

Living with Parkinson's Meetup

November 2023: Q & A

Davis Phinney Foundation

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

Chris Krueger (Manager, Educational Content, Davis Phinney Foundation):

Okay. Hello everybody. Welcome to this month's Living with Parkinson's meetup. I'm Chris Krueger, program manager for educational content at the Davis Phinney Foundation. And like our panelists, I live with Parkinson's. I was diagnosed when I was 37 in 2020. I'm excited to be here for another session of our meetup.

So, today, we're going to be doing a question-and-answer session, and we're going to pick up some questions that we've had in from previous meetups and some questions we got that are new. But before we get started, I want to ask the panelists who are here to introduce themselves and maybe share an answer to the first question of the day, which is one we received very recently, which is basically, "What did you look for what do you look for if you're pursuing treatment with a neurologist for Parkinson's?"

So, I'll answer that question real quick. I was looking for somebody who was active in reading current research when I was looking for my neurologist. I wanted somebody that was up on the latest information that was out. So, that was my answer.

And Heather, since you are the person I see on my screen right now, how about you go next and give us a quick introduction? What did you look for in your neurologist?

Heather Kennedy (Panelist, Davis Phinney Foundation):

Hi, Heather Kennedy. I'm living in the Bay Area with Parkinson's. I write as Kathleen Kiddo. I'm so happy to be here among this panel. I learned so much from every person here. And I want to add that part because it's really important for you to know that this is a support group for us. So, thanks for being here and supporting us, and thank you: We hope to support you, too. It all works together. It's a collaboration.

So, a neurologist, I think part of that answer implies or includes the fact that we have different needs at different times. And so some neurologists are really good at being the first one in with the new people, and they can offer resources. And that's what I would look for. I would look for someone that really knows that you need a whole team that doesn't just say, "Hey, you have Parkinson's. Bye. Here's some drugs." I really wanted someone that could, and I didn't get that, but I didn't know what I wanted until later. So, for anyone who's new, that's what you want. You want someone who can build you a team, who's invested in you, who listens to you, and

who collaborates with you. The second question, second answer to that question is asking, oh, I don't know why that's happening, but happy birthday to somebody.

The next part to that question would be as you progress in your disease, you need different things. And so, I no longer work with my first fantastic neurologist. He was wonderful. But I'm on with a new neurologist now who knows a lot more about DBS, my brain surgery. And he has become my movement symptom disorder specialist just because it works out better for things moving forward. And he is better with the next range. Plus, I think he might be learning from me a little bit, not because he's not seasoned, but because we can learn from each other. I'm kind of a case.

And then the last part of that I want to answer real quickly for everyone listening, is that it's really important to have someone who has compassion. It doesn't matter what gender or where they're from or whatever, it doesn't even matter if you agree with them, but to have someone who can just pause and realize that you're a whole person with a family and that you have very specific needs that will be changing. So, that's just what I looked for. I hope that answers the question.

Chris Krueger:

Yeah. Thanks. Thanks. Kristi, why don't you tell us where you're coming from and what you looked for, please?

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

So, hi, I am Kristi LaMonica. I'm in Troy, New York. So, it's really interesting here. We don't really; I was, oh, I was diagnosed in 2020. We don't actually get to choose our neurologist here. If you go to the hospital where the main office, so at Albany Med, you don't get to choose who you want to see, but I end up being lucky enough that I ended up with a really awesome movement specialist who is really responsive to everything. So, I can email him at night, and I'll have an answer by the morning. We constantly adjust my meds. This morning, I went for ON-OFF testing for DBS, and he's awesome. So, I really lucked out. So, and that probably doesn't help. Everyone can't be as lucky, but I really lucked out.

Chris Krueger:

Good. Well, I'm glad you lucked out. That's great to hear. Okay. So, how about Kat? You're next on my screen.

Kat Hill, RN (Ambassador, Davis Phinney Foundation):

Okay. Hi everybody. Happy November. I am, let's see, diagnosed in 2015, and I am calling in today from Newport Beach, California. We arrived here yesterday. Let's see. For me, I think compassion is really big, but I really want somebody who's going to listen and hear me and give me feedback about what they hear because I really agree that having a chronic illness, you

enter into a collaboration with your care team. And I really want somebody who believes that as much as I do.

So, and it's taken some trial and error for me to find that person. And it's worth it for me to keep the neurologist that I have. Also, she's younger than I am. So, this is another key part so that they don't go off and retire on you. That's the other piece: younger than me and a good listener. How's that?

Chris Krueger:

That's great. Thanks. And Doug, how about you? Next, please.

Doug Reid (Ambassador, Davis Phinney Foundation):

Hi everyone, I'm Doug Reid. I'm zooming in from Lafayette, Colorado, about 45 minutes north of Denver. I was diagnosed in 2010 when I was 36, and I had DBS four years ago. What I look for in a neurologist—this might be pretty basic—but they have to be a movement disorder specialist. I think that's key for about six months, right around the time I had DBS. I saw a general neurologist, and I felt like he was letting me lead my own care. And it was at that point I decided I needed to go back to see a movement disorder specialist.

Secondly, because I've had DBS, I wanted my movement disorder specialist to be familiar with programming DBS and, specifically, the Boston Scientific model that I have. And he's been great.

Chris Krueger:

Good. Thanks, Doug. And Brian, how about you, please?

