being othered or whatever, but I don't know.

Kat Hill:

Yeah, I can, I can appreciate that.

Robynn Moraites:

Yeah.

Heather Kennedy:

I like to talk about the emotional vulnerability part. I have a lot of stories about the physical, including the emergency department, which is a whole nether thing. We'll have to spend hours on what happens to Parkinson's patients in the emergency room. The quality of being sort of like exposed or being attacked or being afraid is what's normally associated with vulnerable. What I'm going to say is our strength is in our vulnerability. It's like where the light gets in, it's those cracks, you know, they all Lenny Cohen, the light Yep.

Kat Hill:

Leonard Cohen. Mm-Hmm.

Heather Kennedy:



<Affirmative> Cracks would like, it's in, I call him Lenny, you know, we go way back, Kat.

Kat Hill:

Mine. I figured kind of like.

Heather Kennedy:

I had Bobby De Niro for dinner the other night in my mind, Ava de Niro's waiting. But in all seriousness, I was supposed to do this great karaoke night and I went up to take the mic and there was going to be some people there, including the person who wrote the song, and they were like talking me up on stage because I used to sing and my meds go off in that instant, and I go tripping up the stairs. And they all started laughing because they thought that I was doing some kind of a side gag, which I would've done back in the day. Somebody's laughing. And I go up there and I go, can I sing a different song to start? So, I chose a different song, which was also by this person, by the way. And I started doing another song, and then I, and I ended up doing this other song, which is called well, let's just say it's by Nathaniel, right?

Looking in the Nice Sweats. And it starts with my hands was shaking, Mahi was breaking, there were bullets scrolling over me, and it ended up working out perfectly. And they still didn't know what was happening at the time. People are looking like, what is up with her? She seems odd. And I never said anything while I was up there, but guess what? It's the perfect song for Parky. Okay? So, it's called SSOBI, Nathan, where I live in the Nice Bed. Just remember, you can always sort of like adapt. Adaptation is the name of the game. And if you need to be vulnerable, I'm thinking emotionally. So, what have you have to lose emotionally in Robynn's case or in the case of people, you know, having some physical threat. Well, that's a totally different thing. We're not talking, I'm not talking about that. But emotionally, go ahead and you know what? You are only live once. Let's do this thing.

Chris Krueger:

Let's do it. I want to, I want to jump into the chat for a quick second because a couple minutes ago somebody mentioned that they play golf and it's, and it's getting worse every time they play. And the question was asked, where is the line that tells me that I can no longer risk looking ridiculous or making others uncomfortable? I think that relates to what you're just saying, Heather. Does anybody have any perspectives on that?

Heather Kennedy:

No longer risk,

Kat Hill:

Oh, I'm sorry. Go. Yeah, go ahead again. I think, first and foremost, we are not responsible for everybody else's reactions, right? I think that that is really important. I think that I think that if one feels uncomfortable or unsafe doing an activity, that's one thing, but I don't think we have to be responsible for everybody else's reactions. For one thing. We don't always, human beings do not always read other people's reactions the way that they're intended. Communication is so complicated. And I think that if you are loving golf, go golf, golf all you want, I will tell you, I would be horrible. I don't golf, I would be so embarrassed golfing. But if I felt like doing it, I would go and I would just tell people, I'm no good at this, or I have Parkinson's or whatever. But I really encourage you not to give something up that is bringing you joy or that you love doing, being worried about other people. Is that fair or to stock off?

Robynn Moraites:

Absolutely.

Kat Hill:

That's perfect.

Robynn Moraites:

Kev?

Kevin Kwok:

Yeah. you along the same lines of that question, and what Steve Qualm asked in the chat is what do you, what happens when you just, you like, you can't do it, you push the envelope anymore. And the thing that is trying to what you said Kat, is that we cannot hold ourselves to the standards of what we used to be able to do. The key is a standard reset, and there's joy if you reset it and then do something. So, I'll give you an example. I used to love to ski moguls. If I skied to mogul now, I would die for sure in there, but I could see groomers as better than I used to be able to before. And it doesn't come like that overnight. It, you have to identify and accept that you can't do certain things.

Kevin Kwok:

And then what you have to do for, in my case, is spend a lot of time dedicated to trying to turn that weakness of, in this case, my balance. I spend at least 30% of every gym day standing on one leg, you know, doing all kinds of dual tasking. And in that way, when I do get back on the mountain, there's joy in, in being out there again. And I'm assuming that I've got that window for about a couple years left, hopefully more, but then you'll have to reset again, right? And so, it is really sort of this getting shedding the denial is so important.

