



Living with Parkinson's Meetup

June 2023: Shame

Davis Phinney Foundation

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

Chris Krueger (Program Manager of Education and Content, Davis Phinney Foundation)

Okay. Hello everybody. Welcome to this month's Living with Parkinson's Meetup. I'm very happy to be here with our lovely panelists. And I just want to introduce myself really quickly. My name is Chris Krueger, and I am the program manager for educational content with the Davis Phinney Foundation. And I'm just really glad to be here with y'all. Thanks for joining us. Some of you know the authority, but some may not. So, I'll just share off the bat that like our panelists, I'm living with Parkinson's. I was diagnosed in 2020 when I was 37. And, you know, I'm just really just, it's just an honor to be here. So, you know, today we're going to talk about shame, and you know, that's a big, that's a big topic. And as I thought about today's topic, I thought, well, how are we going to get started?

And I thought, well, identity is kind of important to shame. It seems to me. It seems like it's related. And so, before we get started, I just want to go around the panel and ask each of you to introduce yourselves and maybe say where you're calling from, because I know some of us are in maybe different places than we usually are. And so, say where you are, and maybe I was thinking where you were when you were diagnosed. And then finally, since we're talking about shame and identity, I thought maybe it'd be good for me and maybe for everybody to get a sense of who you really are. If you would tell us if you were a dog person or a cat person. So, I'll go, I'll ask everybody to go around in and we'll start on my screen. I've got Robynn at the top here, So, I'll ask Robynn to start us off.

Robynn Moraites (Panelist, Davis Phinney Foundation):

Hey. Hey everybody. I'm Robynn Moraites from Charlotte, North Carolina. I got diagnosed in 2015 at the age of 46, but once I understood the full constellation of symptoms, I had been dealing with this since maybe 2003, 2004, since my early thirties. I got diagnosed in Boston, Massachusetts. I was a resident of Boston at the time, and I love my dog Hunter, but I am a cat person.

Chris Krueger:

All right, one on Team Cat. All right. This is going to be fun when we get the cat. Is Kat a cat person? We'll find out. But let's go with Doug.

Doug Reid (Ambassador, Davis Phinney Foundation):



Hi everyone. Doug Reid, zooming in from Lafayette, Colorado. I was diagnosed in 2010 when I was 36 and diagnosed by a neurologist for in Boulder, Colorado. I had DBS almost three years ago, and I'm doing well. I broke my leg at the end of March, that as of yesterday, I can put weight on my leg. So, I'm starting to walk again slowly but surely.

Chris Krueger:

All right, great. I'm glad to hear that it's the recovery's going well. Kevin?

Kevin Kwok (Ambassador, Davis Phinney Foundation):

Yeah. Hi everyone. Kevin here. Dialing in from Boulder. I've been living with Parkinson's since 2009 when I was 47 years old. And the other parts of your question were that I was diagnosed very quickly because I was on a business trip to Singapore when I just locked up and froze. And when I came home, they made the immediate diagnosis, which certainly made for a lousy trip. But we'll talk more about that in a minute. Working with Parkinson's. As far as animal preference I would say I'm very definitely a dog person.

Doug Reid:

And I forgot to mention I'm a dog person. Not a dog owner, but a dog person.

Chris Krueger:

Yeah. Yeah. Thanks. Okay. Let's see. Let's go to Kristi.

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

Hi, I'm Kristi Lamonica. I live in Troy, New York, and I was diagnosed in 2020 and the Albany Movement Disorder Clinic in Albany, New York. And I am a dog person, So, I do have two dogs on Cat. I've always had Salmon Beach.

Chris Krueger:

All right. So, Sree let's go to Sree.

Sree Sripathy (Ambassador, Davis Phinney Foundation):

Hey guys and girls. And they them. My name is Sree. I was diagnosed in 2015, and I will be 50 in two years, So, I'll let you all do the math on that. And when I was diagnosed, I was in the same house that I'm currently in. The only difference is from then to now is that I'm in a different room. So, that's the difference. And in terms of dogs and cats, I like photos of dogs and photos of cats, and I'll enjoy other people's dogs and cats, they creep me out to be quite frank. They're very curious, very intelligent, and they just jump out of nowhere, and I get very startled. So,



yeah, cats are, thank you, Kevin. Thank you for that. Thank you. But I love everyone else's dogs and cats, So, yeah, that's my story. I try very hard not to jump on Sri.

Chris Krueger:

Yeah. So, go to Kat.

Sree Sripathy:

You can jump on me anytime, Kat. Anytime.

Chris Krueger:

Well, Kat, why don't you jump in and introduce yourself to us?

Kat Hill (Ambassador, Davis Phinney Foundation):

Okay. Hi, I'm Kat Hill. Let's see, I was diagnosed in 2015 at the age of 48. Let's see. I am very much a dog person. I'm also a Sagittarian. Let me think about what's up. What else? My favorite color is purple, and I love polka dots, and I happen to have polka dots on tonight. I am, was diagnosed in Portland, Oregon, and, but I am currently in Spain. And I currently live wherever I am. We sold everything we owned and hit the road in an Airstream. And so, right now I live in Oviedo, Spain for the next couple of days. So, that's me in a heartbeat.

Chris Krueger:

All right, great. And Doug I'm sorry, not Doug. Brian, I'm looking at the, you're right next to each other. Brian, please introduce yourself and say hi to everybody.

Robynn Moraites:

You're on mute.

Chris Krueger:

Yeah, I think you're muted.

Brian Reedy (Ambassador, Davis Phinney Foundation):

There we go. Got me?

Chris Krueger:

Yeah. Yep.



Brian Reedy:

Okay. So, yeah, I, let's see. I was diagnosed in 2000 well, 2008. They said if you were young, I'd say you had Parkinson's, but you're, or you're older, I'd say you have Parkinson's, but you're too young. So, then in 2010, I was fully diagnosed at the Mayo Clinic in Utah. And I'm a dog person.