Brian Reedy (Ambassador, Davis Phinney Foundation):

It's interesting. I had mostly, I look for the neurologist, that movement disorder specialist who—sorry, I'm having a tongue tremor—who listens and responds. But I got really spoiled here when I got to Southern California. Because I'm with the VA, and my doctor with the VA, who's amazing, said she doesn't have enough time to help me with a lot of problems, I was having and that I should also get an outside one and then she'll still do the medications and stuff. So, what I discovered is I have a neurologist now who has a nurse navigator and a social worker on her team. And so, I had a movement disorder meeting with my movement disorder specialist last week. And I wasn't looking so good because I recently had a bad fall. And so, they were looking at fixing my back, and then I fell, and I hurt my knee really badly. She saw how bad I looked. She knows I live alone. And she had her nurse navigator and social worker find a place where I could go into rehab. So, I'm at this amazing rehab center now for the next couple of weeks. And they're fixing, they're paying attention to my speech. So, I got a speech, neuro, a speech person, whatever, an occupational therapist, and a physical therapist. But that's all because it's a team right there in that office. So, it's pretty amazing.

Chris Krueger:

Yeah. That's great. Brian, I'm thankful—I'm glad that you were able to have somebody that was so attentive to you. That's, and I'm glad you're in a good spot. And I hope we can maybe hear some more about that as the meeting goes on. And let's get Kevin, though; you're last on my screen.

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

I am muted. So, I agree with pretty much everything that everyone on this panel has said. Oh, I've had the luxury of professionally working with a lot of movement disorder specialists. So, it gives you the chance to really compare. And two things I would say from that is that the neurologist you start with may not be the one that you want to end up with currently. The one piece of advice I got was when I recently attended an award [ceremony] for a lifetime achievement award for a neurologist who's being honored for his lifetime work. And the keynote speech he gave when he won the award was what I have learned from my patients over 40 years of listening to them. And to me, that really hit home because there was a neurologist who would probably have seen every kind of patient you could think of, but still was saying that every day, I learn something new from my patients. That's the kind of neurologist I want- one who's curious, inquisitive, and caring. So, I put that as sort of my criteria.

Kat Hill:

You're muted.

Kevin Kwok:

Am I still, Chris?

Kat Hill:

Chris, you're muted.

Chris Krueger:

Sorry about that. I have a little microphone here, and it's not, uh, having a flashing light I didn't see. So, thanks, Kevin, for wrapping that up for us—a good summary.

So, we're going to do a question-and-answer session today, but I know Sam has put it in the chat already that we're not offering medical advice. It's not our wheelhouse, but we do have practical advice. So, just keep in mind that some of these questions that we get are sometimes hard for us to answer because we don't have all the information and we don't—everybody's circumstance is different. So, please don't take medical advice; don't take what we say to be medical advice. And please follow up with your care team and make sure you follow what they are telling you because they know your circumstances better than we do, for sure.

I want to start us off with some questions we've received recently. And one of them that came in that was interesting to me was, it's pretty broad, but I'm just going to see what we have, what we have to say about it. The question was basically, there are so many options, pharmaceutically and the dosing seems to be a kind of moving target. So, besides just consulting with a neurologist, how did you navigate the variety of pharmaceutical options and also, how did you deal with the dosing issues, and how did you zero in on any advice on that crystal ball?

Brian Reedy:

I wish that I had completely trusted my neurologist.

Kristi LaMonica:

I keep on going OFF, so apparently I'm not doing it right.

Kat Hill:

There are lots of right ways, and everybody's body is different, right? I held off on meds. I was very frightened at first to start medication, and I wish in retrospect that I would've started earlier because I could have maximized the window of time where it would work the best for me. But I think it's an individual ride. I think each of our bodies are really different. Each of our histories are different. Each of our symptoms are different. And so, I think you have to be your own expert, and you've got to be your own scientist a little bit around this. And know that there's a lot of right ways to do things and that, yourself, too, is how you are feeling honest with yourself. Right. And let your provider know if you're not feeling well; they can't know if you don't let them know that you don't feel well and keep at it. And it can be such a frustrating up-and-down process. Talk Kristi.

Kristi LaMonica:

Oh yeah.

Kat Hill:

Yeah.

Heather Kennedy:

So, depending on how you let them know, it can be helpful or not. For example, my chart looks like a Shakespearean tragedy. "I'm at the edge, Doc; I'm calling you from the edge. I'm not sure I can go on. This is much too hard. I can't see the road ahead of me. It's dark out here."

Kat Hill:

And simple, succinct words, right, Heather?

Heather Kennedy:

I'm a poet in there. And they're looking at it. The people at the front desk are going—I can see them looking at me when I'm coming in: “That's the one who writes us really weird messages.” So, keep the facts in there if you can. So that your doctor doesn't get flooded, and they don't have to translate. I was just mentioning that.

Brian Reedy:

Well, and if you do look online, make sure you're looking at reputable sites and be careful of forums where people are just dishing out their own feedback and things that aren't substantiated. So, it's very, very key that you look at the right place.

Chris Kreuger:

Yeah, we have some resources about that.

Heather Kennedy:

Sorry.

Kristi LaMonica:

Just because someone has experience with something doesn't mean that you're going to have the same experience. Everyone is different. Like Kat said, everyone has their own symptoms. Everyone responds differently. So, don't always listen to everybody else.