Robynn Moraites:

And I want to add onto that because I'm going to have to jump here soon to, what Kat said too, in this whole topic is there's a slogan that it's none of my business what other people think of me. And that's good. And it's really hard to apply when you're feeling really self-conscious and different. But that may help someone out there is that it's none of our business what other people think of us.

Brian Reedy:

Well, and I would echo what Kevin said. The idea of the use of twos that'll beat you up badly. And if you look back at it, you just think back in life, you know, when I was a kid, I used to be able to put my foot behind my head. You know, I'm not going to do that now. Life evolves. Life changes. You have to let go of the "used to" s, and you have to look at what you can do now. And like, I used to golf, and I had like, I could easily shoot under a hundred, and now, you know, it'd probably be 140. But if I went out to golf now, I wouldn't compare myself to what I used to be. I'd say, wow, I did pretty well. I hit some good 50-yarders or 75-yarders, or, you know, which would've killed the old me. But you've had to look at the new you and set your new bar reset. I think Kevin said that, also.

Heather Kennedy:

I do get that. Brian.

Brian Reedy:

What's that? How?

Heather Kennedy:

Does that foot thing, why does that go on your dates?

Brian Reedy:

The foot thing. On the dates? I don't go on dates.

Heather Kennedy:

Oh, man, I don't know. Don't do that.

Kevin Kwok:

Yeah, you do!

Heather Kennedy:

Good answer. Good answer. Brian.

Kat Hill:

Kristi, you had your hand up. I want to hear what you have to say.

Kristi LaMonica:

So, to add onto everything, so Robynn, I just, not my circus, not my monkeys. So that, I think we all need that, like, tattooed on something. But I think that what can you do with golf? So, if you're playing, how many holes are there?

Brian Reedy:

18.

Kristi LaMonica:

Can you play like less than that? You know, like why not just change it to what you can do and just be okay with that? Who, who cares what everyone else is doing?

Kevin Kwok:

Or play best ball or do something else, right?

Chris Krueger:

There is another layer to that though, which is just the sort of emotional feeling that, you know, now I've had to give this thing up. I'm already taking these medications I didn't want to take or didn't plan to take. Now I've got this emotional side. So, I wonder if anybody has any perspective. It's all great advice to think about what you can do today, but what about the emotional side? How can we navigate that? Yeah, Kat?

Kat Hill:

So, I have a thought. I, you know, giving up my job with a Parkinson's diagnosis was a really, really difficult thing. And I'm and I still to this day miss it. But I've tried to learn the term it's somebody else's turn. I feel so grateful that I had a turn getting to deliver babies. And I feel so grateful that I got to meet all these wonderful people and do all of these things. And because of my life, which includes Parkinson's, I am no longer doing that job. And it's somebody else's turn. It doesn't mean that I don't feel lost, but even like somebody else mentioned, the process of aging is a process of slowly letting go and evolving and needing to reset. I believe that with a chronic disease, we get the opportunity to perhaps learn sooner what that letting go is like.

And it's not always graceful. Sometimes it's messy. Sometimes it means we trip and break bones. Sometimes it means we push further than maybe we should have pushed. But I think

the alternative is that we sit inside, and we build a bubble around ourselves that is not healthy. We get isolated. We don't move our bodies. We are fearful, we judge everything by are our symptoms coming? Are they not coming? And for me, I go to the worst place case scenario. You know, the worst-case scenario is I could go and maybe I'm embarrassed or maybe my meds go off or maybe I can't finish or do it the way I used to, but I'm showing up and darn it, showing up, builds points, whoever's keeping score. That's, I just have to believe that. And I have to keep believing it and keep taking the jump of faith. And even though I didn't get the mascara on because I can't get the hands together and even though my hair's dirty or even because my, I don't have water on the property, I'm showing up, you know? Dang it, I brushed my teeth today. That's a win. Falls in

Robynn Moraites:

You may not have water, but you have high-speed internet.

Kat Hill:

I do these same teeth. Yeah, I can, yeah. I don't know. Looking good, Kat, it's all good.

Brian Reedy:

Well, I-

Kat Hill:

Sorry.

