



Living with Parkinson's Meetup

May 2023 – Fear & Shame Part 1

Davis Phinney Foundation

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

Melani Dizon (Director of Education and Content, Davis Phinney Foundation):

My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation, and I am here with our fabulous living with Parkinson's meetup. We have Kat and Kevin, and Kristi, and Doug, and Robynn, and Sree, and Brian, and they're all going to introduce themselves. Let's do a fun question. Okay. Your name, where you're calling in from how long you've been living with Parkinson's, and the best thing that's happened to you in the last six months. The most memorable thing that's happened to you in the last six months. Okay. Kat, you're going first.

Kat Hill (Ambassador, Davis Phinney Foundation):

Okay. I am Kat Hill. I am calling in from outside of London, England. Probably the most exciting thing that's happened to me in the last six months is coming overseas. Flying overseas a little over a week ago. And let's see, I've been living with Parkinson's for probably, you know, in retrospect, probably 15, 16 years. I was diagnosed though in 2015. Did I get it?

Melani Dizon:

That's perfect. Thank you, Kevin.

Kevin Kwok (Ambassador, Davis Phinney Foundation):

Hi everyone. Kevin Kwok dialing in from Boulder. 14 years celebrating a wonderful 14-year diagnosis, with Parkinson's. Something great in the last six months. On a personal physical note, I actually feel like I'm getting better in a sport that I've been spending a lot of time this Tron and that's downhill skiing. So, it's something that is just for me personally, sorry. Sorry, echo.

Robynn Moraites (Panelist, Davis Phinney Foundation):

Mel, you need to need to Amber. Amber.

Melani Dizon:

Oh, sorry.

Robynn Moraites:



There you go. There you go. Someone else has got someone. Echo. Got the echo.

Melani Dizon:

Just turn. Yeah, maybe, we can off it's if you're not talking.

Robynn Moraites:

Okay.

Melani Dizon:

Okay. Thanks, Kevin. Yeah. Downhill skiing. It's still possible to learn and do amazing things even after you've been living with Parkinson's for 14 years. I'm going to pull this one up cause this was pretty exciting. Somebody just said that she found out her daughter. Where did it go? Somebody found out their daughter was having twins. Now I lost it. Okay. Kristi your turn

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

Man, I don't know how I'm going to follow up after Kevin in his positivity. I mean, come on. So, hi, I'm Kristi. I'm calling in from Troy, New York. And I was diagnosed in 2020, but I've really been having symptoms back to 2015 and REM sleep disorder back to like graduate school. Something that's exciting that has happened in the six months, past six months. I think a lot of the projects I'm working on are really exciting and I can't wait to see them be released at the WPC, particularly our book on young Onset women and everything that we wish that we knew when we were diagnosed. And also, the PD Alliance Global Support Group, a guide I've been working on, I'm really excited about that.

Melani Dizon:

Awesome as well. Love it. Thank you, Doug. And then Robynn.

Doug Reid (Ambassador, Davis Phinney Foundation):

Hi everyone. Doug Reid, zooming in from Lafayette, Colorado. I was diagnosed in 2010 when I was 36. I'd been experiencing symptoms for at least a couple of years prior, a small pill-rolling tremor in my hand. I had DBS three and a half years ago. And the most memorable thing that's happened to me in the past six months was I broke my leg downhill skiing on March 31st and I'm still in a boot still on a knee scooter and crutches non-weight-bearing until mid-June. But I'm optimistic I'm going to be good to go for the world Parkinson's Congress.

Melani Dizon:



Great. Awesome. So, a cautionary tale, but not really. Because you're probably going to be back skiing too like you love it. Right. okay. Robynn and then Sree.

Robynn Moraites:

Sure. Robynn Moraites calling in from Charlotte, North Carolina. I was diagnosed in 2015 at the age of 46, but when I understood the full constellation of symptoms, I'm going back to 2003, 2004 in my early thirties. And the most memorable thing for me it's not a fun and exciting thing, but I spent over a month with my mother helping get her transitioned into assisted living and she got diagnosed with Parkinson's a few years after I did, but in a way, it's kind of, she's ended up in a beautiful, gorgeous place. Not a nursing home assisted living. They go out and do all kinds of fun things, but it's kind of restored my faith in life a little bit. I don't know how to explain it, but,

Melani Dizon:

Oh, I love that, because that's not often, you know, the experience of a lot of people when their parents transition to something else. So that's great. Sree and then Brian.

Sree Sripathy (Ambassador, Davis Phinney Foundation):

So, hey, I'm Sree from the San Francisco Bay Area. I've been diagnosed for seven years and had physical symptoms three years prior to that, two and a half to three years prior. And Prodromal, I have so much trouble pronouncing this word now. Prodromal. Yeah. Symptoms about 20 years prior, well, 15 years prior to diagnosis. And the most exciting thing that's happened to me recently is I actually got to meet a photographer who I follow on Instagram whose sports photography I love. And it was the most exciting thing that has happened actually maybe in more than this year, last year too. It's kind of so cool to meet somebody that you really admire and respect and love their artwork and then you meet them like just be like, whoa, it was so cool.