Kat Hill:

They don't even listen to us. I mean, listen to us a little bit today, but—

Brian Reedy:

Hear us but take it your own way.

Kevin Kwok:

I think you should keep a log. You take your meds, then you see how you feel, how fast they kick in, how much control you're getting, and what situations are happening that make them not work as well.

Kat Hill:

There are great tools out there, huh, Kevin? There are digital tools, and then there's old fashioned tools like writing it on your calendar.

Kristi LaMonica:

Right?

Heather Kennedy:

Did you say reading?

Brian Reedy:

When Kevin said that I forgot my neurologist when I first got diagnosed had me write down how I was doing throughout the day with it. And that's how we were figuring out the dosage and figuring out actually the medications. Because then we had to switch. So, that's a great one, Kevin.

Chris Krueger:

So, there's a side question to this or a secondary question, which was a question about whether starting levodopa or any treatment earlier is better. Kat, you already talked about that. Does anybody else have a perspective on how you experienced starting immediately or not starting immediately? What do you think about that?

Doug Reid:

I didn't start meds immediately because I wanted to be involved in clinical trials. And I did that for a few years. And then, my symptoms got so bad I had to bow out of a clinical trial that I was in and start on meds.

Chris Krueger:

I'm in the exact same boat, Doug. I didn't start medication immediately, specifically because I wanted to be in research, and I didn't want to be excluded from trials. But that was just me. As soon as I was not able to exercise as hard as I wanted to, I started on medication right away. That was me.

Brian Reedy:

Yeah. I would say it depends. I'm sorry. Go ahead, Kat.

Kat Hill:

No, no. I was just going to say, too, that I did clinical trials also, and as soon as it started impacting me, not being able to go to my exercise classes and work out hard, I did the same thing. That was my tipping point to start meds.

Doug Reid:

In addition to Kevin's point about keeping a journal or a log, I think it's important to keep a routine. So, you're taking your meds at the same time every day.

Chris Krueger:

And Kristi, did you have something you wanted to add?

Kristi LaMonica:

I ignored my symptoms for so long that, when I was actually diagnosed, I needed to take meds right away because I was diagnosed within minutes. Yeah. I went to the doctor.

Heather Kennedy:

Right? The first several doctors that I went to told me that it was all in my head.

Brian Reedy:

Oh.

Kristi LaMonica:

So, you met my OCD.

Heather Kennedy:

When I finally did get it right, it turned out they're right. When I finally did get diagnosed correctly, I trusted the doctor, and he gave me it, he put me on amantadine and all this other stuff that I didn't need. In fact, my dopamine agonists for about four years were not cool. I didn't blow up any relationships. Everything's fine.

Chris Krueger:

So that's actually another question we had, which I'll just take a quick and a quick swipe at here, which is, someone asked this about dopamine agonist withdrawal and take getting off of dopamine agonist, which can be really tricky. So, one thing I want to say about that is they ask specifically what kind of symptoms happen associated with dopamine agonist withdrawal. Some of you probably have some insight into that, but this is really important, and you should really talk carefully with your doctor about this because it can be, it can have serious repercussions for health and relationships, and it can be a big deal. So, does anybody have any perspective on that?

Brian Reedy:

About getting off the dopamine agonist? Yeah. So, I had to do that. I had some negative reactions to it. I had obsessive behavior and whatnot. And we had to taper off. And my

movement disorder specialist was really good at having that taper down. And then she wanted to see me more regularly because we were tapering down. Because I was tapering down. So that's, to me, the best way to do it is hand-in-hand with your movement disorder specialist.

Kevin Kwok:

Yeah. My new neurologist says that with young onsets, he doesn't even try dopamine agonists. The issue of obsessive-compulsive disorders is so high, and he thinks it's highly under-reported. And I have to agree, having experienced that same thing,

Heather Kennedy:

Kevin, do you think that it's under-reported because many of the generations who are getting diagnosed with Parkinson's aren't used to discussing their emotional and mental landscape?

Kevin Kwok:

That's part of it, I think also as patients, we're ashamed of, some of the things we don't attribute to our disease as much as we think, "How can I be doing all of these things?" It's the admission that we're having problems. But I mean, I was not a happy person to be around during the period of the agonist. I would sit there and be obsessed with people trying to do things to me. And it was not a happy place in.

Heather Kennedy:

Been there.

Doug Reid:

And somebody's putting in the chat, I felt shame and embarrassed—that was me.

Kat Hill:

Big time. I did, too. Yeah,

Heather Kennedy:

Me, too.

Brian Reedy:

Same here.

Kat Hill:

And I'm supposed to know better, right? This, I'm the nurse, right? I'm the "care giver."

Kevin Kwok:

I'm the pharmacist. I should know.

Kat Hill:

I know, Kevin, you, and I right up there.

Heather Kennedy:

It turns out that when you're experiencing any kind of psychosis or drug reaction, you're not really aware of it because you're too close to it. You need some perspective. You need to pull back and ask one of your touchstones, perhaps someone that knows you really well and intimately, so that you can really get a key. It's not the same as saying, are you having your period? What's wrong with you? It's, "Hey, can I check my meds out here for a minute here? I'm acting a little bit different. I can feel it." But when your doctor says things, do you see any strange things out of the corner of your eye? I'm like, "I live in San Francisco. What do you think?" So, it's hard.

