



Living with Parkinson's Meetup

October 2023

Davis Phinney Foundation

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

Chris Krueger (Content Manager, Davis Phinney Foundation):

Hello, everybody, and welcome to this month's Living with Parkinson's meetup. I'm Chris Krueger, program manager for educational content with the Davis Phinney Foundation, and like our panelists, I also live with Parkinson's. I was diagnosed in March 2020 at 37.

I'm really excited to be here for another session, and I just wanted to share a couple of preliminaries. First of all, closed captions should be enabled, and you can turn them on or off as you see fit. The chat feature is enabled. And you know we'd love it if you would chime in and tell us where you're calling in from. And also, you know, if you have any questions, feel free to pop them in the chat. And then, of course, we'll be recording this, and it will send out the link to view the recording within a week. Usually, it's out then.

So, before we get started, I just want to ask the panel to go around and introduce themselves as usual and share whether the question I would like them to add to their general introduction today is where you were on the spectrum of learning at all about Parkinson's, or ignore and hide from Parkinson's. Who, when you were diagnosed. Did you take the learn at all, or that this is not a real approach? And I see Kat thinking about it. So, I'm going to start with Kat and just dive right in. So, Kat, let us know a little bit about what you think.

Kat Hill (Ambassador, Davis Phinney Foundation):

Yeah, Hi, everybody. I'm Kat Hill, and I'm calling in today from High Prairie, Washington, which is where our property is. It's a gorgeous autumn day. I hope it's lovely where you are.

Let's see, I think I knew a fair amount about Parkinson's when I was diagnosed because my dad had it, and I think so. I think it was sort of in denial, like, I'm sure they must be in the wrong mode. So, I think I was in denial when I was first diagnosed.

Chris Krueger:

Okay, I got Kristi. You're next on my screen. So how about you?

Kristi LaMonica (Ambassador, Davis Phinney Foundation):



Hello, I'm Kristi LaMonica. I live in Troy, New York. I'm originally from Connecticut, and I really pretty much knew I had purposes when I was diagnosed. I knew a long time before that. It was just crazy being diagnosed. It was just made it more real when I said out loud it wasn't real, but when a medical professional did, it became more real and a little bit scary.

Chris Krueger:

A little bit.

Kat Hill:

I understand.

Chris Krueger: Okay. So, Doug, I'll see you next on my screen. How about you? Go ahead.

Doug Reid (Ambassador, Davis Phinney Foundation):

Okay, Chris. Hi, everyone. Doug Reid and I'm zooming in from Lafayette, Colorado. I was diagnosed in 2010 at the age of 36. So, I've been living with Parkinson's for 13 years now. I did DBS about ten years ago, and I'm sorry. Three years ago. And when I was diagnosed, I took the learn-it-all attitude. I got a book all about Parkinson's. I scoured the Michael J. Fox website. But I didn't reach out to anyone who actually had Parkinson's.

It was ten years or so after diagnosis before I went to a support group. So, I kind of had a hybrid approach to learning and then denying.

Chris Krueger:

Understood. Okay, Brian, tell us.

Brian Reedy (Ambassador, Davis Phinney Foundation):

Hi, so, Brian Reedy, I'm in Westminster, California. I pretty much didn't want to know too much because I didn't want to make noise in my head. I was still trying to teach, so my wife went the avenue of looking everything up on the Internet, which was scarier for her, I think.

And then finally. So, I was like this: in 2010 and 2012, I finally went to a conference. I thought, if I'm going to learn, I'm going to learn at a professional conference. So, it's for young onset put on by one of the groups, I forget who. So yeah, it's kind of denial more than anything, I guess.

Chris Krueger:

Okay, Robynn.

Robynn Moraites (Panelist, Davis Phinney Foundation):



Hey, everybody, Robynn Moraites. I am normally from Charlotte, North Carolina, but I am calling in today from Cincinnati, Ohio. And I on a scale of ones. That's 10. I was at 10. Learn it all. Learning, still looking, you know. Get sick of the Parkinson's news updates in my email box. But I'm on the learning at all spectra.

Chris Krueger:

I think I was attending to. I went. I dove right in amber.

Amber Hesford (Panelist, Davis Phinney Foundation):

Hi, I'm Amber Hesford, calling in from El Paso, Texas. I was diagnosed in 2018 when I was 35 and immediately started sharing on social media. So, I pretty much dove right into it. When I got diagnosed, I was like I knew it was finally an answer. I mean, it was not the answer that anybody wanted, but I was relieved to find and get some answers and know that I was right the whole time. That's what matters most is: that I'm right.

Kat Hill:

That, or having somebody to blame. That's also super important in my world.

Brian Reedy:

Alright, Heather, that's true.

Heather Kennedy (Panelist, Davis Phinney Foundation):

What else? When was it first diagnosed? I think it was wrong. I was just told I might have around 2010, or 2011, and then I took the message in 2012. But the first sentence was way back when my daughter was born about 2022 years ago in that range. But I was insufferable. Completely. Internet. I'm like; I'm going surfing and posting pictures on the interwebs. This is going to be easy. I've got this park is no problem to take the world by. So, I'm going to change the face of Parkinson's. I was insufferable and obnoxious when I was first diagnosed with awful. I believe there's a free park since personality and a parks and personality that starts out very like Gung Ho! Because you get this search of these dopamine agents coming in. that's my theory, and I'm sticking to it.