Melani Dizon:

Yeah. Awesome. Love that, Brian. And then Amber, you're muted, Brian.

Brian Reedy (Ambassador, Davis Phinney Foundation):

Okay, got me. Yep. So, I'm calling from the Huntington Beach area in Southern California. I was diagnosed 13 years ago. And the, probably the most exciting thing that's happened in the last six months for me was when my application to teach laughter yoga at a renewal room at WPC 2023 got accepted. That's just so exciting and it's great because it's on the 10-year anniversary of when I learned it at WPC 2013 in Montreal. So,

Melani Dizon:



Very exciting. Yeah. Thanks, Brian. All right, Amber. Let's give us a try.

Amber Hesford (Panelist, Davis Phinney Foundation):

Can you hear me? Yes.

Melani Dizon:

Yay.

Sree Sripathy:

Yay.

Amber Hesford:

Sorry, I had technical difficulties. I am not sure the questions that we were being asked, but from what I gather, I'm Amber. I was diagnosed, I'm calling from El Paso, Texas. I was diagnosed in 2018 with Parkinson's when I was 35. Had DBS in 2020 or 2021. I don't know. It's all a blur. And the most exciting thing that's happened to me in the last six months I got a grant to attend the World Parkinson's Congress, so I'm so excited to meet some of you in person finally.

Melani Dizon:

That's awesome. Awesome. Okay. Okay. Oh, Amber, can you, oh, Amber can, I think it's like when Amber's thing, I get all I'll, I'll turn myself off, but I do want to say Dave o Hi everyone. I'm Dave Iron, or which is the best name maybe I've ever heard from San Antonio, Texas. I retired some time ago, one and a half years ago, and it's going well, found out about two years ago. Thanks for sharing, Dave. Okay. today we are going to be talking about fear. We're sort of doing two parts, we're doing fear and shame over this session and then the June session. And this session, Robynn has raised her hand to facilitate and guide everybody through the discussion. And next month through shame, we're going to have Heather do it. So, hope that you guys are in for the ride and ready to talk about it. Thanks, Robynn, go for it.

Robynn Moraites:

Sure. Thanks, everybody. So, we were talking about fear and shame as a potential topic, and we just figured that there is so much material here that we wanted to bifurcate it into a two-month topic. And there are different kinds of fears. There are just kind of catastrophic fear-based things that don't have any kind of connection to reality. Then there are fears that are grounded in more real-life experience. So, we all have a whole range of fears, and I won't speak for everyone on the panel, but I know that my fears have changed as my diagnosis has progressed and time has passed. And so, I've got some questions. I've asked the panelists to think about some different stages and things that they experienced along the way. And so, what I wanted to

start with for everyone is we're just going to kind of go around Robynn with this and you can elaborate as much as you want. So, we're first talking about giving one example of a fear that you had either at diagnosis or very early on that did not come to pass or has not yet come to pass. And so, I'm going to start with Kat. I'm going to go sort of zigzag on my screen. I'm going to start with Kat.

Kat Hill:

Okay. Thanks, Robynn. I think one of my biggest fears was very practical. Early on I was really worried about money and leaving my practice as a nurse midwife, a nurse practitioner. And I was worried that it would mean giving up on all of our retirement dreams. And I think that is, I'm very happy to say that that has not come to pass in the last 10 years. We may be doing it a little differently and a little more creatively, but we are still traveling and we're overseas right now. We're very happy. We're still married, and we are not bankrupt. So that was a very early fear for me. So,

Robynn Moraites:

And you're living in an Airstream?

Kat Hill:

Yeah. Yeah. Well, right now I'm living in the hotel room, but yes, this year I'm, we've been traveling the country in the Airstream, so yeah, but we're not going to live in an Airstream forever. I just want, you know, don't worry folks, I'm not coming to a driveway near you. So.

Robynn Moraites:

Okay. Thank you, Kevin.

Kevin Kwok:

Yeah, similar to Kat the fear that I had most was, was being marginalized after I admitted to the world that I had this ailment and feeling like I would be left behind by colleagues and by, by friends. And in fact, some of this did happen. There was a shift and there is a change in people that I used to think we're really close friends through work and professionally, I lost touch with a lot of them, but I think what became really exciting for me is this back bill of new relationships. And so, I survived, you know, and the testimony is this panel, the panel members are, that are all on your screen now are all very dear friends. And I would not have had that experience had I not been diagnosed and left my past life.

Robynn Moraites:



Thanks, Doug. And now for the palace, I do want to remind you, sorry, Doug, to cut you off. We are going to talk about an example of a fear that you had that did come to pass. Right now, it's, we want to talk about ones that didn't come to pass or haven't yet.

Doug Reid:

When I was initially diagnosed, I was really concerned about being alone. I was married at the time, but my marriage fell, fell apart shortly thereafter. And I've found out that my friends and my family are closer than ever. I get lonely at times, but I've got new friends, panelists here, and people from the foundation. And the fear hasn't happened, thankfully.