Chris Krueger:

Great. So, before we have our last panelist, Heather, go ahead and introduce yourself. I just want to remind everybody that we'll make links available through a post later on. And also, if you have any questions, please throw them in the chat for us, and we'll be monitoring that as we go. So, Heather, please let us know who you are and what it is.

Heather Kennedy (Panelist, Davis Phinney Foundation):

I'm Heather and I'll let you decide whether I'm a dog or a cat person based on my tattoos. And I do like cats with a k a lot. And I do like the fact that cats don't give a rip. They'll sit, they'll be like, oh, you're herding. Sorry, I have something to knock off the table and watch it fall. And dogs are just like, I want to please you. Do you have treats? I'm a dog. Do you have treats? You smell like treats. And in fact, I do smell like treats. because I eat a lot of snacks in my bed now because I don't get out of bed that much while my back heals. So, I do smell like treats. I was diagnosed probably 13 or 14 years ago, I think, but I've had it since my daughter was born. I remember having my first symptoms around 21 years ago. I'm on a lot of medications to sit here and speak with you. I'm So, glad to be here. It's good to see you all. I needed to see you today. Thank you. Good

Brian Reedy:

To see you.

Chris Krueger:

Yeah. Great. Thanks for sharing that Heather, and thanks for being willing to lead us through today's conversation. So, if you're all set, I'll hand it over and you can guide us through, through shame together.

Heather Kennedy:

Right? So, we're talking about the same portion, which it's hard to talk about shame, but also acknowledging like the fear and the pain management and the pain itself and the trauma that comes with this loss and grief that we suffer from. Things changing So, much when, you know, what's not really exactly what we had planned. The one thing that we noticed isolated is to make things a lot worse. So, today we wanted to just sort of talk about this sort of aspect of shame that comes with having a disease that affects other people and not being able to

necessarily contain that. I personally can just say I have a lot of shame around the fact that I can't mother the way that I want. My mother was recently visiting, and she actually made me feel better because she didn't know what to do when I had me.

So, I wanted to kick that off by saying, everyone here, we all mothers in different ways. You don't have to have children to mother. You may have a four-footed friend, as we mentioned. And a lot of people here have been nurturing to me. How do we do that when we're feeling So, much shame about what we've encountered? So, I wanted to just sort of start off and let you go around Robynn, just like we did before. Or Chris, you can add to this and just say, let's talk about that intersectionality of the pain into the shame and the fear and the trauma and all the things. So, basically, it's a wide-open forum. Robynn, do you want to kick us off?

Robynn Moraites:

Okay, I was thinking about this a lot because last month our topic was fear. And I do some studies of spirituality and personality types. And we each have kind of a grounded center where we kind of operate from, some of us are kind of more shame-based, others of us are more anxiety and fear-based, and others of us are more kind of anger based. Not that we all don't have all those feelings, but we all tend to have a center of gravity from which we operate. And I'm definitely a shame-based person. I've done a lot of work with it over the years and I'm much less so, but it's kind of my default go-to. And I was thinking about how this shows up with Parkinson's and it's really kind of a double-edged thing. It's very funny to me when looking at it very objectively.

When I got diagnosed, I was ashamed and didn't want anyone to know that I didn't specifically tell and control the way in which I told them. I felt shame talking to my friends at Rock Steady who were more progressed than I was because I felt like I didn't have the right to complain because I wasn't as, you know, as progressed as they were. Now that I'm progressing more, I feel shame about the fact that I'm progressing more, and I don't even want to talk about that here in this forum. It's just really funny. It just kind of cuts all directions for me. And you know, Doug was talking about a problem with his foot. I'm having that too. My toes are starting to curl in all the time pretty perpetually. Like I have, I guess they're called hammer toes, but it's my dystonia going on in my feet and it really hurts. And so, there I set, I set a symptom progression,

But I think that shame is when Chris talked about identity, you know, shame is sort of not feeling good about who you are. It's not about something that you've done. It's kind of more identity based as I'm not okay in some way and believing that I am my Parkinson's. I don't think intellectually that I understand that. But that's kind of like the felt experience inside. And I remember reading an article about neurodegenerative conditions, not just Parkinson's, but because they are So, identity-based and we as we associate So, much of our identity with our ability to think and our ability to articulate and express, and when that gets impacted, it really affects our identity. And so, all the neurodegenerative conditions like Alzheimer's, Ms.

Huntington's, and Parkinson's, have much, much more of a shame-based orientation because it is an identity that's being impacted. So, those are my thoughts to kick us off.

Heather Kennedy:

And it's interesting too, more that we cling to whatever the idea of what our identity is, the more would be dragged, it's like go or be dragged, right? You have to sort of roll with the changes whether you have Parkinson's or not. Right? What do you think Kevin?

Kevin Kwok:

Well, I've gone with a lifelong battle of trying to deny and push shame out of my life, which doesn't mean it's not there. I mean, I've always told close friends that the hardest thing about Parkinson's is the disease of loss, of relevance. And they asked me, what do you mean by that? And I said, well, every day something happens in my life where I can't do what I used to do. You know, if I was in a working meeting, you know, the ability to communicate and articulate a thought or to be precise or to debate, you know, I feel like over time my communication skills have really started to wane. And that to me is really a part of the thing that I'm somewhat ashamed of, which I'm not really admitting, but amongst friends like us. It's true. Right? but this came to a head the other day just on Friday I accompanied my mother to her first appointment at the movement at the, sorry, the Memory and Aging clinic at UCSF.