Kat Hill:

Alright.

Chris Krueger:



Tom, the question on the table is when you were diagnosed. Were you on this? Where were you on the spectrum of learning at all or hiding and ignoring?

Tom Palizzi (Ambassador, Davis Phinney Foundation):

Well, thanks, Chris; I actually saw all this happening. But I wasn't a participant site, so I couldn't. You guys couldn't see me. And I can see you. So. Thanks for rescuing me there. Hey? I was definitely a ten on the learn at all. Part of that, and part of, and that's what landed me in the hospital with that anxiety attack, you know. I walked out of the doctor's office, and I said, no, don't look this up on the Internet. Well, that's a dumb thing to say, I think, somewhere to go to look so. But I got through all that and hearing today.

Heather Kennedy:

Alright. Well.

Kristi LaMonica:

I didn't need to look up because of teaching. And so, we talk about Parkinson's a lot. My classes, and also the lab I was in for graduate school, have the lab worked and neural stem cells; so, and funny, I'm the one who has an agenda degenerative disorder.

Chris Krueger:

Yeah. Well, it's nice that you have the resources around you, though it can be helpful if you want to learn more. Right? So, there's pluses and minuses. Okay? So, I wanted to give a quick intro to what we're going to talk about today. And I want to just acknowledge that you know. This topic was inspired by a comment from someone in the audience in August.

And what happened was an audience member named Deb wrote that she envied the humor that we have just developed. and that she tries hard but just can't get over the sadness and grief, and That really stuck with a number of us. It certainly stuck with me and cause. I reflected on it. I thought, how are we doing? And are we actually, okay? And so today, that's what the panel is—going to talk about the ongoing struggles that might not always rise to the surface during these meetups. So what? What behind the scenes is sort of the lingering struggle for us?

And Tom is going to kick us off, and I'm going to pass it off to him in just a second. But I want to say that you know in the chat, please. If you want to share where you were on the spectrum of learning at all or run and hide, and also if you want to share what your struggle is. You know we'd love to hear from you, so please chime in as much as you feel comfortable. So, Tom, why don't you get us started?

Tom Palizzi:



Thanks, Chris, and thanks again for helping me get my technology ironed out here. So that's one of the many things going on these days. Yeah. This was a very intriguing topic to me, you know. I think we all have to face that at some point in time. Whether we're, you know, going to attack the problem by learning it all or by running. And I, that's all going to be addressed. But

I think most of us, especially on this council, tend to be optimistic. And so, that really makes a difference. Not everybody is an optimist. You know, right off the bat. Some people are. or more the other way, and I always found myself to be more optimistic than not, but I also found myself running and hiding behind the Parkinson's mask. So, I would if I didn't want to do something. I would use Parkinson's as my excuse. I can't do that because of Parkinson's. I can't do that because of Parkinson's.

It reminded me a lot of when I was a young boy. And I would tell my dad. I can't play baseball. I can't do that. He's like, just give it a try. Let's go give it a try. And so gradually, I heard my dad's voice talking to me over the years, and he would, I would hear him say. You know, don't lose the battle before, you know. Don't lose the war before you fight the battle. So that meant to me that I would try to talk myself into the things that I would try to talk myself out of. And I started this a couple of years ago conscientiously, with my New Year's resolution, maybe 3 or 4 years ago.

And it really dealt hard with the situation, but it knelt on the issue of being an optimist. I really had to pull that card out and say, Are you? Are you an optimist, or are you not so? And that's, I think, what people would talk about here a little bit. But I think it's important that we embrace who we are and how we deal with things. To the point where I would challenge everyone on this call, my colleagues, as well as all those who are listening in, to try at least try to talk yourself into something that you would normally talk yourself out of because you had Parkinson's.

And that's got a long way for me to send, really? Well, so I think when you ask the question, are we really okay? Well, no, I'm not okay. I mean, I have Parkinson's. But this year also has dealt with a lot of other significant health challenges, including prostate cancer and pulmonary hypertension. And lately, I've had an inclusion in my right eye. And so yesterday, I had an injection, and they went south. I looked like I had a baseball in my head. And I sent Chris a note. I can't play tomorrow. And then I thought, why am I trying to talk myself out of this?

I'm going to talk myself back into the baseball. I went away, thank God! But I was back at the doctor's this morning at 7:30 a.m. I am trying to get this under control site to be here today because that's what embracing Parkinson's in this community means to me. So, it's not always easy. It won't be, won't ever be. But it is surmountable, I think, to the point where we can do the things we want to do and live well today. So, I think I'm going to throw that out to whoever wants to take a shot and give us your take on it as well; Kat, your hands up there.

Kat Hill:

Yeah. I think for me, I, too, am fundamentally an optimist. And I think Parkinson's has really challenged that for me and kind of taught me lessons that perhaps I didn't want to learn. But perhaps now I can be a little grateful, for I think the process of incremental loss is big. I think that we with a progressive disease that changes over time, no matter what you do right, no matter how much you exercise, no matter how much you follow advice, no matter how well you take your medicines, it's learning too constantly pivot and how to manage the new normal and the normal keeps changing.