Robynn Moraites:

Thank you. Kristi.

Kristi LaMonica:

I think that when I was just diagnosed, when I was diagnosed, my biggest fear was that the unknown, like, I didn't know how fast everything was going to go, how slow it was going to go, or what was going to happen with work. And I was going to have crippling anxiety forever because when I was diagnosed I just, I was taking so much Xanax a day because I was just crippled by anxiety. But that all kind of went away for the anxiety and just moved on to different things and different worries.

Robynn Moraites:

It's interesting, as people are talking already, I'm sort of noticing that we're going to have some overlap in the categories of, you know, it's just interesting. It'll wake for a pretty robust discussion. Sree.

Sree Sripathy:

So, I actually don't remember being scared of anything. That's not to say that I wasn't, I just don't remember. And I think part of the reason, if I truly wasn't that I didn't know anything about Parkinson's when I was diagnosed. I didn't have an image in my mind of what anybody looked like. I that old white man model that people talk about, I had no knowledge of that. I met, I had a family friend who was diagnosed and when I met him, he seemed basically okay right when he, and he'd been living with the disease at that time for eight years. He's not doing so well now, but I had never met anyone with Parkinson's before, nothing. So, it was like a blank slate for me. So, the one small concern I had was that I, what would I do about work. But I wasn't presenting very actively then. So yeah, I think coming from a no fear place was really great for me because I didn't have anything to worry about. When you come to the next question, then I'll have more to say. But yeah. Nothing for me, honestly.



Robynn Moraites:

Thank you, Brian.

Brian Reedy:

I'm kind of in the same boat as Siri. I didn't necessarily look at my life was in such a positive place. I didn't look at things as fear. I think maybe the only thing I did fear was possibly ending up like my uncle who had Parkinson's. And he wasn't very mobile, and all his kids had to assist him when we'd go to the beach and stuff. And just ending up like that old man picture that street mentioned. But, you know, those were really kind of far back in my mind because I was focused on the here and now more.

Robynn Moraites:

Thanks, Amber.

Amber Hesford:

I think my fear has been and always will be how it will impact my kids. When I was diagnosed, they were seven and nine. They are 12 and 14 now. And so, this is a trick question because some ways it has already impacted them in, in the long term. I really don't know where it's going to leave them, or what their level of involvement will have to be. And that's scary. And of course, you know, how long can I work to provide for them? I'm a single mom. Will I ever meet somebody who's willing to take on this burden with me? It's, the fears are endless, but all really surrounding the kids.

Robynn Moraites:

Thank you. Thank you, Amber. You've had to mute Amber. You've had to mute yourself. There we go. There we go. Nope. Nope. All right. There we go. All right. There we go. Nope, nope, nope.

I was a little bit like Kristi. It wasn't that I had perpetual anxiety about the unknown, but I started learning about all the symptoms, and every time I had a new symptom presentation, I would freak out. And I would think that every single thing that was happening was the beginning of the end, but then it would only last two or three weeks, and it would go away and so, and the only thing that has been really consistent has been my tremor. And some things, you know, were there for three weeks never to return again. Sometimes they pop up for three weeks, once a year. But I don't freak out nearly as much anymore. Because I know that for me, the way that my Parkinson's presents, it's a little bit more like whack-a-mole and it just, you know, things kind of pop up and then they go back down, and then they stop. So, but I was, I was just convinced that it was the beginning of the end and I mean, I had real doomsday fears

that I think with just some time living with the disease, we all learned the cycles of our body, the cycles of the seasons, the cycles of our disease, and sort of the rate of our progression, so to speak. Okay.

Melani Dizon:

Also, for those of you who are want to in the chat, you know, feel free to throw yours in there some of your things. We'll get to talk about all of those as well.

Robynn Moraites:

Yep. Mel, feel free to chime in. I can't multitask to that level. so now we're going to talk about an example of a fear that you had at any point in the journey, not at diagnosis, but that did indeed come to pass. And I'm interested in people to elaborate a little bit about how did you handle it; how did you get through it, or did it unfold differently than you expected? I felt like some people already shared on some things that they had fears, and yet things unfolded a little bit differently than they may be feared that they would like, Doug, when you were talking about, you know, the dissolution of your marriage, and yet you have all these other support people that come in. So, I'm going to go in the same order before we just sort of wide open, open it up for discussion. So, Kat, you're up.

Kat Hill:

All right. I, I think it was difficult for me. I felt better once I separated from work, once I figured out what was going on and once, I was able to rest. And so, I think having some regular sleep and a regular rhythm helped me early on to manage my symptoms better once I kind of figured out what was going on. And I think I got a little cocky thinking, oh, I, you know, I've got this, this, I feel better, you know, I'm kind of posting along and maybe I really don't have Parkinson's. Yes. The tremors there and yes, this and that. And I think you get; I got lulled a little bit into a sense of maybe I'll be an outlier in a really slow progressor. And it, you know, and the self-talk and the denial, I think it is a real part of who I am.