And she got her first diagnosis of Alzheimer's. And it just sort of hit me really heavily, right? It's like I was lecturing my mom now on mothering and being, you know, a good parent and not to let this really affect you telling her that it's biological and not a behavioral issue, that she's been forgetful. And so, it's what's been very interesting for me is sort of the role reversal to go from the patient now to the parent to the sibling, the child taking care of their mother. And I know there are a number of us in here who have done similar things on this panel. But anyway, it is a long-winded answer to saying that I think we're on a journey of trying to push back, Shane. We have to accept it; we have to go forward. And to me, the greatest way of dealing with the issue is in fact being with fellow friends, like you all are sharing stories and realizing that we have nothing really to be ashamed of.

Heather Kennedy:

And you touch on dignity too. The idea is that we can do this with grace and dignity. Thank you.

Kevin Kwok:

We would shame is the loss of ego, shame, and ego, sort of our conflict, right? And to have dignity, Heather, you have to sort of set aside your ego.

Heather Kennedy:

Yeah. And Doug wanted to add something.

Doug Reid:

Yeah. For me, I may be splitting hairs here, but I think it's important to differentiate shame, guilt, and embarrassment from one another. The only time I've really felt shame related to my Parkinson's is when I was on a dopamine agonist and my behaviors, my compulsive behavior disorder had me doing things that I'm, I still feel shame for. I would feel embarrassment when it was out in public and shaking, but it wasn't the same as shame. And I would feel guilty in regard to the apathy I have in doing things with my children. But it wasn't ever shame. I don't think we need to feel shame because we have Parkinson's.

Heather Kennedy:

I love that distinction. Thank you So, much for pointing that out to us. And know that Kat and Sree both wanted to add something. Kat, do you want to add something to that?

Kat Hill:

Sure. For me, the shame comes in because I'm a trained caregiver, that's what I've done. I'm a mom, I'm a nurse, I'm a midwife. I take care of other people. And it's been very difficult to think about having to ask others to care for me someday or to ask for concessions. And so, it's a real shift related to my ego. And I didn't think I was So, tied to being, I didn't really think I was So, tied with my ego in my work. I really didn't. I was shocked and leaving my work, I realized how wrapped up in it I was and how much that whole shame piece came in. It's not that I feel ashamed for having Parkinson's. I feel ashamed that I'm no longer feeling as relevant working as a midwife, as a care provider, and that that's not how it's supposed to be.

It wasn't part of the plan. And so, I wasn't supposed to retire before my kids were done with college. I wasn't supposed to go on disability. I was, those aren't things that had shame for me. You know that I'm not working outside the home or earning income that way. So, that's more where the shame has come from for me. It's around who am I? How am I relevant when I'm not taking care of other people? And how do I have grace in receiving care? How, how do I have grace saying I hurt Robynn, I can relate to that I have pain. I'll say, oh no, I'm fine. You know, I'm over here twisted because of my trunk's twisting. And people say, does it hurt? Oh no, I'm okay. I'm okay. You know, I'm holding my breath. I know Kev, it's the hands, it's the trunk, it's the, So, I'm trying to learn grace with it.

Heather Kennedy:

Just reminded, reminded me. Sorry, you just reminded me of that meme where the guy's bleeding and he's like, I'm okay. I'm okay. You know, that's kind of, you know, you're a strong,



the strong silent one, Kev. And maybe we don't have to be right. Sree did you want to add something too?

Sree Sripathy:

Yeah. But can you reframe the question because I think I forgot what I wanted to say?

Heather Kennedy:

You were I thought you might like to add something, but to the previous conversation. But we were talking about how, how there's different types of shame and slight slash embarrassment. Doug had mentioned that and that's when your hand.

Sree Sripathy:

Ah, thank you. Thank you. Okay. So, to what Robynn said, I, that really resonated with me in terms of the progression and all that. It's like she read into my brain and was basically saying what I was thinking in a very cohesive way. So, thank you for that Robynn. I'm your sister in those feelings. And shame is something I very much align with. To add to what Doug said you don't need, you shouldn't feel shame if you have Parkinson's. There's no need to feel shame, I understand that. But for me, the shame just happily came on its way whether I wanted to or not, you know? So, I felt shame because I got Parkinson's and for me, it was like, great, I didn't do this right, this right, this right. You know, didn't make my parents happy with X, Y, and Z and now I am freaking have this disease and oh, I'm getting emotional. So, for me, I think it was hard because when I got diagnosed, that was the time when I was finally coming into my own. I was like ready to settle down, ready to have kids. And then this diagnosis hit, and it changed everything. So, yeah, there's a lot of shame there that I couldn't do all the things that I wanted to do. Wow. I was not expecting to feel this way. Oh my God.

Heather Kennedy:

And you're wildly creative and you're a photographer. I know firsthand. It's hard to be a photographer. I'd put my camera down. Photography and Parkinson's is very difficult. So, I admire you for that.

Sree Sripathy:

Well, don't mention that. Can I feel shame because my lighting is the worst out of everybody?

Heather Kennedy:

Oh, you look great though. Look at,

Sree Sripathy:

Oh, mine's awful, Sri, are you kidding? Look how pink I am. No, I'm talking about the light. Like, it's like dark everywhere and everybody else is like, oh, we'll sit near a window. And I'm like, let's sit against the window So, nobody can see me.

Heather Kennedy:

Well, nobody said you wanted to be a model and a topper.

Sree Sripathy:

Thank you for that. Thank you. Appreciate

Heather Kennedy:

That. And I know that we want Kristi had her hand up too. Kristi, you want to add something.

Kristi LaMonica:

Maria, everything that you said, love it. I with you agree with it.

Heather Kennedy:

And then I know that Brian wanted to add some things here.