And so, I saw somebody say in the chat that they try to look more forward than backward about what it was like before Parkinson's. And I know that I grieve each incremental loss. So, a good example for me. It's a pretty tangible example is I have a lot of dystonia in my fingers, and I've been getting treatment for some time for my middle finger dystonia, and now it's spreading to my ring fingers on both hands. And so, you know, the treatment for this is that I'm grateful I have an option for is Botox injections in the muscles to deaden it? But with each incremental finger, I'm losing more and more function.

You know, I'm realizing there's yet with a second finger affected things that I can't do. I try really hard to focus on just the now and not anticipate that ten fingers rather than four will soon be affected, but I think the grief process for each loss is hard. I think it's important to grieve what's gone and then try hard to integrate it into the now and move on to the new normal, and that's hard. It's hard to do so. You know, I cry, rage, talk to friends, and talk to a therapist. I am treated for anxiety ongoing. I've been struggling with some apathy, you know.

I think we're all dealing with it. And yeah, I think it's hard, and I don't think I have an answer. I have tools that work for me, and each time I get through it, though, I remember, gosh, I've survived other moments like this. And okay, hopefully, I'll get through this one, too. But yeah, I don't know if that answers it. But I also wrote a book about it, which helped, and I'm working on another book, more into the years with Parkinson's disease rather than just sort of the early years. So anyway, that has helped me.

Tom Palizzi:

Let's see, Kristi, I think. Yeah.

Kristi LaMonica:

So, I think that. It. It should be expected that having Parkinson's, we would have some pressure, besides the fact that it is a symptom. But it just makes so much sense to look at thinking from that biochemical perspective. And we're low dopamine. So, of course, your serotonin is not going to be right. It makes sense because everything feeds back into each other. So, if you aren't on antidepressants and need help, don't be ashamed of taking anything.

Kat Hill:

And if you're not taking something and thinking about it, maybe it is an option.

Kristi LaMonica:

Yeah, if you can be feeling better, why not?

Tom Palizzi:

What was that, Kat?

Kat Hill:

I think Doug was going to say something.

Doug Reid:

Recently, I started getting anxiety. And how do I deal with it? I try to live in the moment, I try not to make future trips, and I try not to worry. But I live alone, and we all know it's a progressive disease, and so I don't. I really have to keep a tight grip on where my mind is in terms of worry. And sometimes it doesn't work so well. And sometimes it works okay. But I take so somebody in the chat just said, what anti-depressant does everyone take? I take it well, Beatrix; for me, it works part most of the time to help me not get super down.

But I've considered adding something else to the mix. And I have my annual physical coming up tomorrow, so I'll bring it up to my primary care. Doc.

Tom Palizzi:

That's good. That's yeah. I think that's why I take escitalopram. And that was the first drug that was prescribed for me in dealing with Parkinson's. And that's the only pill I've never, ever forgotten to take because of the level of anxiety that I experienced shortly before I was diagnosed, and then, of course, afterward, scared me, scared me to death. I was really scared, scared me big time, so I totally changed a lot of my life back in those days, but just having that under control is really important. So, if you don't, and you feel at all anxious or depressed.

Definitely talk to your doctors about it because that is. That is key to your survival with Parkinson's, and we all know it's not easy just to walk through a day with Parkinson's. So, is anybody else on the panel? Want to

Chris Krueger:

Yeah, I want to jump in real quick and just say something about the medication questions. It's just really important that you consult with your health team and the entire care team about what you might consider taking. And you know, it's important to talk to people broadly about

what? Especially the antidepressant type of medications, because some they can interact badly with others or in complicated ways with other treatments. So be very cautious when you approach those things and talk to your care Team.

Kat Hill:

And I also, just as a clinician who, prescribed this medicine a lot in general. This medicine works best in combination with other tools, things like therapy and counseling and exercise, and so I don't want anybody to get the idea that you know, you take a pill. And then suddenly, you're happy. It's it, like everything else. It works in tandem. And, like Chris said, it's really important to talk to your healthcare provider. If we have the answer or the pill, Heather, I'm giggling. I she'd be the first one to tell you.

Heather Kennedy:

I just want one drug that works for everything, that's all. Oh, yeah, I'm trying to look really stupid smart with my virtual library. Hello, anyway, the drug that I see most often is Epigone. Something is ending with that lately because it's stretching the life of my Sinemet, which loses this efficacy over time. And it turns out that in greedy mythology, the Epione is a soothing character. Figure all these wonderful names of medicines. But the real problem is that we have so much grief and loss. I mean, how do you reconcile or even lose? Or can you maybe reconcile it, or because there's really no way to give it meaning and purpose? Sometimes, it just is part of life: the agony and the ecstasy.

And so, we find ways spiritually or mentally, or maybe emotionally, to try to deal with that, like Kat was saying, call a friend. You talk with people you read here; here we are. Right now, this is a support group. So, thanks for this.

Tom Palizzi:

Yeah, no kidding, exactly. I think that's really important, too.