And it's partly how I stay positive, but I don't, it did, it has progressed, and it has impacted me more. The symptoms are progressing at probably a fairly normal rate. I'm not some great outlier. Yes, they were right with the diagnosis. So, I don't know if that really answers the question. I, I will say too that my dad had Parkinson's and it, my Parkinson's has been very different than his journey. He was diagnosed much later in life. And his, he didn't have any tremor and he progressed cognitively, I'm a little sleep deprived, so don't take that as cognitive, but it cognitively really differently. So certainly, my cognition and my multitasking ability have kind of gone away. But anyway, did I answer the question.

Robynn Moraites:

Well, it's good, good fodder for discussion. Okay. I mean, and feel free as we go through, if you want to comment on anything that anybody else has said, one of the things that it struck me is that there is a really beautiful book called *When Breath Becomes Air*. I don't know if anybody's read it. And he talks about sort of the accepted paradigm in reverse and accepting the disease. And I feel like that's really applicable for me in that to really function well in my job and in my life. I pretty much have to be in denial. You know, it just, I mean, I don't know if I'm in acceptance or denial, either one. It works fine. Kevin.

Kevin Kwok:

Yeah. For me, my biggest fear was a progression of the disease in general. You know like had the early days of my disease and the journey, I thought I'd eaten this thing. I was exercising, I was doing things like crazy. And it was like those people that I've gone to and who I've seen that have advanced, that's not going to be me. Right. I think I've come to; I definitely have advanced just in the last two to three years. My voice is worse. My ability to cognitively handle multiple things is not where it used to be. But I guess I've taken a lesson now from people like Davis and people like Michael J. Fox who are, who say it's okay to progress, right? So, for those of you who haven't seen his documentary yet, still is really a must-see documentary. It really gets into this. It's okay, you know, the disease that we have, we're not going to be cheerleaders about it. And say it's not a bad thing, but, but we can still remain optimistic and live as things happen to us. So that's more my general gestalt over how I handle a disease that will, will eventually advance.

Robynn Moraites:

It's a limited release on Apple TV, but that movie still. And we watched it over the weekend. I don't even know if it's still up. Cause I think it was very limited. I think it was like a week or two weeks. Kristi, you seem to know you're on mute.

Kristi LaMonica:

It should still be up so that you can if you purchase Apple tv. So, if you have who, if you have the Roku, you can get Apple TV for free. So, you get free for three months so that you can watch it as many times as you want.

Robynn Moraites:

Thank you, Doug.

Doug Reid:

I was very concerned about the side effects of medications and specifically dyskinesia from Carbidopa levodopa. And probably at about seven years post-diagnosis, I was very dyskinetic.



And when I would talk, it would get worse. And so, I found myself isolating and it was, it was debilitating, but I was taking so much carbidopa levodopa and wasn't really managing my medications well in terms of timing and dosing. And eventually I'd watched a Davis Phinney webinar on DBS and decided to take the leap and have since weaned myself off covered Dopa levodopa completely. And I don't take many Parkinson's medications. I just take two sine a day, but my dyskinesia has gone away, thankfully.

Robynn Moraites:

Does the sine help with non-motor symptoms like rigidity or stiffness or things like that?

Doug Reid:

I think it helps with all motor symptoms and non-motor symptoms. It's, my nerve, my movement sort of specialist described it as activating, which I take as energizing it somehow gives me energy and calms my tremors, and it helps.

Robynn Moraites:

That's one of the things that since I had DBS in 2020, I haven't been on any PD meds since 2020, but I'm having some like dystonia in my feet and in my back. And, you know, I've wrote a little note thing to talk about with my movements disorder specialist, who I see next month. So, I don't know what kind of medication options there are, but that's conversation for another time.

Doug Reid:

I recommend trying AEC or Sinemet.

Robynn Moraites:

We'll talk about it. Thank you, Kristi.

Kristi LaMonica:

So, I have two, two things. So, one of my fears that's ongoing is that I feel like I wonder if I'm progressing fast. I'm not sure, because when I'm on like really on, but then I can go off, but then I can come back on. So, it's probably, I'm probably catastrophizing everything, but I just worry, worry. And I'm, and I fear that it's just fast progression, but probably I don't know. I need to talk to my movement disorder specialist, but that's a constant bear. And then another one is this is a little bit more personal, so I'm just going to share with everyone in the world. So, I feel like I missed out on a lot. So, I went to for my undergrad, then I did my master's, then my PhD, then after my PhD, then I did my postdoc, and then I got my tenure track position. So, I was waiting to get tenure to have children, and I got tenure and Parkinson's. So that having kids for me is

not, is not a thing. It's not going to happen just because when I go off my meds, I'm really rigid and stiff. So, it's walking moving is difficult. So, it's just not conducive to raising a family. So, sorry, that's my fear.

Robynn Moraites:

That's okay. And, you know, there are a lot of crossovers of the fear with grief and sadness or shame. You know, we're going to talk about that next month. But it does knock you for a loop. You know, like Kat you were talking about your retirement looks different, you're having a retirement, but it looks different. And you know, Doug, I'm in the same boat with you. My marriage dissolved over my diagnosis. So, thanks for sharing that with us, Kristi.

