



## **YOPD Council: Medications, Side Effects, and Parkinson's**

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Davis Phinney Foundation

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

Hello and welcome, everybody. My name is Melani Dizon. I'm the Director of Education and Research at the Davis Phinney Foundation. For those of you who are new and are just joining us for your first YOPD monthly session, we're so glad that you're here with us today. We have many of our usual suspects—Heather and Gaynor, and Amy, Kat, Tom, Erin, and Kevin. And today we also have a special guest, David Ashford Jones. We're going to be talking about medication, and he's going to have a lot to offer. So we are very excited to be here.

One note I want to make about this session is that we know medication's a really, really big topic. It's a super important topic. And everybody living with Parkinson's has to contend with medications at some point. So we, we hope this is very, very helpful and useful to you. I just want to make one note that we cannot provide any medical advice on this panel. We can't tell you how much your dose should be, when you should take it, and what type of drug you should add to your regimen. None of those things. We can't do that. We can just have people share their stories about the medications that they've taken and the different experiences that they've had.

We do have pharmacy experts here, which is a really great piece of it. I want to let you know, Kevin is going to have to go off in about 30 to 40 minutes. So make sure you have if you have questions specifically for Kevin, that you put those in the chat, so we make sure that he gets it.

Gaynor and David and Kevin are going to be running this, so I'm going to let Gaynor take it over and intro the topic, and let's just get on with it.

Gaynor Edwards (YOPD Council Leader):

I know we have already, I think, established a bit of a history of freewheeling in this group. We can definitely be freewheeling on this one. It's a big topic. I need the help of David and Kevin because I'm a baby as far as this stuff is concerned. All I've got is my own experience. That's all we've all got, and that's all we're going to be imparting really with the group. The first thing to say is Young Onset, it's a different deal. So for you to educate yourself right at the beginning is hugely important, for you to try and get your head round it and work with your care team is essential. So I'm sure there are we don't want to go too much down the route of everyone's individual story.

However, there is something about where you will know that we made mistakes as diagnosed young onset, which had we had another go, now we might play it very differently. I think from my

point of view, there was a different route I maybe would have taken. And I think that's the case with a lot of people. I've got a load of topics, but I think some of them will naturally introduce themselves. So I'm going to try and play it that way if that's okay. So if we can just talk about young onset being different on the basis that you've got so many more years, hopefully, to live with this condition. You need to live well with this condition. So how does that change how you might address your medication, because there's a limited menu here. Kevin, do you want to pick up on this bit to begin with since your time with us today is limited?

Kevin Kwok (YOPD Council Leader and Davis Phinney Foundation Ambassador):  
Hey, really, it is such an important topic. And I think the purpose of today's conversation is really more general point of looking at therapy, because as you've all heard the adage: when you see one person with Parkinson's, you've seen one person with Parkinson's. We're all different. We all react differently to medications. And we're also all changing and evolving all the time. So a medication that may have worked or not worked when you were first diagnosed may be different five years into your therapy. And I think it's really important to keep that in mind that we're in this continuum where for the rest of our lives, we'll have to take some form of medication.

Melani Dizon:

Hey, Kevin, your audio is choppy and you're frozen. So I wonder if it would make sense for you to just go to the audio. That might give you a better connection. I don't want to take you off video, but I just don't think it's working great.

Gaynor Edwards:

Your bandwidth is challenged, Kevin.

Kevin Kwok:

That has always been my case.

David Ashford Jones (guest panelist):

If I'm going to get involved, I'll get involved early. I think it's also worth bearing in mind in that obviously medical opinion changes as well, because it's based on cases. So if you can get initiated on something where everything seems to be exactly right, early, and maybe with the benefit of hindsight, you might have done something differently. But I think that that's the reality you have to deal with with a lot of diseases that last for a long time, is that because we're accruing new knowledge, the knowledge that comes forward means that different routes can actually present themselves. So I think it's not just us that change, it's the understanding of the medications as well.

Gaynor Edwards:

Absolutely. Do you think that — this is open to the group? Do we think that being a young onset it's particularly tricky for you to get the balance of medication? Right. Because there's an awful lot

of people that are very reticent about starting medication. Open to the group.