Brian Reedy:

It's a shame I can't get my fingers sorted. For some reason, I keep having a tremor when I hit the mouse. It was interesting when we started talking about this topic because I didn't really think I had shame. You know, I grew up Catholic, we had guilt and shame to me was, you know, when you did something really wrong and you're just kind of like, you know, and you're fearful of it. But I looked up the definition of it and I love Robynn's definition where she said, it's not feeling good about who or how you are. And I thought that made more sense. But as I looked at have, I felt shame with my disease I think because right off the bat we started off with such Lily and I started off with such a sweet note on it.

I think I've said this before, you know, we got out of the Mayo Clinic's doctor's office and the doctor had just said, you know, to Lily, you're going to be his care partner for the rest of it. Or his caregiver for the rest of her life, his life, loves talking with Parkinson's. And she said, got up there and said, I'm not going to be your caregiver. And I'm like, Lily, and she said, I'm your care partner and we're in this together. And we just, I think that made it easy. And then I always have this kind of gregarious, outgoing, fun sense. And so, I told everybody at work right away, well not right away because I didn't say it for a few weeks at the end of the year. And there were rumors that I was dying. So, I addressed it on the first day of school the next semester, next year.

And then I just made jokes about it. I just said, well, you guys know I've always been a mover and a shaker. Now it just shows, you know. And so, I've always been funny about it. And it was easy to do that because Lily and I always laughed about everything. I mean, through her whole hospice, through her whole cancer care, through everything. And then I went through the depression and then I got through that depression and started getting stronger. And a horrible thing happened that I've never talked about, but it started PTSD or gave me PTSD or however, you describe that. And then I moved, and I was in a horrible car accident that I shouldn't have survived. I went right through a power pole and destroyed my truck and they're still diagnosing me. It's been one year now, and they just diagnosed disc fracture and compression. But it's like my knees went bad, my shoulders went bad. They just found the second tear in my other rotator cuff. So, I'm dealing with all the pain and the depression's there and bad things were happening with the depression. And I was having suicidal ideations. And I'm kind of like, what the leap? You know, that's not me. I'm this outgoing, fun, gregarious guy. And people started pulling away from me, my entire family.

And one of them said, you know, it's hard to hear you talk about suicide. And I just wanted to say, you know, it's really hard to feel like that because it's not me. It's not my nature. I spent 17 years teaching my students about positivity in the face of adversity. Because I lost three students to suicide in my first three years. The depression is part of Parkinson's, it's part of what the brain does. It's, you know, it's the non-movement part that we don't talk about enough. And I got So, desperate recently to fix it. And I heard that one of the drugs that I was on was one that I was on when they were trying to do stuff with my ADGD. And it was Provigil. And when I did Provigil years ago, I noticed that it dampened my personality and I asked the doctor if I could get off and he said, no, because you're dealing with So, much and you know, you've been in this bad state, So, no we can't take you off it.

And he's like, I just don't want to feel this crappy anymore. So, I took myself off it slowly and other things happened. I couldn't sleep, didn't eat, and all that, but tried to manage it myself. But, and I'm sorry I'm going into this, so, long, but what it's become is the depression is my shame. And the depression is just like a tremor. It's a symptom, it's something of, but I feel like everybody sees me that way now. And that's why I love laughter yoga because I don't have Lily here to laugh with. But I laugh every night now online with this international club because that's my healing thing. That's what makes me feel great is laughing. And then I go out and I go for a walk, and I see all these beautiful people, and everything is great until I can't walk because of the pain or the Estonia or the other crap. So, it's, I'd say that's really kind of what I finally found was my shame is I don't know how to get past it. There's a stigma with it.

Heather Kennedy:

Yeah. Yeah.

Robynn Moraites:

Well, and Brian brings up a really interesting and important point that I've noticed over the years is that I'm the one with the disease that I end up caretaking those around me who don't know how to deal with the diagnosis or the symptom that I happen to be presenting or they want to avoid me, you know, and they don't know what to say. And I ended up sending an email out to the whole family sort of saying, I'm living a hassled life just like you know? It's like, it's like it's really a weird situation to be in.

Heather Kennedy:

Yeah. Because when we get into these situations, of course, we get diagnosed, everything else doesn't stop in life. Life doesn't say, oh, I'll just wait for you. I'll make an exception because you're special. You know, we are a fraction of a pixel and a fraction of a pixel in the universe. We're, we know that we're very small, but to us, it feels very big. You know? And there are a lot of people that are willing to shame us, especially the happiness grade. Like, you're not being positive. Shame on you and you and you. And they need to remember that when they're on the way up, they're going to come down that ladder too. So, we all, you know, they just don't know what to do. Maybe. I know, I saw a couple of hands up, Kristi saw she, Kristi, I think your hand was up first.

Kristi LaMonica:

No, Robynn, I'm with you. That's how I told my family. So, I sent an email because I couldn't tell anyone face-to-face anymore that had Parkinson's. I didn't, I guess sick of comforting everyone else around me. And, when it came time to tell the rest of my, like my circle, I told everybody on Facebook because I just got, I was just done. I was So, over having to control everybody else. Like, what about me? I'm the one who has Parkinson's for god's sake.

Heather Kennedy:

Yep. You just made an announcement all at once on Facebook. Yep.

Kristi LaMonica:

Yep.

Heather Kennedy:

A lot of people do that, huh?

Kristi LaMonica:

I had to, it's the only way to preserve my sanity.

Heather Kennedy:



Yeah. And like Brian, you are working as a teacher, correct? Yep. Yeah. So, you have like a whole brigade.

Kristi LaMonica:

The students and everyone else I work with, they're, they're fine. It's, they're different. I don't have to console them as much, but it's like the other people in my life.

Kristi LaMonica:

So,

Heather Kennedy:

And I know she wanted to add something and then we could ask Chris too.