Robynn Moraites:

Yeah. I'm sort of a delayed processor. It takes me time to really recognize how I'm feeling. I usually try to deal with my problems with efficiency and efficacy, like there's a solution to this. I just haven't found it yet. And so, it's taken me some time. But all of you know, I lost the marriage, which actually, in hindsight, it was a blessing. Thank God, I'm so much happier now, and I have a really wonderful partner. But, you know, I attended a talk by an Olympic athlete the other night, and he was talking about his physical body before he was ever diagnosed. He was talking about the changes that he noticed in his performance.

And it's weird that it's been so many years. But my ex-husband used to criticize me all the time, saying that I was lazy and that I wasn't trying hard enough because of the metabolic component, not the tremor, but the metabolic fatigue component. I couldn't exercise the way my friends could exercise; I would get winded on any kind of hike like unbearably winded.

And I remember, even at the World Parkinson's Congress. I was walking in with the woman to the convention center. She was a presenter and a Md. Or whatever. And she said, wow, I wouldn't even know that you had Parkinson's, and then we started up, walking up that dinky little hill and stepped to the convention center, and we were like halfway across the concrete slab, and I'm sucking wind. And she said, oh, now I can tell, and it's weird. But I get comfort from knowing like.

When Amber said that she was relieved, like, there's an explanation for what's going on, and it's so interesting to me that so much of what my husband used to criticize me for, and I can make give you a long list, which I will not, But they're all symptoms. They're all symptoms of the disease, and there's nothing kind of fundamentally wrong with me. as a person and as a soul. As you know, it's essential for me to try to unlatch Identity from my body.

Doug Reid:

Crystal mentioned in the chat that she broke her hip last year, and getting back has been very hard. I can sympathize with that. I broke my leg on March 31, and it's really kept me from exercising. And for those that don't know, I've had a couple of other surgeries on my other foot, and it's been almost seven months now of just idle time waiting for the healing process to go. And it's hard. But you have to stay positive. You have to remain optimistic.

Tom Palizzi:

Yeah, did you have something? Okay? Amber does. Okay? Sorry, Amber.

Amber Hesford:

So, I think I'm the opposite. I've never considered myself an optimistic person. But I think. Never have I ever considered myself an office person, but I hear from people all the time that I handle it so well or that they can't cope with the way that I do, but I think I just do it on a lighter end, making fun of it because that's just the way that I cope with things. And at the same end of it. Oh, I lost my train of thought; it disappeared. Does that ever happen to anybody?

Kat Hill:

Oh, it's not; I want to ask you a question because I love you. I have found your what do they call TikTok, or your reels, or whatever so funny and so right on that I how do you turn to that? I mean, I just I'm just so impressed by that. So, I think you have a great sense of humor, at least a

sense of humor that really speaks to me, and I find that amazing, and the fact that you had that, like right off the bat, has really been inspiring to me, and I think to a lot of people. So, is that always being your way?

Amber Hesford:

Yeah, I feel like whenever my dad has told me something serious. He's always halfway laughing. I just don't think that we know how to cope with things. He'll be telling me something horrible, but he's got a smile on his face, and I'm like, are you kidding, or are you serious right now? Like, I don't understand what's going on. And you agree, deadpan. Yeah. So, I think it's just the way that we do things in my family. But yeah, I think that's one of the things that's helped me is making jokes about it, laughing about it. I mean, it's not funny to most, but I mean, what else can you do? If I'm not laughing, I will sit there and cry.

I mean, I have. I know a lot of people think that all I do is joke about it, but I mean, there have been days where I've been really dark, and the apathy kicks my butt daily, but the depression has crept in there once or twice, and that's hard to. It's hard to kick. And I think that I know a lot of you have talked about grieving the past, but I think I don't think I've done that. I think more. I try not to think too far into the future, which is what helps me. I try to look for a session I look forward to. But not to look too far into the future cause. Then I started like, oh, my God, how bad is it going to be then, or and I will spiral quick with, yeah.

Kristi LaMonica: yeah, me, too. And amber. I want to add something to that because I think that's important not only in that.

Chris Krueger:

It's helpful in thinking about things like injuring your leg, for if I've sprained my ankle all the time, it's like it's like a regular occurrence for me. And if I think about it, if that happens. And I start thinking about all the things I have to do now because of my ankle; I get really bogged down. And so, I think that's true, for thinking about Parkinson's generally, but also in specific instances, like, you know, when Doug broke his leg or when.

I'm sorry, I forget the name of the person who said they had broken their hip, but that thought in those instances if you start going too deep into the future. You can really get trapped. And I think it's having to be kind of one day at a time and try to move forward incrementally.

Brian Reedy:

And adapt to the changes as they come, and sorry. I think somebody, maybe with Brian, were you about to? Did you raise your hand while I started to talk? No, you're great; that's not an issue. I wanted to echo what Chrissy said because I think it's so important that, you know, this is

part of our brain change. It's not something that we're necessarily bringing upon ourselves. It's within the chemistry of the brain also.