Sree Sripathy:

Oh my, how do I follow up from that? Yeah. Well, I was going to say, jokingly say my biggest fear was that the Golden State Warriors would not beat the Lakers. And that has definitely come to pass. They did not beat the Lakers but go dubs. My sweatshirt is on. But I worried, I think when I meet people with Parkinson's, I see what symptoms they have and when they mention how they're progressing, I worry that, oh my gosh, that's going to happen to me. One of those issues was swallowing and not being able to speak as well. And similar to Kat, I actually lived in, I didn't even know you felt that way, Kat. So that's really kind of refreshing to hear because I thought I'm the only one who lived in glitter denial land. We're like, wow, I'm not exercising, and I haven't done any exercise in two years, and I don't seem to be progressing at all.

So, I'm that magical special person that the Parkinson's fairies have chosen to just bless. And then you wake up and you realize, oh my gosh, I have progressed. And what world was I living in? And so, for me, that was swallowing and not being able to speak as clearly, which was something that really worried me. And then it happened. And it's not been easy. I have to be careful now about what I eat, you know, like chips, no eating while I'm driving, eating in smaller bites, chewing more, which maybe is why I've lost so much weight, because I'm chewing a lot more. So, burning calories, yay. Good for that. So that's come to pass. The other one is, I think Doug mentioned dyskinesia. I had met a beautiful, amazing person with Parkinson's who had a very severe dyskinesia.

And I thought, I hope that never happens to me. I definitely don't want that to happen. And over the past year, that's definitely happened to me. Even on the smallest dose, I get very dyskinetic. It's extremely uncomfortable. And I also feel like I need to hide in public and, you know, like kind of contort my body into stillness. And I think people don't recognize or realize that I'm dyskinetic. I'm like, oh, nobody's saying anything. So clearly, I just believe I'm dyskinetic nobody else believes I am. And then I'll look at a video or I'll see like something a friend posted or somebody will come up to me or my mom will say, why does your head move that way? Like, what, what, what's going on with your body? And so, it's been, it's been painful, it's been



painful, but at the same time, these levels of acceptance come slowly. And I try not to fight it. I try to just accept it and I don't want to say embrace it, but when I fight it doesn't help me mentally. I physically, I just feel worse. So, the acceptance for me is what really is helping, I think we'll see how it goes.

Robynn Moraites:

And to get to acceptance. There is sort of a process of surrender to reality as it is unfolding.

Sree Sripathy:

And a lot of sugar and chocolate.

Robynn Moraites:

There you go. And grief.

Kat Hill:

And I think there are grief and I think for those things that we wanted, that we may not have and that I think that's real. And I think in order to get to acceptance, we have to grieve.

Kat Hill:

You know, whatever that means to you, you know?

Sree Sripathy:

Yeah. At some point I want to cry, but I haven't cried since I got first diagnosed. So eventually those tears are going to have to come, I think. I don't think I've let myself properly grieve, but that's a good point.

Robynn Moraites:

You know, it's really weird because I haven't really cried over my diagnosis until I watched the movie. Still, I cried my eyes out at the end of that movie. I don't, you know, just, it was like, I don't even know why, but just all of it, all the grief from diagnosis to present day. Brian, what you got for us.

Brian Reedy:

Well, just first I want to interject as I'm listening to all of you, I'm getting this greater awareness by understanding, listening to this committee over the many months about women's issues with PD. And I love how Kat and Sree and others are really bringing this to the forefront and having Kristi share what she shared. I thought it was very bold and it's also really significant part

of women with PD. So that's I'm just very proud of her sharing such a difficult thing. And mine, I was like, Kat, I was in, I was swimming in, I used to tease people that I was swimming in denial. And it's not the river in Egypt. It was truly something I didn't want to embrace was Parkinson's. So, I was a high school teacher. I taught photography and video production at the same time.

I had a TV studio, I had kids doing photo projects, and community projects. I also worked in summers at Adobe and would get trained in products and go around the country and teach other teachers. And so, I didn't want any of that impacted by Parkinson's. And I was in huge denial as to how it was impacted. And it was about four years into it, that one night I came home, and I just could not move. I was absolutely frozen and lying in bed. And my wife came to my bedside and just started crying and said, this is just so hard to see you like this. And that's when I realized, okay, you know, I had seen it coming because I never had a student aid before, and I had six of them for seven periods of teaching. And I went and gave my notice the next day.

But then, my fear was that I was going to lose my job. And I did. But it turned out to be a blessing because the next year Lilly was diagnosed with cancer and I was able to be there for her full-time, which I couldn't have been otherwise. So, and then that went on for five years. So, I don't look at it as a curse, it was just, it was a hard transition. So, it got realized, but I think as if we hear from everybody, better things came down the pike. You know, Lilly and I had amazing five years together. That wouldn't have happened otherwise.