Brian Reedy:

The story about the emotional vulnerability that's a hard one to share, but I think it's important. It's one that popped in my mind when Chris first started talking about this. But about a year and a half after my wife died my father went into hospice care and I got down there the day after he was sent to hospice and he said, Hey, everything's fine. I've lived a good life. He was 90. He says, I'm just going to have fun. You know, I'm here with my family, everybody I love, this is all that matters. I was the only one of the kids who could stay home at his house and take care of him. And through the night it got to be where I wasn't sleeping, and I wasn't taking my meds well. And his last day before he went into, he slipped into a coma.

I was totally off meds. My emotions were all over the place. I hollered at my sister who had done something negative to my father the day before. And then I was out in the patio, and everybody was going in to say goodbye to him and just be with him. And I couldn't move. I was frozen. And the family didn't understand that. And then my two sisters came out and they were being real sympathetic and that just made it worse. And emotions just went all over. So, there's a really hard time and nobody understood the Parkinson's, and I think I don't know how to get

through that one. You know, doing it again, I would just try to communicate better, but I think many of us have said family doesn't like to talk about Parkinson's. They don't like to deal with some of the things that happen.

So, this is an extreme thing, and emotions are all over the place for everyone. Period. And then, you know, not taking your meds, not sleeping well losing your father who you love very dearly and being there, but we have lots of humor in towards the end. But it's more than just the vulnerability of having the Parkinson's, it's the Parkinson's making the vulnerabilities worse. So, it was a real challenge. And I'm I still have family members that won't talk to me now because they thought I was such a mess. They think I'm an emotional ruin.

Chris Krueger:

Yeah. So that's one of the things that can happen, right? That that is maybe not only limited to family, either you can lose connections because of this to family, to friends, to like Kat was saying to employers and that relationship. And actually you know, I don't want to zoom away from that, but I just want to acknowledge that I saw a comment previously, earlier in the chat from, from Sharon asking or describing a circumstance where, where they were pushed out of a, of their, their work, which is, you know, obviously a different sort of situation, but it's in the same category as what you're describing, Brian, where people just see this thing and they, they just don't want to look at it. And that can be really challenging. So does any, I mean, that's, it is socially isolating. So, what do we do about that? Right? I mean, you're socially isolated from your work or from your friends or from your family. And as Brian described, what do we do?

Brian Reedy:

That's exactly right. No, and I, yeah, I don't know. Yeah.

Kat Hill:

And I think it's all, there are all those risks, you know, there's not, we say things like, well, we've got the American with Disabilities Act in the United States. The reality is though, that people do fear for their jobs, and there are people that are getting marginalized and pushed out of positions because they have a disability. So, I wish that I had like the perfect answer, don't we? All right. And I think we have to dig deep and feel and do what's comfortable for us. And I think there's an element of grief and loss, and I think there's also an element of like, that reset, Kevin, that you were talking about, trying to be honest with yourself about even what do I want and what do I feel like my limits are, and can I take care of myself in this moment, Brian, like, you know, can I take care of my dad if I'm really not taking my medicines and taking care of myself?

And we're all presented with those challenges every day. And they're hard. And I don't want to minimize how hard this stuff is because I know we're kind of making light and pushing each other up, but it's hard to feel vulnerable and it's hard to change, and it's hard to lose. And, but I

do think that if we can look at it honestly and grieve and be sad, and then try to move past it, whether it's reaching out to other people, whether it's finding a support group, whether it's starting medication for depression, whether it's, you know, making a move, leaving a relationship, starting a relationship, you know, I wish that there was the answer, but I think it's part of the journey is that this is hard stuff. And it's also worth it if you can get to the mountain and the valleys. I'm sorry, I'm preachy today. Goodness, I'm off. I'm muting myself. Sounds

Kevin Kwok:

Great. Sound great. Keep it up. You, I appreciate it all. I think you hit, hit, hit, hit the nail on the head here. You know, I think the one thing is we're all, we're everyone on this panel. One of the attributes that I love about all of you is I know each and every one of you has your dark days. We all do. But the key is somehow we've all been able to find our own way to get out, be it exercise, be it in our writing, be it in our socializing with other people. We find our own way. I'd like to share my most recent period of vulnerability, which happened two days ago. So, I attended the local picnic here for the Boulder Support group, and they started, it was held at this gathering where there were about 40 or 50 people, which is a great turnout.