Kat Hill:

You're on Zoom calls with me.

Kristi LaMonica:

I have to say that I think that Larry Gifford's podcast with Vicki Dillon was really helpful. So, I knew what to expect. I knew what to look for. And when I noticed that there were too many boxes outside my house, I had no idea what was in them. I was, okay, it's time to come off. I'm done.

Kat Hill:

It helped that my movement disorder specialist had a discussion with my husband and I before we started on them. He really was my touchpoint, and I'm blessed to have him. He's still here, too. I'm blessed to have him still here. But he also was kind of watching for the symptoms because I had a heck of a time identifying it.

Chris Krueger:

So, that actually points to a couple of other questions that we had. And I'll go two questions that the same time that we got recently. And they're sort of related, and you'll see why. One is, someone wrote in that their husband is experiencing uncontrolled movement, and it's making his driving unsafe. What do I do, basically?

And then the second question was a little bit different but the same sort of theme, which is basically, what can I do besides putting handrails in and being careful to remain in my home as

long as possible, especially in the context of living alone? So, there are two kinds of practicalities of living with Parkinson's, questions that are a little different. Yeah, Kevin, go ahead.

Kevin Kwok:

I think you have to have a “come to Jesus” conversation with yourself. I still drive, and when I sold my home, I bought myself what I said was going to be my last car. And I've had such a great time with it. But I realized that there is another question in the list there. What I'm finding is sometimes, when I'm driving during the course of the day, I blink, and they don't open. And that's not a good person to have on the road, right? And so, I think you have to say to yourself one thing is your independence, but when are you going to become a danger to yourself or to someone else? And that's not an easy conversation to have. But I think it's really important that we all have a reality check on—I mean, I love independent living, but I do know that there's going to come a time when I'm not going to be able to do it. And I don't want to be told that it is time for you to go to assisted living. But I want to be part of that conversation. So, I would encourage everyone to be very objective about your safety and the safety of the people around you.

Chris Krueger:

Yeah. Kat?

Kevin Kwok:

Yeah, Kat?

Kat Hill:

I think it's a hard situation if you're the care partner that's observing the issue. And I have an uncle with Parkinson's disease and my aunt asked me, quote “the nurse,” to evaluate his driving. And I said, what I did is I went to the Davis Phinney Foundation checklist that talks about what's safe. I don't want to be the one telling somebody, somebody objective needs to help make that decision if he's not able to make that decision for himself, perhaps enlist the help of a, tool, like on in Every Victory Counts manual, perhaps enlist the help of your primary care provider or your movement disorder specialist. Because it can't always be coming from the spouse, I think. I think it's a tough, a tough thing. Are there kids involved? The other thing is that that can be powerful is to say nobody is going to ride with you while you drive. That's a powerful statement I've gotten before. Pardon me?

Kevin Kwok:

I've gotten that before.

Kat Hill:

But I mean, it's a statement or, "Honey, the grandkids aren't going to be in the car with you if you're driving." So, I mean, you can only own so much of those pieces. And as somebody's niece says, as somebody's daughter that have both given up driving because of Parkinson's disease, it's a hard thing to discuss. But I think it's part of that open communication that you need to be having.

Doug Reid:

Coincidentally, I had an appointment earlier today with an occupational therapist and the subject of my driving came up and she offered to give me a driving assessment. I didn't take her up on it, but I got a little nervous that she would find problems with my driving—

Heather Kennedy:

No pressure.

Doug Reid:

--encourage me to give up my license. But she said, my goal is to keep you driving as long as possible. So, tap into the occupational therapist resources.

Kevin Kwok:

I have a question for the people on the panel here. If you are driving and you get in an accident, do you jump out of the car and say, sorry, I have Parkinson's?

Heather Kennedy:

No, I jump on and I say, "What are you doing?"

Kevin Kwok:

Well, there, there's an issue of liability of admitting it. Right? And so, it poses the question for you to say, "Well, if I got in an accident, how would I feel if I hurt someone?" Because if you tell them that you are driving and you have a disease that can impair you are really setting yourself up. I'm curious what others feel.

Brian Reedy:

So, when I was having problems with, what was it? We were just talking about the medications that with the obsessive behavior?

Kevin Kwok:

The agonist?

Brian Reedy:

Yes, from the dopamine agonist. So, I had a, I passed out, had a seizure or something mild seizure or something with the dopamine agonist is what they concluded. And so, and I self-reported the accident because they, I hit a bunch of bushes and just whacked the bottom of the truck and knocked the mirror off. But I self-reported because it's scared the hell out of me. And so, my doctor had to sign off on me being able to drive every year for like five years. And that's kind of a good thing, but that's also kind of down the line. You want to get ahead of it more. And what Doug was saying, actually I'm going to have them do here at the center I'm at, they have a computerized thing that can test you. Because I've been looking at getting a new car and I'm looking at what the safety features are that can alert me if I'm doing something wrong. And is it something that I can see, like if it's just a noise, what does that mean? Is it a lane thing? Is somebody, too close? So, I want to see it. So, I've been looking for that kind of thing, too.