Robynn Moraites:

And I think that this panel does a good job of focusing on the positive, the silver linings, the unexpected blessings. It's the living your best life now because there are a lot of that too. So, but I just like to hear how people are, I'm seeing some really good comments too in the chat, Mel, if you want to take a moment. But you know, it's neat to hear how people process their fear and are moving through it. But Mel, you were going to read some of the chats.

Melani Dizon:

Yeah. Sam has provided a bunch of tips for people who've said several things. And Brian, I wonder if you could, and some of you, I mean I'll think a lot of you can speak to this, but a couple of people talked about how in the world you deal with this alone when you're alone. And Brian, somebody, in particular, their fear, they said their fear is that they will outlive their partner and they think there are no way they can handle it. And I feel like you would be a really good person to talk to about this. Certainly, you don't have to tell a long story, but you know, just, I'm sure you never imagined that would be, this would be your situation either, but you're doing it. Yeah.

Brian Reedy:

No, that's interesting. And I'll try to keep it really brief, but it's interesting when, when I was first diagnosed, the doctor said you know, you've got Parkinson's and you basically get your affairs together and your wife's going to be your caregiver for the rest of your life. And Lilly walked out of the room and said, I'm not going to be your caregiver. I'm your care partner. We're in this together. And we really, I think that was the beautiful part of Ava. So, when she was gone, it's like, what the hell? You know, when she was in hospice, it was so beautiful every single day and we just saw so many blessings. I didn't prepare myself. You can't I think it's been a hard road. And I went through a really rough depression from her dying for about six months. Then I found the road that I wanted to be on, and I turned my garage into a physical therapy space, and I lost 80 pounds and I just got back into shape.

And then other consequences happened in life that kind of brought me back down to different things. But what I've learned, each knockdown that I get is basically this community, this Parkinson's community is unlike any, you meet people with Parkinson's and it's like all the pretenses come down and people are genuine and they're heartfelt and they're real. And their help is genuine. And, you know, the foundations you know, the Davis Phinney Foundation, the Fox gosh, I can't think of one that isn't good. They're all just great. And I think that's what holds it together for me. So, it's hard like Doug said, you know, there are times where it's lonely, but I'd rather be alone than with the wrong person and have the wrong things. So, I think the thing that keeps me going is, is finding things that I love to do, like the laughter yoga. And there are really, someday I'll have to get around to showing it strong ties to how it benefits Parkinson's immensely. But doing that and finding other ways to make a difference for people and make a difference for cancer those are the things that keep me going. So, it's, I have a full schedule every day. Thanks, Robynn.

Robynn Moraites:

Okay, we're going to circle back up to Amber. Don't want to skip her.

Amber Hesford:

I feel really boring because ultimately, it's still the kids. You know, really what, how it's going to impact them. My grandma has Alzheimer's, so every time I forget something I worry about that eventually developing for me and what that's going to do to them, how they're going to manage that. The other day my kids found my paperwork for the testing that I have to do because I have swallowing issues. Like Sree was talking about HRO, except it's not on food, it's always on my own saliva. And so, they found that, and I think that freaked him out a little bit. They were like, you never told us that you have problem swallowing. What are you talking about? And I'm like, it happens like daily and now they're hyper-aware of it. And so, I worry about what that does to them emotionally, psychologically. Sorry.

Robynn Moraites:



It's okay. It's okay.

Amber Hesford:

Yeah. But it's them, they will always be my biggest fear. And I think that's true for any mom or any parent. No matter what, even if you don't have, sorry, even if you don't have Parkinson's, I think your kids are always your biggest worry.

Kat Hill:

Amber, I don't want you to be sorry. I appreciate how honest you are.

Kevin Kwok:

Amber. Amber, I saw the hosting of your son singing Obama the other day on I was in tears. I love that.

Amber Hesford:

Oh, you and me both.

Kevin Kwok:

You've raised good children.

Robynn Moraites:

And there we go. Amber, I'll email you after two are your kids getting any counseling?

Amber Hesford:

No, they're not. They're much like their mother, and they handle it with humor. I honestly don't know why I worry so much because they are resilient, and they make jokes about it. And my oldest son has been like, so when you get really bad, are you going to come and live with me, like in my van down by the river? So, I really don't know why I have so much worry because they seem to be handling it well. It's just I'm their mom. So ultimately that's my job, so

Robynn Moraites:

Thank you. So, my turn. Give examples of here that I had. And how did I handle it? I, this is circling more back to Kevin's fear. Originally my fear was I didn't want anyone to know unless I told them I didn't want to be stigmatized. I didn't want it to be, I didn't want to be marginalized and I wanted to control the narrative of how people found out. I was especially concerned for my job. I didn't want my employer to know. And little did I know my husband, my ex-husband was telling absolutely everybody, even though he told me he wouldn't. And little did I know

everybody knew, and I didn't know that they knew even strangers. We owned a business at a retail storefront type of business and had a lot of clients and you know, it was just it was a little bit, I was shocked. I did feel initially demoralized by it, but like, so many of my particular fears, nothing came of it. It was no big deal that everybody knew. And it was only a big deal to me. But that one, that topic was very interwoven with my shame. That fear was very tied to shame about how I'm perceived by the outside world. I had more fears about that than I did about the progression of the disease.