So, there's a lot of aspects to it. But I think that's really important. And then with getting treatment, I think the biggest thing that's helped me is not so much just the antidepressants or whatever. But it's to have therapy to have somebody to talk with about the challenges that getting that out there and finding a psychologist is like dating. You know, you're going to have some really bad ones. And you're going to have some really good ones. And I've heard people say, oh, I tried once, and it was horrible, and that's their whole take. It's like, no, you've got to try again, and it's okay just to make one appointment. And yeah, that's not for me.

But that's really important. I think, along with the medication, it's kind of what Kat was saying about. You know you have to do the work with the exercise, and for me, at least right now, with the level of depression I'm dealing with, to have a psychologist to talk with really help. So, I just wanted to echo some of that kind of because those all-tie in.

Kristi LaMonica:

So, when I was trying to find my first psychiatrist, I never actually found one. I ended up finding this community. So, it brought me to some local people that brought me to some more people, to some other people. And finally, here, I mean that just kind of worked out for the better.

Tom Palizzi:

Yeah, I responded to someone in the chat a few months ago that was saying. You know, they don't know where to go, that they were diagnosed just recently. I think she said she was in her early sixties. We got a couple of grandkids. That kind of thing, I said, reach out to us, reach out to our ambassador group. That's really what we're here for now. We don't pretend to have any of the answers, and our answer may not be the right answer, but we can guide you somewhere to help you get some help with that. So again, feel free to tap into this network. Like Kristi was saying, it's very invaluable.

And I want to be clear. Not everyone is an optimist. Right? I mean. We all know that. But the whole idea about humor. It really cracks into it. Well, and I've always enjoyed that part. That's why we've always been around our house has been. You know, making jokes about it, and sometimes they're not funny, but they are. They are funny, in a way. So, I just it's helped me come to terms with my mortality, you know. I think that's important. Also, to understand that this disease is not going to go away. It's not going to get better.

But I have a lot of life left to live, and I'm going to try to keep doing the best I can. And so, you'll hear us talk a lot about exercise. And I want people to understand that exercise isn't necessarily always just about your Parkinson's symptoms. And again, it's just your motor symptoms primarily; although it does, it does help with your non-motor symptoms. But exercise is also



about keeping you in somewhat better shape to survive all the other things that you're going to get hit with. So, I preached that for years and got hit big time this year.

So, and that's helped me keep my feet on the ground, my head in the air. And you know I wake up in the morning, and I'm seeing, I'm seeing flowers and not roots, and that's important to me. So, anyway, not roots. Heather?

Heather Kennedy:

For someone who's been through so much. Hell, you're looking good, Tom. I'm really impressed with you, and with your grace and perseverance, you've shown really impressive. There are also some things that are harmful to us, such as you look great, though. Oh, you look so young, or how about when? When there are certain things, people will say, "Oh, I just exercise it hard, and I go off my meds. You just need to exercise differently. You might be. Why did you just say? Come again? I'm like, heck! How long have you had this disease? And do we have the same?

I don't think we're talking about the same thing. It's super that easy. It's like, see, I never thought of that, you know, or they'll say, just change your diet. There's a guy on the Internet who's very outspoken about this. I can't say any names, but I've challenged him many times, publicly and privately, and he just keeps coming with it. It just says all you have to do is exercise. I go. Okay. Yep. No problem, man.

I give up. So, there are things. Who, what are some things that have been tossed around you all?

Kat Hill:

Cinnamon on my feet?

Kristi LaMonica:

What? Yes, cinnamon on my feet. What's the explanation for that one?

Kat Hill:

For symptoms

Tom Palizzi:

Sinemet or cinnamon and drink? Yeah.

Kat Hill:

Just that they offer, or that you don't look like you have Parkinson's, I know, and that yeah, and I don't know quite how to answer that. And I, you know what I like to say is, if you think I look good now, you should have seen me before, Parkinson. I mean, how do you answer that? You know? Thank you. I mean, I don't. I don't know. I don't know. It's interesting. It's, and it's very common, and I think people don't know what to say. And so, they feel like that might be a compliment. And yeah, but I do like, I like all of the suggestions that people have; people mean well but don't always come across well, doesn't always come across. Well.

Kristi LaMonica:

So, my two favorite things were. Once I was. I was going for my first mammogram, and the nurse said, "Oh, you should have parties! Oh, oh, thanks! My brain didn't get the memo left off the message. And then my cousin emailed me and said, oh, I hope you get better soon. Yeah, I'm going to get everything. Don't worry.

Kat Hill:

Right, right? Or isn't there a medicine for that, or and I think it times too? I don't know if the other panelists feel that way there. There are times when I have the energy to try to share information, like it's partly being an ambassador. Share information about what it's like to have Parkinson's. I like to say that to anybody that'll say it. But you don't look like you have Parkinson's. And I said, well, there's a lot more Parkinson's of looks. Then, you know. Then also is what I'll say. But there are other times that I don't want to discuss it, right? I don't want to take on the education of everybody and cause that's exhausting. It is exhausting. I think it's constantly having to explain when you don't always have a lot of energy already to be out at the market and shaking, and but oh, you can't have Parkinson's. I don't have the spoons. I just came to get some rice and beans and some broccoli.

Kat Hill:

So yeah.