Kat Hill:

I think that's a good point, too, that it's not just about Parkinson's disease. There are other diseases that—our son is a type one diabetic, for example. And before he got his license, we had a lot of discussions around times when it might not be smart to get in a car. And so, if your blood sugar's low or a little unstable, that's maybe not the best time. We'd rather have you be late, not show up, not go to school, whatever. But get your blood sugar under control before you get in and operate a car because you're putting yourself, but you're putting everybody else around you at risk, too. Same thing with epilepsy or if you've had a seizure, same thing with Parkinson's. Same thing with probably Alzheimer's. There are cognition issues, right? So, I love the OT input. That was really great input and I love that they've got some, some actual tools that maybe can help you measure your response time. That's very cool.

Heather Kennedy:

Interestingly enough, I know a lot of cops and I do take the sobriety test before getting in my car every single time I drive. I do it because I want to know—exactly Kevin. Exactly. It really does.

Kat Hill:

I don't even know what it is. You're going to have to tell me.

Heather Kennedy:

Yeah. I can't wait. I'll show you. We're going to have so much fun on the dance floor next time we go out. Oh my gosh.

Chris Krueger:

So, I just want to drive home the occupational therapy point that Doug touched on, that an occupational therapist can help in so many ways at home. And they can even do a at home assessments, not at home, so to speak. They can do, you can walk them around with a be

careful if you do this, but you can walk them around with a camera and show that they can do it remotely or come to your house. So, just don't overlook the value of an occupational therapist.

And speaking of therapists that are sometimes overlooked, Brian mentioned speech therapy before and somebody had asked us a question about exercises that can improve swallowing. And I don't know if anybody has any perspective on things that have worked well for you when you've worked with a speech language pathologist. But anyway, did anybody have any perspective on exercises for swallowing?

Yeah, Brian, since you're doing it right now?

Brian Reedy:

Yeah, and I'm doing it right now. Because I told them about my tongue tremor and that I've had trouble swallowing my medications. And so, what they're doing is they're monitoring me because I'm in this facility. They're, they're monitoring me, it's an acute care facility by the way. It's not like a nursing home, but it's at breakfast this morning they were monitoring me. And yesterday I was at lunch and yesterday at lunch they caught a few things, and they said one thing I hadn't figured out is if you're eating and you're coughing, because you're clearing your throat, that means you're swallowing too fast or you're not having enough moisture in there. And so, you need to take a sip of something. And if water isn't working, then it needs to be something like a juice. (Or I got it. Yes. Thank you. No, okay.) Sorry. Hospital type stuff. But it's awesome to get that feedback from a speech pathologist. And then just the regular speech programs that they put you through are really hard. I found they were harder than any of the physical therapy I went through, but they're also extremely beneficial and they'll help you develop stronger muscles for swallowing, et cetera.

Doug Reid:

I just saw a speech pathologist last week and she recommended that anytime I sit down to eat, I take my spoon or my fork and press it against my mouth but forcing my tongue into it for a count of 10 and do that a couple times. Just pushing your tongue into a stationary object is strengthening the muscle.

Heather Kennedy:

I've done that before. So, anyway, moving right along. I think maybe for swallowing, too, maybe garbling also making the noises as if you were warming up for singing. Opening the mouth more and, obviously you need a mirror to do this because we don't know how we look. We can only see the people in front of us and so on and so forth. And I've also been told like a warm honey tea can help out, which is what my friend Mike does before podcasts. Many people get Botox in their throats as well. And that sounds really painful, but might help, I don't know.

Brian Reedy:



The warm fluids are a great one, too.

Doug Reid:

One of my fellow Davis Phinney Foundation Ambassadors told me that at his Pedaling for Parkinson's classes, the one person will ask a question and then they'll go around shouting out the answer. So, just shouting and repetitive yelling. Yeah. So, you could add that to your exercise classes. What's your favorite food? French fries!

Heather Kennedy:

If aliens came to Earth to observe us in that exact moment, what would they be like? Like the warmups for theater students.

Kat Hill:

I've been trying to sing really loud in my car. Just-

Heather Kennedy:

You're still married.

Kat Hill:

Well, I know, and I'm still married. I don't do it with Ken in the car. I sing it. You might check in with him later about how he feels about that.

Kristi LaMonica:

Same.

Kat Hill:

Yeah. Singing in the car, Kristi.

Kristi LaMonica:

Yeah. With them, or by myself. I don't need that. Mark doesn't need that.

Kat Hill:

And it's fun, huh? I find it lifts my mood, too, depending on what I'm listening to.

Chris Krueger:

So, this actually relates to something that I don't think we actually need to go, too deep into, but somebody sent us a comment a while back that said, do you know about drumming for

Parkinson's? And the answer is, we have some content about that on our website, but music in general can have you do some dual task things. So, if you, and that can be useful in a, in a variety of ways. So, drumming is a great thing to do for coordination and all that. Yeah. There he is. Go, Kevin. Go.

Kat Hill:

We need volume, man. Are you muted?

Heather Kennedy:

No, we want to hear your concert, man.

Kat Hill:

We want to hear your—he's got a drum, he's got a guitar.

Chris Krueger:

The drum at the same time.

Kat Hill:

Yeah.

Kat Hill:

Love it.

Chris Krueger:

So, I want to look at another question, a set of questions actually about sleep and mornings and difficulties with both sides of this.

So, we have three questions, and I'm sorry to do this to you panelists, but I'm going to ask three questions at a time. It's terrible of me. We got a question about nausea on waking and how do you deal with sleep issues that relate to that. You take your first dose of the day at, of the day and it makes you nauseous and then not only are you waiting for it to kick in, but you're lying in bed, and you're feel nauseous at the same time. That's one thing. Any tips on morning? Waking up in dose regulation?