Robynn Moraites:

So, moving on, what's a fear that you have today, Amber? We know the kids What's a fear that you have today? And based on your personal experience so far, do you think it's a legitimate fear? Why or why not? And how do you handle fears that crop up today? Kat,

Kat Hill:

I'm going to unmute. It was very sweet. Joe just said on the chat, he's never seen me look so sad or so tired. I was feeling very moved by Amber's story, So I've got tears and I'm traveling, so it's late in the day and I'm always I'm tired late in the day. So anyway, I wanted to thank you for your concern, And Robynn, tell me the question again. I got sidelined here.

Robynn Moraites:

No, sure. A fear that you have today and based on your experience so far, do you think it's kind of a legitimate fear based in reality? Why or why not? And how do you handle fears that crop up today? I just, and anyone who wants to speak to, like, the evolution of your fears.

Kat Hill:

Yeah, I will, I will say today, today's a really good day to ask. It was a travel day for us. And so, we were on the plane, well, not planes, but trains, multiple trains, train stations in very busy places. And those are really hard for me to navigate. And I get very symptomatic, and I get very fearful about losing my way. I have like this teapot feeling like I'm constantly at a simmer. And if things and it's not based really in reality, I know that I can always ask for help or and I'm traveling with my husband who helps me navigate. But it is getting harder to do that. It's getting harder to travel. It's taking more energy and more recovery time. And so, I think that those are things that I need to be more aware of in my planning. I'm not going to give up travel, not today. But I think as things progress, I need to accept that that's part of it and so plan differently. So, I hope I answered that.

Robynn Moraites:



Yeah. My partner and I have, we've made an agreement that we realized it's not just the two of us traveling. There are three of us and my Parkinson's, and we need to take all three into account. We're making our travel plans.

Brian Reedy:

Well, I had to cancel my travel today. I was supposed to go to Boulder. But I have some physical issues that are making it more difficult, so. You have to flow with it.

Robynn Moraites:

Kevin, what you got?

Kevin Kwok:

Oh, well first of all Brian, I'm sorry. I was hoping to see you here in Boulder, brother. Yeah. We'll find a way to catch up.

Brian Reedy:

We will.

Kevin Kwok:

But, so, fear, one of the things that started materializing for me is I used to like to sort of dominate the conversation. I was very much in the type A and would always, you know, have the funny anecdote, or could finish the conversation. I'm noticing now that the slowness and the paucity of my conversation and thinking plus the mechanics of getting words out without sounding like I've got a mouthful of marvels, was it started to make me become more withdrawn. And so, I, you know, if I'm in a loud restaurant, I'll just sit back and not even talk. And to me maybe that's a good thing, right? May maybe my ex-wife be happy now that I'm not talking so much all the time. But it's something that I'm noticing and it's progressing. It's one of those things where just communicating is becoming a daily challenge. And for a guy who communicated for a living, it's shocking to my system.

Robynn Moraites:

I think for a lot of us, those symptoms are the most shocking. Thank you.

Kat Hill:

Kevin, do you find you're being a better listener?

Kevin Kwok:



What was that?

Kat Hill:

Are you finding I mean, I'm, are you finding your being smart Alec? Okay. Didn't even get it. I get it now.

Kevin Kwok:

No, I definitely am. I find that actually by listening I'm actually hearing and learning a lot more.

Robynn Moraites:

Yeah, it's interesting too. I have that too, but I just, I'm comfortable just, I don't need to be the center of attention. I don't need to be the showstopper. I could just listen. I think it's really important too, for those of us who come from more of a performative perspective to learn that we have inherent worth and value, even while we're not performing, doing whatever that our friends, our family, the universe, everything is okay and they we're still worthy and loved and it's all okay.

Sree Sripathy:

I wish I was as good as Kevin and Kat, but I just find it harder to interrupt now. So that's-

Robynn Moraites:

Doug.

Doug Reid:

Am I muted? No?

Robynn Moraites:

No.

Doug Reid:

I have poor balance and being on crutches now and non-weight-bearing, I'm very afraid of falling. Even before I fell and broke my leg, I was constantly bouncing into things and having near falls. But having to use crutches every time I go outside these days, I'm not going outside all that much. I know this is temporary and I'll heal, but it's ongoing fear of falling and watching the Michael J. Fox movie still. I mean, he's taken some nasty falls recently. It's not the pain of the actual fall, it's how the recovery will go. That gives me anxiety.



Robynn Moraites:

There is so much uncertainty. Sometimes I think the trick with Parkinson's is mastering living with uncertainty. That's sort of like the most difficult skill of all, you know? Anyway, Kristi,

Kevin Kwok:

I always use the say I don't fear falling. I fear the day when people won't let me fall.