Kristi LaMonica:

I was just telling somebody that it's

Amber Hesford:

Sorry, Kristi. I was just telling somebody that Parkinson's is so hard because. You have to have a disease that you work at because you have to educate because there are so many people that don't know anything about it, or say stupid things, or ask questions that could be hurtful to some people. So why couldn't I just get a disease like I don't know that everybody knows about, so I don't have to answer questions all day, and you know we're all here as ambassadors, or you



know, trying to raise awareness or working in advocacy. But could I have gotten something that I didn't have to work so hard at? Careful of what you wish for. Right?

Robynn Moraites:

Sometimes, we are frustrated with that, too, just the level of effort it requires to deal with the disease. Sometimes I'm just like, Oh, my God! Can I just live a normal life? My biggest frustration is I just feel like I have to start going to speech therapy soon because, depending on the day I'm sick, my tongue or my mouth isn't working, or I'm starting to choke and have swallowing issues, or I sound like I have a frog in my throat because my vocal cords won't close.

You know, and it's like I've been to, you know, physical therapy off and on for years. Now, I have to start speech therapy, and it's like it's really frustrating that you have to spend all this money and go to all these therapists to do what you used to take for granted. That's really frustrating to me. It gets very aggravating.

Tom Palizzi:

I think that's why they say Parkinson's is a life sentence and a death sentence. People told me that when I was first diagnosed, and I kind of took it to heart, and I get it now. The other thing I wanted to add to that real quick is Parkinson's is the kind of disease that you can sort of keep up with as you need to learn about it. You can learn, and it's kind of nice. I think it's a gentle pace as opposed to some of the other things I've dealt with this year. It's like getting run over by a train. You don't have time to read about it. You've got to make a decision in a split second to save your life or to save your integrity in some cases. So that's why I really came to appreciate Parkinson's this summer because I didn't. I can. I was thinking I was having fun living with Parkinson's. I don't like this other stuff.

So there, I say that. But it's really kind of how I felt then as I was coming out into the fall. But anyway, Brian.

Brian Reedy:

I just wanted to say one of the things about looking at Parkinson's and somebody saying, you know, you don't look. You look good today or something like that. I usually just say, well, the meds are working really well. But also, I think, to avoid some of the rabbit holes that we've talked about here, I got taught this by somebody in the Davis Phinney group here. But avoid the use if you go down that hole; that's just a hole, and it's just going to go down deeper and deeper, like what people are saying about looking towards the future. That's the most important thing. And then talking about the speech. I'm so glad that you brought that up, Robynn, because I've done speech therapy in the past, and it is to me.

It's the hardest thing to do. It's harder. But it's also the most worthwhile because it teaches you to swallow better. It teaches you a lot of proactive stuff, and like. Now I'm getting the tongue tremor, which I don't know if any of you have had that cause. You get tremors all over the place. But it's really weird cause I start to say a word, and then my tongue gets stuck up there, kind of flapping away or something. But speech therapy helps. The last time I had that. So?

There's just a lot of benefits to that. So, I just kind of wanted to echo some of those thoughts. And then the last thing because everybody's talking about how it changes things. That's the one comment I made as I noticed things changing. I remember Michael J. Fox saying, Parkinson's is the gift that keeps on taking. Yeah, you look at it lightly.

Tom Palizzi:

And are you that?

Chris Krueger:

So, I want to jump back to something that happened that somebody mentioned in the chat, which was the complication of differential diagnoses and how to navigate that level of uncertainty caused. Not only does Parkinson's keep taking, but what it takes can change. But at some points, it's not even clear that you're dealing with Parkinson's directly. Maybe you're dealing with an atypical Parkinsonism. So, I'm wondering if anybody has any perspective on that. I would just say one quick thing: it looks to me like that's a future-looking consideration on some level. Right? What exactly is the diagnosis in some sense? I don't want to say it's irrelevant, but you can take action today regardless of what you know with certainty or don't know with certainty. And I think that it's so challenging when you're faced with uncertainty on any level, and I'm just wondering if anybody has any perspective on how to navigate those sorts of uncertainties.

Brian Reedy:

Well, now, with the back troubles that I'm dealing with and the impairments that are happening because of it. And it's kind of begun a cycle. It's hard to know what's Parkinson's and what's the back cause. They found a piece of my desk. Just get wedged into my nerves, and, you know, go away or not. But that's that. But then I'm having difficulties walking and having all these other things. And it's like, Okay, so what's Parkinson's? And what's not? And you know. Nobody can answer that. But at least I have that dialogue with my doctors and my sorry, my neurosurgeons and orthopedist, as well as my MDS. And then we kind of find that medium in between, and the best thing is, you know, when you're in doubt, just talk about it. And at the same time, physical therapy works on both avenues. So, it's because you can't always differentiate. Sorry, yeah, Kat.

Kat Hill:

I just think it's really important that if things aren't feeling right or feeling better, or we're taking the advice of our providers, and to keep speaking up, we need to be our own advocates. We need to be our own scientists. We need to, not if we aren't getting relief from the tools that we are trying. We need to ask for more tools. And I think that sometimes even ourselves we tend to say, Oh, it's just Parkinson's. Oh, it's just Parkinson's. Well, it's not always Parkinson's; you know we are. We have definitely in our logic system, and it might be Parkinson's. But if things aren't better with the usual Parkinson's tools. It's important to keep bringing it up.