Another question just generally about what do you do to get ready to go in the morning or do you experience fatigue that's more extreme? And then a question about falling asleep and having a hard time staying asleep. So, both sides of the spectrum and yeah, Kristi, go ahead. Take a, take a crack at it.

Kristi LaMonica:

Okay, so, I was having a really hard time sleeping and I take Trazodone now every night. And I was really reluctant to take it, but now I take it every night because it really helps me fall asleep. I fall asleep within like 10 minutes and if I get up, I go to the bathroom and I go back to sleep. It's amazing. I've, I'm so lucky that it works. I'm so happy.

Heather Kennedy:

Kristy, does it affect your ability to get to the bathroom? Safely?

Kristi LaMonica:

No. No, I only take one. I can take up to two, but two is, too much. One is like perfect. I can like walk, I can move like the same as I could before. Like it's not, I mean, I can't move very well at night, but I can get up, get up from, get, get to the bathroom. And waking in the morning, I have to wake up an hour earlier than what I need to because I have to shuffle to, shuffle to the, let the dogs out and shuffle to the couch after I take my meds to let them let myself come to life. It takes about an hour before I can safely shower. So, I have to build that in to like my morning routine.

Heather Kennedy:

Yeah. And some of us are going through menopause simultaneously, which is an extra special bonus. Waking up soaking wet—

Kat Hill:

Shaking, baking, and shuffling.

Heather Kennedy:

And trying to roll over and get out of bed soaking wet, it's like—ugh.

Kristi LaMonica:

Oh, great. Something to look forward to because if sweating profusely isn't enough.

Kat Hill:

Yeah. It's a glamorous life we have. Really.

Kristi LaMonica:

I know. It's so great. It's so sexy.

Doug Reid:

Somebody asked a question earlier in the chat about diluting carbidopa-levodopa in water? And my former movement disorder specialist, when I took carbidopa-levodopa, I'm off it completely now because of DBS, but when I took it, he recommended that I dissolve my first dose in water because he suggested that it would be absorbed faster.

Kristi LaMonica:

Mine said to chew it.

Heather Kennedy:

Also taking vitamin C or some sort of little bit of fruit juice or something that has a little bit of a pop to it. Maybe a little fizz.

Kat Hill:

Sparkling water. I think there's that carbonic acid, that little bit of acid in there may help it absorb.

Heather Kennedy:

Doesn't it get absorbed in the small intestine though?

Kat Hill:

Yeah, but it'll help it break it down. I think. I don't know, Kevin, you have to comment.

Heather Kennedy:

Yeah.

Kat Hill:

We need Kevin's specialty.

Doug Reid:

We're dealing with nausea. Maybe have some ginger snaps with breakfast.

Kevin Kwok:

Doug, you mentioned earlier having a ritual or something very organized. I find that in order to wake up in the morning, I almost go immediately into exercise. So, I have my ritual where I brush my teeth and do 50 squats while I'm brushing. And then afterwards I'll stand on one leg because I've heard that mortality is tied to balance and those become the morning ritual. It's even before coffee now. It used to be coffee first, but now I do this just as I get up and I'm finding actually that routine works well for me.

Heather Kennedy:

Kevin, I wish you had a body camera or someone had a camera. Oh, that is awesome.

Kat Hill:

I'm thinking that that routine might lead to my mortality. I'm kidding. I'm kidding.

Heather Kennedy:

I say that most of—

Kat Hill:

I'm super impressed. Squat and brush. I'm super, that's amazing. Alright, I'm going to try it.

Brian Reedy:

Kevin, I'll, I want to step back, step back to one question. I wanted to chime in on that. I didn't have the word for now. I do. But for getting to sleep I do the melatonin, but I get it at Costco where they sell them that can go in sublingual, which is under the tongue. And so, I do two five milligram tablets under the tongue. And by the time they dissolve, I'm pretty much asleep. Because they get into the system so fast and it's all natural.

Kat Hill:

I have not, I have not figured out the sleep thing. My sheer exhaustion helps me to sleep better after course of five or six days of not sleeping well. Regular exercise helps me, a really good hard work out. But sometimes that can make me more dystonic. I think it's an up and down thing and I think, pardon the expression, yeah, the up and down thing. You got that Heather; Heather's cracking up. I always say I'm going to sleep later in my next life.

Brian Reedy:

Okay. Yeah. I think I miss a whole day, a whole night's sleep—at least once a week.

Kat Hill:

Yeah.

Brian Reedy:

Sometimes three times a week when I'm having a bad week. But yeah, there's nights you just can't do it.

Heather Kennedy:

That's why we have the insomniac gallery. How do you have so much time to paint Heather? Well, I have trouble falling asleep. I can fall asleep anywhere doing literally anything, which hasn't gone very well for my relationships. However, I don't stay asleep. I'm up at two and four and I'm just up all the time. You'll see me on Twitter or something in the middle of the night. I can't sleep, well, I mean, insomniac club because it's hard to sit still. You can't really do anything worthy of your time. It's not like you can do your taxes or something. You can't concentrate. So, it's empty space.