Kristi LaMonica:

But filtering off what Doug was saying that I think that like having to have all the pins that the Michael J. Fox had in his hands, and it pins in his all, all those space things that he is broken. I feel like the anesthesia from that, I just, that scares me. Having them having to have that much anesthesia and being in the hospital for that long. What about your meds being off is just uncomfortable that I would just hate to be off for that long. Possibly without me, that just scares me. In addition to, and so I'm giving a talk at my movement specialist conference and June. And what terrifies me is that I'm just going to go off in the middle of my talk. That just, yeah, terrifies me so that timing. Sometimes I can time my meds, sometimes I can't. And I just, that just is a constant fear of going off and not being able to function.

Robynn Moraites:

That's what prompted me to get DBS. My medicine was effective for like 59 minutes, then it was effective for 55, and then 54, and then 50. And it was like, yeah,

Kristi LaMonica:

Once I turn into the tin, man it's just impossible because then it's like I feel like I can't speak right because my base just, everything just feels, feels slow and I just can't do it. So, I'm just terrified of that, but terrified of taking too much. So, what if I'm moving too much, then I have to give my seasickness warning, you know, that I'm sorry about my dyskinesia. Please look away if you get motion sick.

Sree Sripathy:

I think one of my fears now is falling and freezing. The freezing, I'm not sure when or how that will happen. My doctor, my neurologist says there are no indications last appointment that it would happen anytime soon. I don't know. You know what I mean? I wish there was like a sign you'd get a letter in the mail that says from, you know, next week you'll start freezing. But no warning like that the falling is actually more of a real concern because I definitely have balance issues now and I worry that, you know, houses are not made for people with balance issues. Right. Especially if you work in a kitchen or you have stuff stored up high and if you live alone or

if you live with short people. I live with short people, so we all have to get up on ladders to get things.

And I'm looking at these people who've designed homes. I'm like, did you not consider that people age whether you have Parkinson's or not? We're not going to all be able to get up on a ladder. So, I am now trying to move all my stuff to the lower level so I can be on my hands and knee and crawl. Because that's of course very comfortable too. and store things. But yeah, falling is a big issue. So, I really need to go back to doing Tai Chi, Argentinian, Argentine tango, whatever it is to get my balance steadier and then learn how to fall, you know, because it's going to happen and I need to learn how to fall as properly as I can, as best as I can. And I know Jimmy Choi has some videos on that and it's just been something I've been putting off because it terrifies me because I was terrible at gymnastics. But yeah, there you go.

Kristi LaMonica:

Can I just add that? So, I fell a few times in my, like my kitchen and also in my bedroom. I fell and smashed my face into a book bookcase. I have, there are, I practiced falling at boxing and stuff and at, at the gym and it's just, there is nothing that prepared me. I'm sorry, don't, don't mean to be Debbie Downer, but there is nothing that prepared me for that falling, it just happened. I was what, Debbie? Yeah, I know I was open that I was down. I don't know what even happened. I don't even know how it happened. Yeah. Next thing you know, my face was in the bookcase. I still have the hematoma from like a year ago. I can still feel it. Oh, ouch.

Robynn Moraites:

We've only got a couple; we've only got a couple of minutes less I want to get to everyone. So, Brian, you got anything there quick for us?

Brian Reedy:

Just, and I think this is probably everybody's not having my world defined by Parkinson's so much. I don't want to get where my world gets smaller and smaller, and I have to live by the MDS or just all the constraints that can happen. And like not traveling, you know, making that decision to not travel was painful, but it was right. I just don't want Parkinson's to define my whole world. I think that's the biggest thing that I'm working to stave off. One thing about the falling though, I wanted to mention this gym I go to, they put a big board on wheels, and they just have you stand there and then eventually they pull it out and you have to move your feet to catch yourself. Yeah, no, it's really hard. But it really does kind of prepare. But you know, you have to do it a lot probably because it didn't help for my last fall, but I thought that was a great practice.

Robynn Moraites:



Amber, you want to finish us off here with the final comment.

Amber Hesford:

So, I'm not going to talk about them, but, no, I mean, I agree with everybody. The progression, the choking, the falling. I wear two-inch heels now and I feel like I'm on stilts. The memory because I look at my grandma and I think like that's going to be me and I just hope you guys have fun with it when I get there and I can't remember, you know, the name of a dog or anything and just make stuff up. And there, there, there are so much to be fearful of so much that I don't know. And I just try to laugh at it as much as possible because that's the only thing getting me through.

Brian Reedy:

You were.

Amber Hesford:

You were.

Melani Dizon:

Humor, were you, thank you all so much for this conversation. So many great comments and people appreciating the conversation and there is a lot more to talk about. Somebody did mention no one's scared about dementia or knows I saw that. I think everybody is a little bit, unfortunately, we're going to have a session next month. We're just going to continue this move a little bit of fear into shame, which I think a lot of that will relate to that. So, thank you. We'll send you the recording, the transcript, and every, you know, all the links that were shared today. And definitely reach out to blog.dpf.org if you ever have any questions. And we hope you have a really great May, the rest of May. Thanks, everybody. Thanks, friends.

Amber Hesford:

Love you. Bye. Bye, everyone.

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