It's important to advocate for yourself in a clear, concise, and consistent manner because we will have back-to-generation. If we're old enough, we live long enough to have an older back, right? If we get the privilege of old age, we will probably have vision issues if we will. Probably if we live long enough with Grace, maybe we will get things like other chronic illnesses, you know, I'm trying to. Instead of dreading that process and dealing with it, be sad with every process I'm trying to remember. It's a privilege that I've made it to 50, some odd years old now, right? Yeah, I'm trying.

I'm sad about it. I'm sad that I added that I need to go from the smaller pillbox to the giant pillbox, and I still have that my symptom that I'm learning a lot about off time. But I am still grateful to be here, and I'm grateful to be able to try to contribute. And so, I'm trying to learn the balance of grief and loss and also trying to move forward with having goals to help some of the apathy. Does that make sense? Putting something, scheduling something with family eating the ice cream some of the time? I mean, I'm really trying to do less dairy and sugar. But gosh! There's nothing like a little, a soft serve very clean.

Kristi LaMonica:

Even if it is PD, you shouldn't be satisfied if your meds aren't working right. If things aren't working right, you should always go and check with your doctor because there are always other meds that can be added on; in addition, let's say you're already taking.

Tom Palizzi:

When you meet with your doctor, it should be a conversation, not an Oh, please tell me what I need to do kind of thing. I've always held that tag, and I've always interviewed my doctors before I even go to them. I'll have an established care meeting with them so I can understand that they understand me. And that's so important. That's so important.

So, when you go to your doctor, you're talking to them about what you want to do, what I want to do to them, and I want to help me get to this place if possible, and that's been a great deal. So, when I was diagnosed with pulmonary hypertension this summer, I was like, how the hell do I get that? I mean, how does that just happen to me? I think I see this coming.



And my neurologist from my MDS. Said, well, I asked her. I said that this could be related to Parkinson's. She's no, are you sure? She stopped for a minute, looked at me, and said, how can it not be related to Parkinson's when it really deals a lot with the diaphragm and the stiffness of my diaphragm and being able to breathe? And she's like. You know, you could be right. I'm like, why, I think I might be right because I mean. I don't know, doctor, but I am a doctor; I mean, I have. I have learned this. This is my life.

It's my disease, and I tend to really dive in deep into what could be affecting me. So, we've had this ongoing conversation. I really like it. She's a great girl. And then, we really try to study this and figure out if it can be a problem related to partners. And so

Heather Kennedy:

It goes a lot to what you said earlier, Robynn, about not being able to walk up a hill.

Tom Palizzi:

I couldn't go 10 feet without losing my breath this summer, and I've never been like that in my life, and I thought something couldn't be right here this, anyway. I remember one of my very first webinars with you guys. We're talking about exercise, and someone put in the chat.

Robynn Moraites:

Can you exercise when you can't even breathe? I just remember that chat. I think Kat read it out loud, and I've always thought of that.

Tom Palizzi:

I definitely think it. It is breathing obviously is connected to Parkinson's. We all know that it used to be when I was younger. I described it like this: if I start to run. My body takes off running, and my heart and lungs are going. What are you doing now? Let's Catch up, one step behind my brain.

Heather Kennedy:

Right?

Tom Palizzi:

I liken the whole thing with a pulmonary hypertension is not much different than what I'm talking about that. But anyway, I think they are. Somehow, I think they are somehow connected. But then you just deal with it.

Heather Kennedy:



Like when your knees remind you. Do you know how old you are? What do you think you're doing? Get off the trampoline? You're going to pee your pants. Wait. I'm already ping my pants, not even on the trampoline. Yet what is happening? Like? It's like we're aging faster than our peers. What's happening, guys. And yet, there's some fun stuff that you can do.

You know, I mean, when life gets shorter, don't you take more risks that are actually kind of fun? I'm not talking about jumping out of a plane, Joanie Lowe; I'm talking about like, you know. Just the little things like the kid that said he loved me, though they'd walk on the street. I was like, how great is this? Now, we can savor things more.

Robynn Moraites:

I found that to be true. I think I've been misidentified as an optimist because I have, you know, taken advantage of the silver lining of Parkinson's. I am as pessimistic as they come, and my sister is as optimistic as they come. And we realize she saw a documentary on it, and it's like optimists don't want to know the obstacles they just feel down the road. They feel like they'll be able to encounter them when they get to them, and if you give them a lot of information upfront, they get very overwhelmed and depressed.

Pessimists are the Opposite. They want to know all the bad information that's coming so that they can plan for it to overcome it. And so, I think that I am a pessimist by nature. I'm in a pessimistic job, and that's what fueled my wanting to be a ten on the scale of learning as much as I could try to force, stall, or avoid what I could, and I do think there's a lot to be said for diet and exercise. If I hadn't done that, I would have been in way worse shape when I first got diagnosed. But there are limits. If it were only diet and exercise, I would be healed. So, there are limits. It does help, but there are limits.

