



**The Victory Summit® Virtual Event:
Our Voices, Our Stories: For People with Parkinson's,
By People with Parkinson's
"The Embarrassing Side of Parkinson's"
Davis Phinney Foundation**

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Now I would like to welcome Kevin Kwok and Kat Hill. Kevin and Kat, would you turn on your videos? Some of you who are watching will recognize Kat and Kevin from our Young Onset Council. And they volunteered to join us today to talk about some of the embarrassing sides of Parkinson's and specifically focusing on some of the physical embarrassments and the cognitive embarrassing moments. So perhaps we could start with physical, and I'd love to throw it out to the two of you. Tell us a little bit out how are the physical symptoms of Parkinson's embarrassing and how have you handled some of those moments?

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

Polly, before we dive into physical, I just wanted to say that when you have Parkinson's almost everything can be embarrassing. The question is what is embarrassing and what is shameful? And the key is to get over the shame and turn it into something where you can be sort of self-deprecating and make light of what it is, because that's how I handle the embarrassing situations. Almost every month, something new seems to pop up physically or cognitively that we deal with. So that's my view, Kat, I don't know how you feel about that.

Kat Hill (Ambassador, YOPD Council Member):

Yeah, I agree. I think that we all have a choice about how we reflect about what's happening to our bodies. And I also think sometimes the things that we notice and we get embarrassed by, like, I might worry that my tremor is really spilling things all over, it also, not everybody always notices it. We may feel more embarrassed than even people are noticing. So, I think getting past shame is smart. I also think the word grace is really important in my days, that I accept that I'm different than I used to be. And while I may be having trouble doing things like multitasking, even this morning, something came up, my son texted me just before I was getting ready to sit down and do this. And I got completely overwhelmed. I call it like the teapot thing, like, oh my gosh, I've gotta respond to him right away.

But I, oh, but I've also gotta get on this webinar. Years ago that wouldn't, I would've handled that just no problem. Oh, I'll get back to him. But it takes a lot of energy to go through in the brain and say, well, I can get to that. Okay, Kat. Grace. One thing at a time, one thing at a time, one thing at a time. And Kevin, I don't know about you, but I know for me, the cognitive parts have been probably for me more embarrassing almost than the physical parts, because they can't be seen. It can't be measured. I know my partner, Ken, is wonderful. He's a Charlie from earlier, from Carol's presentation. But our communication has changed and even that's

embarrassing, how he has to communicate with me about specific details because I don't take it all in. Does that happen to you, Kevin?

Kevin Kwok:

Totally. I mean, you know, I recently left work because of communication, the ability to vocally speak. I'm always sounding inebriated, slurring my words, but I'm also finding that it's not just the physical act of speech and communications, it's word finding, it's forgetting things. I mean, I used to have a photographic memory for work and used to be sort of this person that always could be counted on to give the good presentation or to, you know, debate or negotiate. And I find myself just a slight bit slower than everybody else now. And so, what happens in the communication is that the conversations are happening, and I almost can't even infuse myself into the conversation. And so, what happens is I tend to just quietly sit back and watch things. And when you're in a working community or in a family or a social situation, when you're known to sort of be the center of the party, all of a sudden having to step back is a difficult thing to deal with.

Kat Hill:

And I think it feels embarrassing because it's really different for us than it used to be. It's embarrassing. It's also, it's ego. It's our egos that we're used to be having a mastery in a realm that we no longer have or feel mastery or aren't seen as having mastery and effectiveness. And I think shifting the way that we view ourselves can help us deal with shame and embarrassment and talking about it, I think is important. You know, I think the physical symptoms sometimes get the big attention, cause they're easy to see. They're easy to quantify. They're even easy to talk about in doctor's appointments, but there's this sense of self-worth that feels you feel less than, you feel smaller than, and yet, I pose that perhaps in this community, this is maybe where we can help deal with some of that stigma. Kevin, what do you think about that?

Kevin Kwok:

I could, you know, rather than lament what you couldn't do, it's almost like turning it into what can I do with the skills that I have. I mean I used to be a great orderer, but a lousy listener. I'm a lot better listener now than ever before. And I think I'm more empathetic because of that. You know, I always liked to get the last word in in the conversations and that'll never happen anymore. Right.