Amy Montemarano (YOPD Council Leader and Davis Phinney Foundation Ambassador):

Yes. So I would like to talk to that really briefly, in that when you are diagnosed young onset, many of us, if not all of us, are still working, and that's a really big concern, right? How to manage the meds and the side effects while also being at work, particularly if you haven't disclosed your condition. And I think that's something that's really different for for the medication for young onset. And I personally, five and a half years ago when I was diagnosed, was really resistant to taking any meds at all.

And now that I'm on the other side of that, and I'm happily on my meds, I would have changed — Gaynor, you were talking about what you have changed — I would have gotten on meds earlier and then a little bit more open to different options, you know, different ways to approach them.

Gaynor Edwards:

I think that's very common. I think there's a lot of people and it's always like, it's a pride thing or whatever. I'm going to see how long I can last before I go on the meds. And someone said to me, it's almost, you know, so much better to have a little bit of oil in the tank. Yeah. Don't run it dry.

And I think a lot of people, they also don't realize that they want to medicated.

David Ashford Jones:

I think it's trying to work out how you're going to live the best day you can that day, isn't it? And I think if you kind of get your mindset to that point, then you can actually embrace the medication as a positive, rather than as a negative.

Kevin Kwok:

Right. You're not a hero by not taking medication. Many of us, you know, just by nature of being on this call, feel that we can use our, you know, mental well-being to overcome anything. And the exercise will require that you don't have to take meds, but everything has to work in concert together.

Steve Hovey (YOPD Council Leader and Davis Phinney Foundation Ambassador):

Yeah. I just saw a comment come through. Like what about food? And I know that, as you know, over the years, as my Parkinson's has progressed, I have to be really, really careful about the timing with food and medicine. A perfect example was Thanksgiving, right? The timing of the meal happened to correspond right with my medicine. And I took my medicine and I ate a big turkey dinner, and it was — my medicine was worthless. So, you know, and I keep making these mistakes and like it's the first time. And, you know, it's like, I should know better, but yeah, I mean, I think when we being early diagnosed and we're younger, we're stronger, we're working, we're exercising hard. And, and our body, we change faster because of the Parkinson's. And I think

we're always learning like, oh, you know, if I'm going to go on that long bike ride, I better take my medicine. I better be really diligent about taking meds while I'm on the ride and working out or staying out late. It's just, it's tricky because from where you start, it's almost like for me, it's almost like I'm denying the progression, and I've always gotta be reminding myself like, Hey, you know, I've got it. The medicine's important.

Tom Palizzi (YOPD Council Leader and Davis Phinney Foundation Ambassador):  
Yeah. Good points there, Steve. I think it's important for people to know what it is that they're taking. What you're consuming and with what and how it interacts. So some of the best advice I got early on was get to know your pharmacist because they tend to be a good right arm and a good source of information for not only the Parkinson's medications, but how they interact with other medications you might be taking. So that's an important thing to do and pay attention to it as well.

Gaynor Edward:  
And they can bail you out if you make a mistake, if you run out.

Kevin Kwok:  
I think it's also really important to be very honest to yourself and your caregivers who surround you on how the medications are really working. Because you may not see things that are actually happening to you, that someone who you trust around you can see. And I think it's really important to be able to report those findings back to your neurologist, because if you don't tell them, they don't know.

Heather Kennedy (YOPD Council Leader and Davis Phinney Foundation Ambassador):  
May I also add something else? Kevin, are you done? I just wanted to make sure I didn't cut you off. This is so important. I often ask my friends and my family this question, and you are going to laugh because there's no way to answer this with me. I say, "Am I being weird?" Right? So find a way to ask your people, your touchstones, the people who knew you before, "Am I acting a little suspicious?" Perhaps be open to that, ask for it, because if you get really sensitive and you know, like the kind of person that would be upset, you know, if a man would ask a woman if she's having her time of the month, don't be like that. Just say, "Hey, I'm on a new medication. Could you give me some feedback over the next few weeks if you happen to notice anything different?"

I think that's entirely cool because, you know, the original parties as I call them, like John Stanford and Vicki, and you know, all of the people who've been here before and who've done so much for our community must be laughing as we all come in all cocky. I'm out of my honeymoon period now. But I was cocky when I first started this. I'm like, "I got this, no problem." Oh, I had no idea. So, you know, brace yourself and just kind of pace yourself, as everyone's saying.



Gaynor Edwards:  
But Heather, we enjoyed cocky, didn't we?

Heather Kennedy:  
Oh boy. It was fun while it lasted.