Sree Sripathy:

Yeah. So, similar to Kristi, I came out on Facebook to everybody that was my Facebook friend, and I got a lot of support and encouragement, and love. The thing I struggle with now, I don't know if it's shame or embarrassment or frustration, is that when I have symptoms, I have to explain to people again what Parkinson's is. You know, I send them helpful links, I send them links to the Davis Phinney Foundation, I send them the links to the webinar. These webinars, I give them summaries. And the number of people who've read them is maybe like two out of, yeah. Multiple dozens, including the people that are closest to me. So, then when something happens, like I get disc kinetic and someone says, why is your head doing that? I feel dizzy looking at you. I, you know, or when somebody asks me, how's your health? And I want to say, why are you asking me about my health? My health is fine. I am not my Parkinson's, but at the same time, I am my Parkinson's. And for me, the embarrassment or the shame is when I have to like tell coworkers or colleagues, sorry, I couldn't get to this because of my Parkinson's and I, and I'm getting used to new symptoms as they hit me. So, it's like having to train people on how to deal with the old symptoms while I'm learning about the new symptoms.

Heather Kennedy:

Yes. That is So, huge. All these things are having simultaneously we have to be like the care and the cared for when I'm off and I'm trying to describe to the home healthcare person, like where things are that's maddening and then they send a new person each time. So, I'm like, oh, the scissors, oh, during the drawer to the, I don't know, just forget it, you know, after a while, you know. So, I wanted to ask Kevin, and then we're, I'd like to have Chris chime in as well. Kevin.

Kevin Kwok:

Yeah. Heather, you put in the chat room the issue of impulse control. You know, we all have a disease of dopamine deficiency and dopamine is the gratification hormone that we need and crave. I've had this conversation with my neuro therapist who said that it's not just dopamine agonism that can create this impulse behavior. Dopamine itself can do it. And I think that we're all sort of striving for something that we can't get. It's forever chasing that thing on the, So, yeah, I think it was said earlier it was Doug who said that impulse control with agonists is the one thing you're shameful of. I can echo that. But I still am in this search for trying to understand more about why I need gratification. I don't know if others feel the same way.

Heather Kennedy:

You have to live now.

Kevin Kwok:

Yes.

Heather Kennedy:

The timeline goes tick, tick, tick, tick. We're thinking, oh my God, I haven't done half my bucket list. I better hurry. Yeah. Want to do everything, feel everything, you know. Now. Now, now what do you think? Anybody? I'm channeling blue velvet Kat, did you want to add something?

Kat Hill:

Yeah, well I wanted to touch on it, I don't want to shift gears if we're not ready though. Oh. If we're still wanting to talk about compulsive stuff.

Heather Kennedy:

I would love to add to this conversation, people mentioned ADHD in the chat, right? Yeah. And that's part of it with ADHD we're all a little bit like Dory. We have a six-second you know, focus here with all the shining lights and things. Some of us, not everybody, but does anybody feel shame from anything like gambling or hypersexuality or anything like that that they're willing to discuss at all? Kevin and Sree both have your hands. Yeah. Kevin, you want to

Kevin Kwok:

Well, I think it ruined my first marriage for sure. Impulse control. You know, you engage in behaviors that you're not proud of and I think many of us have felt that I don't know how to go into any deeper without sort of playing, laying out my soul here. But it's something that really is, the disease is not painful or shameful, but some of the behaviors that are offshoots from it, I think I do consider shameful. And finding a reason why is sort of now our lifelong search.



Heather Kennedy:

Yeah. I have blown up a lot of relationships. I've acted impulsively, especially when I was drinking. Not good. Sree and Kat, you wanted to add to that either?

Sree Sripathy:

Yeah. So, I don't know if this is compulsive behavior, but I have had struggles with money and spending. Maybe not at the level of somebody that's on like Mirapex or something like that, but definitely to the point where it's caused problems in my life. No relationships. I've been lucky enough to hold on to most of my relationships and my friends just kind of got used to stuff saying that's just me. And when I finally got diagnosed with ADHD, everything kind of clicked. Maybe it was Parkinson's, maybe it was ADHD, maybe it was Sinemet. I don't really know. I just know that it was there the other day. I like, I think, who was it? Brian might have been saying that Sinemet causes cravings as well or could have been. Kevin. I went and bought like pounds of sugar nerds, Sweet Tarts, and Rack chocolates, which are better than Godiva because Godiva is no longer available in the us.

Pocky sticks. I would eat like a box every day. Boxes. And then I had a negative reaction to my Parkinson's medication just this past weekend, which was pretty scary. And it could have been because of the sugar in my body. It could have been because I wasn't eating enough protein. But I'm not going to go into details about that. Let's just say my mom was freaking out and thought she should call 9 1 1. And I'm like, relax. I know exactly what's happening. It's fine. You know? I had some glass that shattered against my face and all sorts of craziness happened, but I threw out the sugar right after. But immediately I-

Heather Kennedy:

We lost you, Sree.

Kat Hill:

Oh, sure. You froze.

Brian Reedy:

It's a cliffhanger.

Kat Hill:

I was just going to say it's just like those, you know. Oh, there you're back. Ok. Thank goodness you left us hanging, Sree.

Sree Sripathy:

What did I say?

Kat Hill:

You-

Brian Reedy:

You were talking about just got rid of it and then you,

Kat Hill:

And then you-

Sree Sripathy:

Oh my god. I'm great. My storytelling is getting so much better. So, I got rid of all the sugar, put it in the trash can, and I was very tempted to go back into the trash can and pull it all out because the craving was So, strong. And in reading about sugar, sugar gives us a huge rush of dopamine. Huge amounts. And because if you're dopamine deficient, you want it, even if you have the right amount of dopamine, you still want it. And then when it counts to money, I'm looking at my like credit card bill. I'm like \$60, \$120 on sugar. I don't have that kind of money to spend, you know? So, there's a lot of shame in terms of that. You know, not only the sugar cavities.