Kat Hill:

I try to be more accepting of it also. I think getting upset about it and staring at the clock hasn't been helpful. And so, depending on if you can build it into your life to take it, take a nap, and give yourself permission to rest a little bit the next day or maybe not expect so much from yourself the day after you haven't had a good night's sleep. Not everybody has the luxury of that. Many people have to go to jobs or are raising kids or have a schedule that isn't flexible. But if you do, maybe giving yourself some space around that and flexing a bit with it. I don't have a super regimented medication schedule or awake/sleep schedule. And I try to accept that my days are going to be different. I know like on our travel days, I need to be a little bit more scheduled. So, I'm careful that I give myself enough time in the morning to get up and get ready and moving and then to get in the car and I may need actually more doses of carbidopa-levodopa the day that we're traveling, and I have an agreement with my moving disorder specialist around some as needed dosing.

So, I think, again, we're back to that. We just don't have one, a one-size, one answer fits all kind of thing. There's just so many different ways to do it.

Chris Krueger:

So, I have a thing that works well for me and I'm curious, I'd love to hear from, from you all on the panel if you, and from anybody in the audience, if you try this with regard to staying asleep. It is, works like a charm for me. It's like magic. It's like a magic bullet for stay, for getting back to sleep. I breathe in for a four count. It doesn't matter how long it is, but I breathe out for a seven count. And just something about thinking fours and sevens because that's like adding four and seven when you do the cognitive assessments track. Yeah. Right. It's something about it just makes me go right back to sleep. It's like a, it's a godsend for me. So, if you try it, let me know how it works.

I want to jump over some to some questions about DBS tremor and dystonia. And I know a number of the, we got a bunch of questions about dystonia, but I'll ask one of them here. So, we got a question about someone who's a little hesitant to try or go down the DBS path. And they're being encouraged because of some, partially because of some dystonia. So, they're, they're asking for perspective on DBS for dystonia, basically. Anybody have any input?

Heather Kennedy:

I was someone stiff, not shaky. I can just say that I had not the subthalamus nucleus one, the GBI, and I couldn't lower my medications because it has a gone great for me, but that doesn't mean that it wouldn't work for someone else. So, I wouldn't be against it. Be aware though, that some of the aftereffects of brain surgery tend to be very close to a traumatic brain injury. I wish someone would've warned me about that first. But yeah, it does work for some people.

Doug Reid:

And I think from my experience with DBS and co-leading a support group, DBS from my understanding, is approved to help with tremor, rigidity, and slowness of movement. I'm not sure if dystonia falls in those three buckets. And I think it's a hit or miss if DBS will alleviate dystonia or not, unfortunately. Kevin, do you have any insight on that?

Kevin Kwok:

Yeah, I've been—my neurologist at Stanford even suggested putting a third lead in, which I didn't want to do at the time. I'm finding that all the adjustments on for my increasing dystonia aren't really helping. And I'm really relying on outside physical therapy to try to combat the issues with dystonia. I think there's, they're still learning a lot about dystonia and where it comes from and the origins. So, I don't think they have the answer. Some people tell me that they do with an adjustment, their dystonia goes away. But I don't hear that as often as I'd like to hear. I-I'm looking for the magic bullet for dystonia myself.

Kat Hill:

Yeah, me, too.

Brian Reedy:

Well, and it's, I have dystonia in the feet and it's interesting, I read recently that most young onset diagnosis for Parkinson's come because they have dystonia in the feet. But I get treated and I've been treated with this for five or six years now. Every three months, I get Botox in my feet. And that helps tremendously. And before that happened, I was in complete and utter pain. I was just taking the feet; I don't care. Yeah. It was so bad. And the Botox really helped. And I've been as to pose in feet magazines because they're so sexy now. So, kidding. Okay.

Kat Hill:

Yeah, I do the same for my hands every three months for my fingers. And it's spreading. It's starting to go to multiple fingers. So, yeah, I know Kev, that's, did you have Botox, Kevin?

Kevin Kwok:

Yeah, I did. Botox, fingers, feet, eyes, and parotid [gland] for drooling.

Kat Hill:

Got it.

Heather Kennedy:

Sorry. Can you tell them why you got it in your eyes? I don't think people know what you mean.

Kevin Kwok:

Oh, I get it in my eyelids because when I blink, the eyes don't open sometimes.

Doug Reid:

And you're vain about crow's feet.

Kevin Kwok:

Oh, there you go. It's all about looking good.

Kat Hill:

Look, at how beautiful he is! Look at that. It's so he can continue his modeling career.

Kevin Kwok:

There you go. There you go. In my mind. Right?

Chris Krueger:

Okay. So, let's, let's move on to a question. Because I want to get to it before we're, we're at the end of our time today, which we're coming up on. Which are any tips for anxiety around OFF time? Just point out the big guns at the end.

Heather Kennedy:

I'm all ears.

Kat Hill:

Yeah. Exercise. I try to just get out and breathe and exercise, singing in the car, do something and I know makes me feel good.

Doug Reid:

And I go back to having the routine and the same pattern every day. So, you'll, you can journal and notice when you're getting dyskinetic and document it and then you can discuss it with your movement sort of specialist, and you can mentally prepare yourself for going OFF or however your meds affect you on a day-to-day basis.

Kristi LaMonica:

I wish I knew. I go OFF so many times a day.