Kat Hill:

I heard Davis say that this morning that he's a good listener and I loved that. A good observer, I'm trying to be a better observer and maybe learn those skills even in terms of you know, if I can't go for that long hike or I'm having some dystonia, parking myself and letting my family go on and taking notice in different ways. But I think acknowledging that there's a lot about disease and chronic illness, that it does feel embarrassing, that feel humbling.

Kevin Kwok:

It's a loss.

Kat Hill:

It's a loss, it's a loss, you know, even having to plan the day near a toilet is a real difference. You know, I was used to doing long hours and paying attention to everybody else's needs in a hospital. The last thing I was thinking about was caring for my own physical function and it's humbling to say, oh, I'm sorry. I can't, you know, I need to be closer to that building right now. Or.

Kevin Kwok:

I mean, I had a situation just last night where I fell and I broke a rib.

Kat Hill:

Oh, Kevin.

Kevin Kwok:

And last night sleeping, I couldn't even roll over to get to the bathroom. And I was like, oh no, what am I gonna do? And I was a guest at someone else's house and trying to figure out just how to negotiate the night, right? But, you know, I woke up in the morning and made light of it. You know, and here we are now, right. But that's what my point is saying that every day, every month, every year, something new is gonna come up that's gonna possibly be embarrassing. And we just have to learn how to flow with it.

Kat Hill:

Yeah. Yeah. One of the funnier, embarrassing moments, Kevin, I know both you and I deal with hand dystonia. Yeah, I had, my middle finger was the first one and I couldn't get it of the erect position. So, like I would be driving, and I would be flipping the whole world off in the steering wheel. Now I was able to laugh at that most of the time, but that's not really my MO, I mean, I like to think of myself as funny in other ways, but it didn't feel very gracious, but it was one of those things that I really couldn't control. Yeah. So, it's, so again, laughing, a little of that self-deprecating humor. I also try to use it a little bit, if I'm shaking, having trouble reaching something, having a spasm at the market, it's also a little bit of a teaching moment for those of us that are comfortable with advocacy saying, hey, I'm really sorry. I know I'm in your way, but I've got Parkinson's and I can't reach this can of, you know, chili up here. So, I try to do that also, even though in the moment I'm embarrassed, I feel like maybe I can shed a little light to others about what chronic illness looks like.

Kevin Kwok:

I mean, one of my pet peeves is things that are childproof and childproof packaging, like a simple thing, like getting a bag of pretzels on the plane.

Kat Hill:

Yes.

Kevin Kwok:

I used to almost wanna cry when I get 'em now I just laugh and I hand to the passenger next to me and say, can you open this for me?

Kat Hill:

Right. Yeah. Human proof.

Kevin Kwok:

It is. Human proof. But the key is, the bigger theme is don't be afraid to ask for help. I think people need to know what you're, they can't mind read what's going on either in their mind or physically. And if you're expecting them to, you'll only be disappointed, but if you reach out, you'll be surprised how many people do help.

Kat Hill:

Asking for help for me in the beginning was embarrassing.

Kevin Kwok:

Me too.

Kat Hill:

Because I was the helper. I was the mom, the nurse, the nurse practitioner, the wife, the daughter, that's very much what I identified with.

Kevin Kwok:

Yeah. As a male, I was the karate man. You know, it's like Eddie Murphy, you say I bleed on the inside, not of the outside.

Kat Hill:

That's right. But all of that comes back to kind of that ego and I think learning to have some flexibility and grow and some squishiness inside and accepting, I'm really bummed out that I can't open this pretzel package anymore, or I am flipping off everybody at every stop sign. You know, I know, I notice. Maybe we can share enough here so that others can be a little bit more gentle on themselves in how they feel about their own symptoms.

Kevin Kwok:

I actually have a humorous symptom that's been embarrassing for me during COVID, but thank God for masks. Right. But what I find is that, you know, more lately I've been salivating and drooling a bit more, but thank God we all have to wear masks. So, you get this little thing catching it all the time. I'm a little sad we're gonna have to get rid of those, you know, hopefully as we get outta COVID.

Kat Hill:

Yeah. Yeah. Well, I think you know, and I think it's important too, in Edie's video, she touched on, you know, being embarrassed sometimes to bring things up at the doctor's appointments. I think it's important if there's a symptom that's troubling us drooling, dystonia, urinary dysfunction, bowel function. Those may feel really embarrassing, but it really is also sometimes there's some tools that can be, can help us with them if we can be brave and bring them up at our appointments. So, I encourage that too, as much as it's hard to say, that's why we're there.