Kat Hill:

Shoot cavities. I'm going to fill in for her. My dad was a dentist. I know that word.

Robynn Moraites:

I thought she was going to say caffeine. My money's on caffeine, sugar,

Kat Hill:

Caffeine. It's, I'm on cavities. I don't know.

Sree Sripathy:

That

Heather Kennedy:

Was great. That was great. Sree, you're freezing against her. We're like, Kat, chime in here.

Kat Hill:

We're filling. Yeah, we were filling in. I know that I personally had troubles overeating when I was on the agonist. I gained like 40 pounds and that there's a huge amount of shame with that. You know, I'm short, I was short, shorter, and rounder. It seemed like, like I lost weight. That was a good eating that much So, that, you know, it's since gone come back off. But it's hard, you know, and the hypersexuality was okay for our marriage, but it was definitely noticeable. So

Heather Kennedy:

The first time they gave me, they did not warn me. Nobody said anything back in the day.

Kat Hill:

I was well warned. and my husband was at the appointment with me. And so, we were both pretty cu cud in. It was a hard decision to have though, because even though I had heard it didn't totally matter to me. It was a weird thing. And Kev, I'm sure you knew too.

Kevin Kwok:

Definitely. But you kind of justify it, right?

Kat Hill:

You do. And I know I'm a healthcare provider, you know, I did that whole thing. That's

Kevin Kwok:

Right. I can

Kat Hill:

Yeah. Yeah. I know. You and I can relate on that one.

Kevin Kwok:

We all think we can beat it, right? Well, we all think we're a little different.

Kat Hill:

Yeah. What I,

Heather Kennedy:

What I don't like is when people, even within our community, shame one another for that behavior when we know where it's coming from. These are not personality flaws per se. They can be right exaggerated by that, but they don't usually, how about this, how about instead of moralizing it, make it into a health issue, you say, have you checked your medication levels? Yeah, that,

Kat Hill:

Yeah.

Doug Reid:

In my darkest days of depression, I was craving sugar and eating So, much sugar, sugar, sugar. And then I went in for an annual physical and my A1C was elevated, and I was not pre-diabetic, but my primary care doc warned me about it. And it was kind of an eye-opener that my behavior is not good. You need to change your behavior.

Kat Hill:

Yeah.

Heather Kennedy:

Brian.

Brian Reedy:

Yeah. And when I was on the dopamine agonist, I had, I had probably two addictions. So, one was the one that you hear about, but very few talk about. And that was the addiction to porn. And the second was this addiction to building things. Because I had had had to stop teaching. And I found that I could build things. And so, I built like three sheds on the yard, one So, I could build stuff and the sheds So, I could, anyway. But the addiction to porn was, was, you know, being raised Catholic, I had all this guilt about it. It's like, what the hell am I doing looking at this stuff? I'm married to a wonderful woman. You know, this is just wrong on every level. And felt shame. Are

Doug Reid:

You built a shame, shame for that.

Heather Kennedy:

The porn she shed talk.

Brian Reedy:

No, but that would've been, that would've been really bad. But anyway, I ended up eventually telling my wife about it because I was just feeling So, horrible and our relationship was struggling. And the moment I told her, she said, oh, I was just waiting for you. You know, I knew something like that would happen. I was warned about it, you know, I expected it. So, I'm just like, oh God, you're amazing. But then I got off the dopamine agonist and well, and I had stopped at the moment. I told her, because once you tell her, you no longer feel the guilt, it no longer has power over you. And I found that's a great way to stop these addictive behaviors. But when they wanted to take me off the dopamine agonist and I was still building things, I'm like, no, no you can't. That's my superpower. Because I could lift things and carry things and I built an eight by 12 shed all by myself, you know, framing everything. It's like I'm a superhuman with this stuff. And she's, that's exactly why we're taking you off.

Heather Kennedy:

I know where we're going when the Armageddon hits. Yeah, totally. Building sheds and stuff.

Brian Reedy:

That's how you-

Robynn Moraites:

Well, that's the thing. It's not only the impulse control, but it can throw you into hypomania kind of like a bipolar hypomanic episode. And then there's embarrassment around that. I did not have that happen, but my mother had that happen when they adjusted her meds, and it threw her into total hypomania for about 48 hours. And we had to stop her meds immediately and readjust. She's living in an assisted living facility, So, it's like a college dorm, you know, there's people around. It's, it was embarrassing.

Heather Kennedy:

Wow. I love these transitions that you speak up to. because we're all going through all, we're all headed in that direction. Maybe, Chris, did you want to chime in on this?

Chris Krueger:

Yeah, you know, I've just been really, it's been pretty moving to hear the variety of ways that the identity and shame and the sheer variety of things that have been shared are really moving. And it makes me think about the way people talk about Parkinson's affecting the whole person. And it makes me think about how that relates to the plans we might make and all the surprising little twists and turns that Parkinson's can, can throw at you relative to your plans, relative to things you hoped for, whether it's, you know, relative to your diet or relative to your marriage,

for example. I mean, these things can be large-scale or small-scale. And it's been really interesting to hear the variety of ways that Parkinson's has changed the plans for people on this call in those small and obviously much more significant ways too. And the way that intersects with the shame, you might feel about not succeeding in plans you have made. So, that's the main thing I'm hearing is that pattern,

Heather Kennedy:

Right? And going on and off the meds causes a whole another wave of titrating and, you know, prescribing?

Chris Krueger:

Yeah. It can happen again, right? I mean, you can finally feel like you've grabbed control of the plans again. Yeah. And then, okay, now there's this new thing. My foot is acting differently than it was and now I have to adjust plans again and I can't do the things I'd already set, and so, it's a continuing cycle and I've been really moved by the way that you've all been expressing the way you've sort of powered through those things. It's been really admirable.