Erin Michael: (YOPD Council Leader and Davis Phinney Foundation Ambassador):  
I wanted to go back to something that Gaynor had mentioned. So for me personally, being Young Onset Parkinson's and having to be on medication, the first time I didn't realize there was the possibility to become over-medicated. So with the medications that they put you on, you have a ramp up period. So once you have that "aha moment," and, you know, I was up to six pills a day, I think for carbidopa/levodopa, which is absurd, looking at it. Now I'm down to one pill a day.

I started jittering and twitching all over the place and my side effects were worse. And so then I started panicking like, "Oh my God, I've never had these symptoms before. I've never had my legs twisted. It was just — and my hand, what's happening? Why, why all of a sudden this is happening so much faster than I thought it would?" And I didn't realize that it was a side effect from the medication. So I think it's also educating yourself about exactly what you're taking, talking to people that are a little bit more trusted than just where you would naturally go to look for information and really trusting your own body and saying, "Hey, something isn't right here. Just because somebody that went to school and has a medical degree says I should be taking this many pills, it's not necessarily a fact." Right? So are going to know best what works for you.

Gaynor Edwards:  
I had a guy off license giving me the benefit of his opinion on how my medication was working or what I should do next. No, you're absolutely right. I think there's an awful lot of fear as well, isn't there? Some people worry about dyskinesia, worry about body image, worry about agonists and the impact of agonists and all of these things, you know, they don't necessarily get addressed properly. We don't necessarily give the full story to the neurologist, so they don't have the complete picture and the honest feedback.

Kat Hill (YOPD Council Leader and Davis Phinney Foundation Ambassador):  
I'd love to chime in, too. I also think sometimes when you're in the exam room, you're not, you know, you're nervous, you're doing a whole bunch of things, and it may not be the easiest to remember everything that's discussed also. So if you can take somebody who you trust with you, when we're not in a pandemic, or have somebody on your call with you; a second set of ears is just a really helpful thing. And it also if you go with somebody who's a care partner or one of your, you know, your core, tight group of people, they also can help be accountable. You can say, "Hey, I want you to watch out for those things." And, and you can even tell them how you want to hear, how it's really okay hearing, "Yeah. I'm acting weird." You know, I tell my husband, "Okay, honey, I need you, if you're seeing the facts, I want you to approach me, but this is how I'd like you to

approach me. I don't want you to do it when at night, I don't want you to do it when I'm super symptomatic. Can we do it over a meal where I don't feel blindsided, because I'm more able to hear it?" And so setting up that, how you want feedback, can be a really helpful thing too, so that you can hear it. So that's, that's my two cents worth.

Gaynor Edwards:

Yeah, absolutely. Just in response to one of the questions, to go back quickly to a little bit of the gut feeling. You know, I think, David didn't you, was it lamb? You ate something that just floored you.

Davis Ashford Jones:

Yeah, I was going to say there's a few questions around protein and the interaction. So it might be just worth covering that because I think as Kat said, if you don't hear it the first time you tend to miss it. And we're all told to take medication on a full stomach traditionally, and that's absolutely *not* what you need to do with your carbidopa/levodopa. So people kind of think they're doing the right thing by eating food with the pills, but it's actually the wrong thing. And it's specifically proteins because levodopa is actually actively taken out of the gut by a transport system that competes with amino acids. So a turkey dinner will have a lot of those amino acids in it. So the lovely story about the turkey switching you OFF and is absolutely the protein competing with your Sinement and not being able to get into your blood. So that, that's something that's very worthwhile. I think the guidance probably would be to try and take your tablets an hour before or something like two and a half hours after, or load your proteins into one meal. That's all the sort of stuff that I've tried.

Melani Dizon:

Yeah. And we have [a video](#), I think Leigh put it in the chat, with Dr. K and he explains really, really well what's happening with your medication and the power of drinking it with a large, full glass of water every single time. So definitely check out that video. He really explains it better than anyone I've ever seen, explains the whole medication issue and how it's actually working in your intestine and stuff. So check that out. Leigh put it up in the chat. I also want to make sure if you guys maybe saw the question about addressing, people saying, "What do the panelist members think about delaying using carbidopa/levodopa in favor of using an agonist instead?" I'd love to hear some of you speak to that.