Heather Kennedy:

Me, too. I think one thing I try to remind myself is that everything is impermanent and that it's a flowing state. Like when you meditate and you can watch your mind a little bit as the witness, you just sort of watch your thoughts go by. If you can do that with your OFF times, you're a boss because you can say to yourself kind of, remember when you were in high school or grade school, you thought like this your whole world, and everything was such a big deal. You thought you'd be with these people for the rest of your life. Thank goodness that's not true. Same thing with your OFF times. Picture it like the mean girls are here, but you can say bye-bye in an hour. You have to deal with them while they're there, but they're going to be gone. Know what I mean?

Kevin Kwok:

Hopefully, I think mindfulness, and I'll quote from Michael J. Fox in his movie *Still, I'm waiting* for the bus, or I'm on the bus between doses, and I can feel it come on. And when I'm on the bus, I feel okay.

Kat Hill:

I also am going to say acceptance, too. Don't add self-judgment or shame on top of anxiety. It's hard enough to manage and ride the anxiety train or the bus. I'm going to, sorry, I'm going to paraphrase there, Kevin, but let's try to be gentle with ourselves and accept that this is hard and even make a list of tools that might help because I don't know about you when I'm in an anxious moment, my brain can't think very well so, go to that list. Okay. Phone a friend, it's like, "What are your lifelines?"

Kristi LaMonica:

And sometimes the bus is just late. We need to accept that. Sometimes, it's late; sometimes, it's off schedule. It happens.

Kat Hill:

Yeah.

Kristi LaMonica:

It will get there eventually.

Kat Hill:

And you're not alone. Know that you're not alone. That we see you, we hear you. We are—

Kristi LaMonica:

There are probably other people waiting for that bus, too.

Heather Kennedy:

Yeah. And we shame ourselves because of how it affects others as well. So, it's like we get double shame. So, just remember that a lot of people just aren't even paying attention. Like you might feel totally OFF, and people don't even notice. They're too busy looking at their phones.

Kat Hill:

Yeah. Yeah. Good point, Heather.

Chris Krueger:

So, this is another thing that is sometimes an anxiety provoker is leg fatigue and getting legs and gait issues sorted out. I mean, I'm asking hard questions at the end, but I wonder if anybody has any perspective on tips for navigating when your legs just don't want to go the way you want them to go.

Kat Hill:

Patience.

Brian Reedy:

Yeah.

Kat Hill:

Again, it's temporary usually, but don't push yourself because I think that's when falls can happen.

Kevin Kwok:

Yeah.

Brian Reedy:

I think, and I—

Kevin Kwok:

Go ahead.

Brian Reedy:

I was going to say I got into the habit because of my leg. I have a leg tremor, and so sometimes it's not so good. So, I have a habit of bringing a cane when I go out in public. And if I feel good, I'll leave it in the car, and if I feel bad, I can go and get it. Or if I feel bad enough that it's not going to be good enough. So, I always have a cane in the car.

Kat Hill:

Have your tools ready, right?

Heather Kennedy:

Kevin mentioned to me once he had a walking stick to cue where the ground was, not to hold onto it and lean on, but just so we could cue where the ground is look up instead of down. It also cues other people once again, if you're paying attention, it cues other people to sort of give you just a little more space. You'll get some stares, but who cares? You're safer.

Kristi LaMonica:

Yeah. I have a, I have a walking stick in my car, like for hiking, or that I can use when I walk anywhere that I can just pull out if I need it.

Kevin Kwok:

Yeah.

Kristi LaMonica:

They're pretty inexpensive if you want to get them.

Kevin Kwok:

I go almost everywhere with a walking stick now, but I don't always use it. But if the one tip that I would do is slow it down a little bit and think about posture if you actually stop stooping over it and just elevate up, I find that the steps kind of come a little easier at that point.

Kat Hill:

Back to that in the moment. Right, Kev?

Kevin Kwok:

Right.

Kat Hill:

Mindful.

Chris Krueger:

All right. Kevin, I have a question about that. Do you find that it's upper body? We hunch over, maybe, but do you have to focus on your posture at your hips, too? Are you rotating your, tell me more.

Kevin Kwok:

Well, it's this entire thing of just lift. So, it's back, shoulders, and even thinking about a string pulling your head up, it's almost like a dancer skillset that they go through. And if I do that, it doesn't always help me, but it gets me back into getting back into a rhythm on my gait.

Chris Krueger:

So, the reason I ask about the hips is that for me, I've just started to have some gait issues that are difficult for me. And I find that one of the things for me is I know my hips are, I'm always like tucking my myself into like this little ball. And if I have to lift, starting by rotating my lower body back. So, I'm like pushing back through my butt almost. And that's, if I don't do that, I can't get upright like you're describing. I can't pull myself forward or up from the shoulders. I have to start at my hips.

Kevin Kwok:

You mean like you got to, when you brush your teeth, you got to do your squats.

Chris Krueger:

I love that I am going to start squatting in the morning because I bet you that would help with some other issues I have, too, with just some hamstring and knee problems.

Hether Kennedy:

Sorry, I didn't mean to throw the balloons up on your comment.

Chris Krueger:

Well, I'll take balloons any time of the day. So, speaking of the time of the day, we're at our time. So, I think we'll wrap up. But I want to say thanks to everybody for asking us the questions that you sent in. And please continue to send them, and we'll try to do as best we can to answer the questions as they come to us.

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