And in the first few minutes of the event, they announced the names of the people that were no longer with us, and we had a quiet moment. And that list was really long. And that really kind of hit home for me that this is not funny stuff that we're living right now. And I was calling texting Davis after this event saying, this really has bummed me out. You know, and there, I think it's all the more reason, you know, we were sort of saying each other that you know, we are doing very well, the people on this panel, we have our hardships, but somehow through the group interaction with all we've been able to sort of hoist each other up in there. And I think theme that the David Spinney Foundation, so stresses, right, is living quality life today, which, and that's either riding your bike or doing whatever you can to define joy and quality. It gets harder when as we progress. And that's all the more reason this is a muscle or Chris, as you call it, a superpower that we've have to really home in, into develop now. So, I'm also getting preachy, Kat.

Kristi LaMonica:

But-

Kevin Kwok:

But this topic is getting preachy because we really need to be, put ourselves out there, be vulnerable, admit that we have this sucky thing in our life, and try to find some joy in all of it, right? Yeah.

Heather Kennedy:



It's a crap hand. Kristi was.

Kristi LaMonica:

Going to, yesterday was actually my, one of my really vulnerable days too. So, Kevin, it's interesting to hear that yours, those two days ago. Mine was yesterday. So, I went off at like 10 30 in the mor, no, 10 15 in the morning. Don't know why my med should have lasted a little bit longer, but I did. We had to get two socially and enough dogs to the vet for their checkup and knock on, so I can barely get my clothes on. I got some clothes on, got a, got a sports bra on because a real bra wasn't working, put my slippers on because I couldn't get my sneakers on fast enough to get into the car. And my meds didn't come back on all day until about six o'clock at night. So, I had to go to, with my husband to take the two socially up dogs to the vet and function while at the vet, while shuffling all around at a snail's pace and figure out how to pay the bill and all sorts of things that I would've normally stayed home. I would've never gone out into public like that because I mean, I wonder what everyone thought. Did I look like I was drunk? Did I look like I had a stroke? Do they even know what happened? Or do they know? You know, what's, it was just, it was really tough being outside my comfort zone for that long. Yeah. Yesterday,

Heather Kennedy:

May I mention something about comfort zones? Oh, Robynn, you have to, bye Robynn. It was good to see. I'm glad you stayed so long.

Kristi LaMonica:

I'm glad you're alive. Yes,

Heather Kennedy:

Thank you. Yeah, right on being.

Kristi LaMonica:

Made over the bridge,

Heather Kennedy:

I wanted to say something about being uncomfortable. We have to get really uncomfortable to love. Let's face it. Loving requires deep vulnerability beyond right doing and wrongdoing. There's a field, I'll meet you there. I have to drop all my stuff and try to compromise. It's not easy. Love is hard and love requires intimacy and vulnerability and deep honesty about who we really are. And we have to really, that mirrors right in your face. So, there's nothing better than vulnerability, in my opinion. I love being disabused of my illusions of self. I love being removed



of my illusions of how things are supposed to be. That is the deeper lesson here that I learned from Parkinson's. Unfortunately, the hard way, I'm a slow learner. I had to go, go dragged. So, there's that too.

Chris Krueger:

There's an element of spirituality to what you're saying, too, right? I mean, that's, that overlaps somewhat, right? Just, just coming to a deeper sense of peace or ex however you get there that seems related to what you're saying to me.

Brian Reedy:

Yeah. Well, and I think the main importance that we all agree on and Kevin Kat, we're actually touching upon this, but it's a community. It's a community of people that you can trust. To me, that's your family. That's the people that, you know, be it people with Parkinson's, which I find you can easily just break all the barriers down. And you're, that's why I love these conferences. Everybody's just themselves. There's none of that. And when I was with the Disabled Vets, it's like I felt a community there, and I could talk about things. And it's, that's what you need to find is as you hit all these hard points these times that just crush, you have to find that group that you can share it with, that group that you can be honest with, that you can open up and feel normal with.

Kat Hill:

don't have a community or don't have people. But we can be your people. And there's, you know, the Davis Phinney Foundation has a great ambassador program, and there may be an ambassador in your area. There may be groups that you can attend. I mean, I wish again that we had all the answers here today. I wish them most for myself. And I wish them for all of us. But don't, if you're feeling alone, reach out. You know, log on, show up, you know, be brave. You know, and it's worth it. Like Heather put in the chat, you know, some of these people saved her life. I feel the same way. I feel like this foundation found me at a very, very low point when I was transitioning out of a career that I adored and felt very lost. And gave me an avenue to pursue a philosophy that inherently believes in, which is that we can let live well or be well no matter what. And it's the story we tell ourselves that is the most important story. So maybe we need to think about changing the stories we're telling ourselves. And anyway, I feel so privileged to be here, and thank you for letting me go on and on today, you guys. I'm sorry. New days.