Heather Kennedy:

And Kat and Brian both had their hands up. So

Kat Hill:

Yeah, I wanted to touch on a little bit about the shame of trying to do everything right, and yet the disease still progresses. That there's this sense of failure a little bit. And I think we all have at moments of had, oh, that that might happen to them, but that's not going to happen to me. Right? Like, like, and if I do everything right, these are my air quotes with my hand, dystonic hands, air quotes. If I do everything right, maybe my progression will be nice and slow, and yet here I'm progressing. So, I must be doing it wrong. That sometimes is the cycle of what goes on in my brain and you know, am I not exercising enough? Am I not taking my medicine on time? Am I eating too much protein in my meals? And yet I think we can get stuck in that cycle of constantly trying to do everything right, because we want to stave off progression and then we feel like a failure and feel ashamed because oh, here's another symptom, here's another pain, here's another, this, another that.

And I see, and I think I want people out there to hear that it is the nature of having Parkinson's to have progression. Having another symptom or having it changed does not mean you're doing it wrong. It does not mean that you're a failure. It does not mean that you should feel shame. And I'm saying that partly to myself as I'm saying it out loud. It just means that it's part of the game and we're all running as fast as we can theoretically, philosophically, and sometimes physically, right? Or cycling pedaling as fast as we can to stay ahead. And yet it still comes. So, I

just want you to hear that from somebody who gets it, and you know, who watched my d dad die of Parkinson's and my uncle died of Parkinson's and I have an aunt that was just diagnosed with PTSD who's not doing great. You know, I just, we've had to remember that we're all, everybody Parkinson's or no, Parkinson's is just out here doing the best they can, but life is progressive and degenerative, right? None of us don't. I sound like a ray of sunshine today. And

Heather Kennedy:

Fatal.

Kat Hill:

And fatal.

Robynn Moraites:

Kat, you just, well,

Kat Hill:

I'm here. My inspirational talk at WPC.

Robynn Moraites:

Kat, you just described my thought process completely. Like it's not going to happen to me that whatever, you know, you just described it tot Yeah. But what has happened is that instead of thinking that I've done something wrong, it's not that I go there too much anymore, I get very defeatist. Like what does it matter Anyway,

Kat Hill:

Then, I probably the, I'd probably be here anyway, even if I hadn't done all that exercise. You know, I get really, I should go ahead and have the chocolate. It's still exactly.

Heather Kennedy:

You're speaking my language, Kat.

Kat Hill:

I know. Sweets.

Heather Kennedy:

And when we're in a state of shame, we feel responsible, like for the disease and for how it affects other people too, which we're not, we're not, you know, Brian, what did you want to add?

Brian Reedy:

Well, and one of the talks that I saw recently, it might have been one of the David Phinney talks here, something, but somebody recently addressed the things that we're doing, the addictive behaviors, you know, corn, the sugar, all that we're chasing that dopamine high again. And that the, when you're on the dopamine agonist, your kind of doing that on steroids, but you're chasing what you're missing. And that's what a lot of this is. And that's the stigma that to me helps remove the stigma of the actin. And I think the best way, and this is kind of going with something either Chris or Ka was saying but it's, to me, what empowers me through these strife and struggles is the community. And it's being able to talk about it. When I had that addiction to porn, I shared it with my support group.

Lily and I led a support group in our community. And then people started coming forward and saying that. And then when I had the suicidal ideations, I shared that number one, it takes away the power from them. And number two, you find out you're not So, alone and you're helping others. And I think that's the beauty of what we have here. But it's the community, you know, I'm done looking at my family to understand or find grace from them because there's too much they don't know. And like Sree, I think where Kristi was saying, you know, sending them information and telling them, you know, the brain is doing this or that and it doesn't help. What matters is being with people who understand it. So, you're not fighting that fight for people who don't understand and don't have the bandwidth to take into it. And that, so, that kind of is so significant and so, underestimated.

Heather Kennedy:

I've been shifting from trying to be understood to trying to understand.

Brian Reedy:

Yeah.

Heather Kennedy:

It's helped a little bit. And I'm not, I'm not telling you to do that, I'm just saying.

Brian Reedy:

No, that's exactly right. That's what I'm saying.

Heather Kennedy:

Hard people understand. Just give up. You have to give up. Yeah.

Brian Reedy:

You can't make the family understand, you know, if they, it's like somebody said in the chat room, you know, if they, if they don't have it, they don't have it, you know, you have to let go and move on.

Heather Kennedy:

And I just want to tell a really quick story here because this is where it fits. My grandmother was disabled in a wheelchair, and she lived with us for 11 years. My father, God bless him, used to lift his mother-in-law all six feet of her. And he wasn't quite six feet, I think maybe six, all six feet of her, and let her put a towel over her and he'd look away and he'd lift her gently into the tub, lift her back out every single day for 11 years. And you, I say this because she had a pill fall once and she was in a wheelchair and she called up to me and I was a teenager, I was a jerk teenager. And didn't I take my time coming downstairs to get that pill? And how many times have I dropped something, and I can't pick it up, I have to call for my daughter. Boy, do I know how that feels now? I didn't know any better. I didn't know that I was causing suffering. So, just want to add that sometimes if you don't know now, you know what I mean? So, I know that Sree or Sree did you have your hand up?

Sree Sripathy:

Yeah, I did, but I don't remember what I wanted to say other than I think I'll just fill in the space by saying everyone had such wonderful things to say and I think everyone, what something that everyone said really resonated with me and with Brian, my God, I'd love to be able to take that advice with family. I really would. But I find the need to still try and con, you know, make them understand to some level what it is. Because maybe not the deep details, but just at a basic level. But at the same time, no one's going to understand unless you've actually been in their shoes, unless you've, you're in it. And the thing is, I actually have nobody near me that has Parkinson's that is a good friend of mine that I see on a regular basis. So, for me, my friends and my family are really my support other than, you know, you guys and my virtual world.