Tom Palizzi:

I think that's definitely the case. And I think we all experience it. We're going to experience it. And there are a couple. There are some like the silver lining things that you talked about. My silver lining is the pace with which my life goes today. It's slowed down so much. and that has also taken a lot of my workload off because I simply can't get it all done in a day. So, it doesn't. If it doesn't get done, it doesn't need to be done just the way it goes. So, thanks; my eyes are on that one for sure. And it's been nice in that sense.

Chris Krueger:

So, I think we're getting close to the magic hour, or another few minutes we're approaching. I want to jump in with something that I just learned from Heather like right now. I learned something just in this very moment because Heather just made me laugh when she said something like you're going to pee your pants or something. I did not expect that to be the next



words that came out of Heather's mouth, and I just realized that one of the things that you know, since this whole conversation was premised on someone observing that.

You know, our humor sort of sometimes makes it seem like we're experiencing something different than some other people who live with Parkinson's. But I think that it might just be a way of approaching the unexpected because that's if you can. If you can find pleasure in something that comes up with those surprises, you like what Heather just said to me or not to me, but to everyone, that's where humor comes from. Maybe I don't know if that's true, but it seems like it might be that humor is when something surprises you, and if you can maybe laugh at the things that Parkinson's does to you when it's appropriate. I mean, sometimes it's not funny at all, but some of the surprises are kind of funny, like when you.

Well, for me, I drop things all the time, and I need to learn to laugh at that because it's always taking me aback. You know I do. My laundry takes me about an hour and a half.

Tom Palizzi:

Really good points. I have the same thing. My favorite thing right now with partners is disconnection. If you haven't noticed, that's why I'm moving all over the screens. But when, especially when I talk to them faster, I talk more and move, it is really kind of fun. But the best thing about it is. It's one of the best weight loss programs I've ever dealt with. So.

Brian Reedy:

So, as you say about Chris's comment about what? Where things just come in. And suddenly, I was in the hospital, and the nurse was going to perform something, and she had to get something really quick, and she had all these needles and stuff on my chest. She's holding real still. I'll be right back, and, like my wife's been telling me that for years, because anyway. I think that's the humor, is. It's just. It's having to be present in your thoughts that you can't take everything too seriously.

Robynn Moraites:

Yeah. You lose the perfectionist real quick. Don't sweat the small stuff; don't sweat the small stuff. Amen. Well said. Well said, and it's all small stuff, right? So much of it.

Tom Palizzi:

I think that's part of it, too. With Parkinson's, you narrow down what's really important.

Kristi LaMonica:

I used to get stressed out about work and stuff. I don't really care. It's not worth it. It's not worth getting upset. It's not worth getting stressed out. Who cares? I turn off my like work,



stop at like 80'clock at night because you know what? Because I can't actually do anything past 80'clock at night because of Parkinson's. But I just don't want to. It's just I'm done. I'm done, so it's let me set boundaries.

Brian Reedy:

What one thing that I've been doing. You know, I do the laughter yoga stuff. And so, I've gotten really big into the laughter stuff. But I've just noticed people smile more. And so, when I see somebody smiling, just a really beautiful smile, and I don't care what they look like physically. I just say, wow! You've got a beautiful smile. I find that smile back from that just makes me feel 100% better. Just noticing nice things and saying something nice to somebody can really get you out of the humdrum.

Heather Kennedy:

Dopamine, Sinemet, the release Doug mentioned. Those are the small stuff. Author Richard Carlson was on a flight in some 2,006 when he had a blood clot and died instantly. So, it's true, and he lived full-on. I've met, I've met him before, and he really lives. So, you know what it's all about now. We don't know when we're going to go. We don't know what's ahead. We know that we have a little P. We have more pain, and some people, maybe less than others. And here we are. We're all making this work. The human experience is extremely complex. And it's hard to have relationships. I will put a plug in.

For one thing, speaking of what Doug said about not swinging the small stuff. Get rid of things that you cannot carry anymore. That doesn't belong to you if you can. However, you can do that: emotional things, physical things, books, things.

Kat Hill:

House things.

Heather Kennedy:

I've learned a lot about that, stripping back to the very, very bare minimum. Whatever doesn't fit in the trailer doesn't go?

Kat Hill:

Right now, it's true, although we did just buy a shed. I appreciate you so much. And I really appreciate it. We want people to know we're really listening to your comments. And it matters to us what you think, and we want to be really there for you. So, we can never get to everybody's questions, but we certainly try. So, thank you.

Tom Palizzi:



Don't be at all shy about reaching out to us; our emails are on the Internet. Sogo to the Ambassador page, www.dpf.org, and you can find the ambassador that's near you or may have something in their expertise level that appeals to what you need. And that's a great resource, and we all love doing that.

Chris Krueger:

And if you can't find a way to get a hold of any of somebody you're looking for. You can always email blog@dpf.org, and that'll get to either myself or Sam, who has been awesome in the chat today. Thanks for that, Sam. I just want to plug in our next meetup, which is November 16. We'll meet again. It's always the third Thursday, and we'll get the recording of this published as soon as we can. And thanks for joining us; we look forward to seeing you next month.

Tom Palizzi:

Bye. Be well.

Kat Hill:

Be well.

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