Kevin Kwok:

You know, and here, I like to link to this part of the mental wellness and health part of what we have, you know, for the longest time, I sort of battled with impulse control issues. Some of it was based on, you know, dopamine agonists, but I started seeing a neuro psychiatrist and began this therapy conversation. And she actually told me that just straight dopamine replacement can cause that.

Kat Hill:

Yes.

Kevin Kwok:

So, I started to feel like, hey, maybe some of these and things that I deal with. And to me, that was the hardest thing to come public with because now you're talking not about a physical ailment, you're talking about things that people can associate behavior with. And to me, that was the, that was one of the more shameful elements of living with Parkinson's in the first several years.

Kat Hill:

Right. And many of us are put on those agonists initially. And I know I had some struggles as well and a great amount of shame around that for me around food, around eating. And I think we have to be aware of those things and give people permission to talk about that a little bit and partners also to watch some of those behaviors. And if they're noticing things to bring it up yeah, those are, it's not just always the disease right sometimes it's side effects from our treatments that we have to watch out for.

Kevin Kwok:

That's right.

Polly Dawkins:

How did you all, you know, Kevin, you started this session talking about shame and moving away from shame, and you're talking about using humor and bravery. How do, how did you all navigate that part of moving from shame to acceptance, bravery, humor?

Kat Hill:

Hmm. That's a good question.

Kevin Kwok:

You know, it doesn't come always automatic. It's something that I think you constantly have to be reminding yourself that things could be far worse and it's not as bad as it seems. And I know that rah rah cheerleading thing can be annoying at times, but I think taking a positive outlook is so imperative on what, when you have a lifelong disease like this, you're always gonna have to sort of remind yourself. Being around other positive people really helps too. And I also find that by counseling, other fellow Parkinson's people, it really has helps us, it helps me. I've said that before other webinars, but reaching out to someone else, helping them makes you realize that it's not so bad, what we have.

Kat Hill:

I agree with that. I also think, I wanna put a plug in that, you know, as a disease, as life and disease progress, mourning, what is, and being sad for a bit, it's okay to be sad for a little bit. And for me, I kind of have to work through each step, but then getting back on the horse, you know, getting back on the things that I know that bring me joy, you know, my connections with others, this community talking about it also somehow brings, makes me feel less embarrassed, less shameful, less, and hearing that it happens to other people and finding things to be grateful for even when you shift jobs, right. Kevin, even, you know, I stopped working right away for, because of the work that I did. And that was devastating to me. But once I kind of moved through that, I've learned to do other things. I've learned to paint. I've written a book. I've, and that's been part of my process in healing. Why are you laughing, Kev?

Kevin Kwok:

No, I'm congratulating you but I can't clap.

Kat Hill:

Yeah. Well don't yet. It's not out yet. See if you like it first before you clap, but that took time, you know, that took me, you know, time to work through that.

Kevin Kwok:

You know, tying to your book and what Polly asked that question, Michael Kinsley wrote in his book, *Old Age A Beginners Guide*, got one line in there, which I thought was brilliant. That line was, we are now sent as emissaries to the future of the prematurely aged world. And then we're asked to come back now and report back what we've learned and all of the symptoms that we're talking about will eventually happen to everyone as they get older, we just get a sneak preview on it. And so probably that thinking about it in those terms really helps me a lot.

Polly Dawkins:

Yeah.

Kat Hill:

Yeah. And I know those, you know, I'm sure everybody out there, including those without Parkinson's have embarrassing moments where they feel shame where they, and I think it's part of the human experience. And like Kevin said, we might just be accelerating our opportunities for that with Parkinson's. If we can laugh at, with each other, be kind to one another, be kind to others and maybe do a little teaching in the moment and you know, and being gentle with ourselves. Yeah. I heard Michael say how, you know, how hard our own self critic, that's the beginning of acceptance and forgiveness is being able to do that for ourselves. Yeah.

Polly Dawkins:

The comments in the chat indicate that you are doing this with such grace and grit and courage and sharing this with our audiences. So, if you're giving us a preview, all of us, of aging, you're doing a great job.

Kat Hill:

Oh, what a privilege to be here. Kevin, you take care of that rib.

Kevin Kwok:

Hey, I've gotta get ready to watch the game today. That's the key is always be a kid. That's the one thing that we have, that's going for us.

Kat Hill:

Yeah. Play and laugh and find joy you guys.

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