So, without that support, without that understanding, it is tough. It is tough. You know, I wish I could move to Colorado and be near the DPF folks or to Portland where like the Bryan Grant Foundation is, or other hubs of Parkinson's communities. But when you're in a community where it's just your family and your friends and no one else around you really gets what's going on, you keep trying to explain and then you feel, you know, shame that you have the disease embarrassed that you have this condition, embarrassed that you're late for this or not able to make it to that or have to cancel attending your cousin's concert just an hour before. And it's frustrating, but it's life, you know, it is what it is.



Heather Kennedy:

I really feel that. Thank you.

Kevin Kwok:

You always have the invitation to come visit us and we're only a phone call away.

Sree Sripathy:

Ah, thanks.

Kevin Kwok:

You have, you have the community of us. Thank you. You know, I want, with all this talk of shame is shameful to me, right? because I also want to talk about how we cope with it. How do we get over it? And I think it's okay to say that we feel shamed at times. That's all right. It's part of it's part of the journey that we're on. But the key is to find out how we can shake it, right? Just like depression, just like shame. These are things that we can control, or we should try to control, I should say. I don't mean to de demean it in there, but find joy, right? I mean I'm finding new things that I can do now and treat it as a challenge. My latest obsession I can tell you is that hand exercise to try and help my dystonia. It sits right back here. It's a ukulele that my girlfriend gave it deep. I'm actually getting dexterity back in my fingers. You're taking ukulele lessons. I'm doing it online, but 30 minutes every day and the fingers are coming back, you know-

Kat Hill:

Are they?

Sree Sripathy:

Oh my god.

Kevin Kwok:

That's the point that I would be performing a concert for you Kat.

Kat Hill:

Oh, man.

Kevin Kwok:



But just the sound of getting a good chord to me is just beautiful right on there. And so, it may take me like 30 seconds to get the fingers just right, but

Kat Hill:

As long as the music's in the same chord the whole time, we'll be okay.

Kevin Kwok:

There you go.

Kat Hill:

Music helps.

Kevin Kwok:

But finding something that gives you joy is a good thing in there. And we can all find that one hobby, that one thing. And the issue is, we've talked about impulse control, not letting it get too far ahead of you. Because I feel like it, I border on that in almost everything I try is this obsession, right? But I think it's okay to give yourself that chocolate. It's okay to give yourself that you know, power tool that you want to work with provided you do it safely.

Sree Sripathy:

Kevin, I just threw away all my chocolates. I'm going to have to try and switch to power tools. I have to go with something safer for my teeth.

Kat Hill:

Were you going to say cavities or were you going to say caffeine? Do you remember Robynn and I had bets about you? Cavities.

Sree Sripathy:

Cavities. Cavities.

Kevin Kwok:

Cavities.

Robynn Moraites:

You got a Kat, you won.

Kevin Kwok:

You win the pony. It's an invisible

Kat Hill:

The pony that'll fit in the Airstream. Super well, thank you.

Robynn Moraites:

I want to pick up on something that Kevin said about how you cope with it and Mark put it in the chat. I've always been an obsessive-compulsive perfectionist, but Parkinson's has taught me to accept less than perfection's silver lining. That's the flip side of this for me is that I've gotten really good at accepting what's good enough that, you know, sort of this heightened level of perfectionism, kind of obsessive-compulsive type A stuff. I can't afford to be type A anymore. I have my little checklist of the things I have to do at work. You know, my list of stuff. And it's like, if it's good enough, let's just cross it off and move on. I think that the flip side of this is that PD has given me tremendously. It's weird. It's like I was more shame-based when I was super perfectionistic and it's kind of coming at it from the other side. But I am way more accepting of myself now. I am way more relaxed with myself and I'm really, and then it allows me to be much more relaxed with other people.

Heather Kennedy:

Yeah. And they say the difference between misery and happiness depends on like what we do with our attention. Like, can we stay here now? I don't know about that. Kevin. Kevin and Brian. Brian. I think Brian has been,

Kevin Kwok:

Oh, sorry, go ahead, Brian.

Heather Kennedy:

Will do that, Kevin. Yeah.

Kevin Kwok:

Oh, I just want to tap on what you said. Robynn, my neurologist back at Stanford when I was living in California told me that Parkinson's is the curse for type A personality. She said, I see all of you, all of you even in exercise and rest and vacations always are pushing, pushing, pushing. And she said you guys will just benefit from slowing down and slowing the roses. Right? Well, if we're, I know we're about to hit the hour and there's one thing that I wanted to say which is unrelated to Shane. But I just wanted to thank Mel because this is her last call with us. Mel.



Mel, I just wanted to say that when we had this conversation a couple of years ago on how we should turn a pilot young onset group of Zoom into an ongoing panel, you said, yeah, that sounds like an interesting idea. Let's try it. And I could tell you there's not a meeting I go to where someone in the audience doesn't say, I listen to your panel religiously. We get So, much joy out of it and no one has a better Parkinson's IQ than you do. Yeah. And I think we all just owe your deep gratitude and thanks for this.

Heather Kennedy:

Well, thank you So, much. I remember that conversation, Kevin, like it was yesterday and it's three years later. It's crazy. And yeah. I love all of you and I love all of you in the chat, and you're not getting rid of me, So, you're still going to see me also. Yay. Good. Thank you. Thank So, much, Kevin. That was lovely. Thank you. Thank you, Kev. That was perfect.

Brian Reedy:

Thank you, Kevin. That was important. Very important.

Kevin Kwok:

You're always part of the family now. Love you, family.

Heather Kennedy:

You are. Thank you.

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