Kristi LaMonica:

A new day too. So new day. Today's a bad day. If today's a bad day, don't quantify. Don't say it's a bad day. Just say it's a day, and then the next day, it will; it can only get better.



Heather Kennedy:

Yes, everything is fine. I, Kat, you're still giving birth to many things now. They're just projects and books and helping; you're always in service and hopefully-

Kat Hill:

Water and septic and, you know, you're always in service.

Heather Kennedy:

So, thank you. Kat and Ken Hill have been very active in many things, including the WPC and Davis Phinney, and we're just really appreciating their presence. Thank you. And Kevin, everyone, everyone here. Thank you so much.

Chris Krueger:

Yeah. So, we're coming up on the end of our time, and it's really, I feel like I should jump in and say that we're, you know, I am grateful for being welcomed into this community and being and welcomed into this call. So, so brilliant, thankfully, but also for all the ambassadors and for the viewers of the webinar and for all the contributions that people make to make this community really thrive. And so, I'm so glad that everybody was able to join us today. I'm so glad for the panels, you know, honesty and candor, and we're just really glad everybody was able to join us. And you know, I look forward to seeing you at our next meetup, which will be, I believe Thursday, September 21st. And you know, that'll be here around the corner. And in the meantime, I think Sam has put in the chat that if you have any questions for us, you know, you can find the ambassadors on, on the website, but you can also email us@blogatdpf.org if you have any questions or if we can help in any way. So please don't hesitate to reach out, and thanks again for your time, and we look forward to seeing you next month. Great.

Kristi LaMonica:

Don't feel alone. Anybody, please reach out to us.

Kat Hill:

We have three minutes, and still to end. Heather, you want to send us off with a little song.

Heather Kennedy:

You're not going to believe who it was.

Kristi LaMonica:



Oh,

Heather Kennedy:

Are you ready for this? Can I say a bad word in the song?

Kat Hill:

I don't know. I don't care.

Kristi LaMonica:

Heather Kennedy:

This is what I'm getting done. You have a bomb, and you know, sings that song. Well, she was there, and I was like, oh my God. Every time you come around, you got to bring Jim, James, Kevin, and Brian.

Kat Hill:

There you go.

Heather Kennedy:

All I know is that showing.

Kat Hill:

Up, like we said. Yeah. Yeah.

Heather Kennedy:

I'm not a singer.

Kat Hill:

Baloney. Yeah, right.

Heather Kennedy:

But if I had been like Linda Rods, I might've been a little bummed out. In other words, we can do it. We can do it right now; everything is finite. Enjoy the moment, sandwich. You know, go for it. Nothing will, and

Kat Hill:



Look slim and shaky. It'll make you smile. Yes. It's a great video. They call me slim. Shaky.

Heather Kennedy:

Stand up shaky, slim.

Kat Hill:

Slim

Heather Kennedy:

Keep going. Again. I like, I like Joni's lines when it's like, forget it. I've grandkids to me. Do you know? Yeah. Sequoia loves; that's Sequoia low. He did that when he was in high school. See, we can do anything, guys.

Kat Hill:

Yep.

Heather Kennedy:

We're only here once. Yeah,

Kat Hill:

That's right. Thank you, Chris, for leading us through this. This was a tough one. So, we all survived. We made,

Heather Kennedy:

And we brainstormed together very well. We do.

Kat Hill:

We have a good record of surviving. Yeah.

Heather Kennedy:

Right. Good point. Kristi.

Kat Hill:

Right. We get a hundred percent. Yeah.



Heather Kennedy:

Undefeated.

Kat Hill:

That's the only thing that we're a hundred percent at. Right.

Heather Kennedy:

Right. Sure. Kevin

Kat Hill:

And Kevin, I saw Kevin's killing the Ken jacket.

Heather Kennedy:

Oh yeah.

Kat Hill:

Yeah. My Ken would love that. That's my husband's name. But I'm not Barbie. We'll leave on that.

Chris Krueger:

Thanks, everybody. We'll see you next time.

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