Tom Palizzi:

I went down the agonist path first. That's how my doctor prescribed it. I didn't know what the right answer was. And it seemed to have worked well for me. I got onto carbidopa/levodopa about three years or four years later, and I'm doing that ever since. And everything seems to be A-okay.

Steve Hovey:

I think a lot of us don't want to take the medicine, you know, when it's first prescribed. I mean, I

think that's pretty natural, and I know I held off for probably four-plus maybe even you 4 to 5 years before I really started taking, I took one Sinemet before I went for a bike ride. Like that was going to be the answer. And it ended up not being.

But somebody just asked a question that came through, and I think it's really important: "I suppose you're all on low doses of Sinemet." And I am, I only take a half a tab of Sinemet, but I take three tabs of Rytary. And the reason I do that, so I'm getting a lot of levodopa and I need that to make it through to the next round of medicine. But the beauty of the Rytary is, it's slow release. And if I took as much Sinemet as I really needed it, that one time, I was actually starting to get some dyskinesia. So my movement disorder specialist put me on Rytary. Fortunately, it worked really well for me and it's been a lifesaver. And I almost look at it like it's like, eventually a lot of us are going to need the DBS, deep brain stimulation, to make it to that next phase in our journey with Parkinson's. And and I think if it wasn't for Rytary and I just started, about four or five months ago, with INBRIJA, which is a rescue drug. You inhale it. That's been awesome, but, you know — it's kind of like you're buying time. I almost look at it that way.

David Ashford Jones:

I would agree. Sorry, coming back to the question about taking an agonist rather than carbidopa/levodopa early. Was that the question now? 'Cause that was the path that I went down. So they started me on a dopamine agonist with the logic that it would actually delay any dyskinesias due to carbidopa/levodopa. And then there was a big study done out of Birmingham University that I think proves it doesn't really matter how long or whether you actually delay the carbidopa/levodopa, if you're going to get dyskinesia as you'll get them appearing and pretty much the same time anyway. So again, with hindsight, I might've started on a low dose of carbidopa/levodopa like Steve was talking about and then had that rather than kind of deal with some of the challenges with the the agonist.

Gaynor Edwards:

One of the things that you spoke about — sorry, I'll come to you in a minute — one of the things that we've spoken about in the past, David, is the withdrawal of agonists, which I don't think had been flagged up majorly before.

David Ashford Jones:

No, I think it is called the dopamine agonist withdrawal syndrome. And I think it was first characterized in about 2010. Then the first publication was in 2013. So I actually started on it before I actually knew about this syndrome, but in checking before I came on, it looks like there's about 12 to 15% of patients will get it. And so when you actually try and withdraw, you can get profoundly depressed. It's like a rebound depression. So it's definitely something to kind of think about.



Gaynor Edwards:

And agonists anyway — as the Davis Phinney webinar that Mel was talking about earlier, as the neurologist there pointed out, there is a natural, well, not natural, a factor of agonists includes an antidepressant. So when you come off of that, I think people, they discount that. They don't realize that actually you're missing an antidepressant in your drug regimen.

David Ashford Jones:

It is profound. And it's something that I'm quite quite convinced more people should be aware of before they make that choice, because, it's almost now like, I've had DBS, I'm off of my medication, but I'm still kind of taking the agonist because I literally can't come off it, if that makes any sense.

Melani Dizon:

Right. Heather, can you chime in on that? Because I know you have a lot to say, and I think it's super important for people to hear your experience.

Heather Kennedy:

So I was diagnosed approximately 10 years ago. I left that doctor's office — not my current doctor — with Amantadine, Sinemet, and Mirapex. Not once did that doctor ever say anything about the Mirapex. I blew up a few relationships. I was already going through a divorce. People that I knew were dying. I thought I was losing my mind because I had nobody to talk to at that point. So I joined a bunch of support groups online and I found Davis Phinney Foundation and a bunch of organizations like the World Parkinson Congress who helped me understand what was happening. And the only reason that I could figure that out was by talking to other people with Parkinson's. So please do not just leave your physician's office and trust everything and just take what they tell you, take the pill and be a good patient. Do not be a good patient, please. Okay. Don't do what I did. Just trust me on that.

Kevin Kwok:

Yeah. You know, the thing that I've learned is that, you know, if you go to a physician, you can get very lost in the jargon and be almost intimidated by this pharmacologic speak that goes on there. I think that one of the terms that I've learned from my workshops with the FDA is that patients have what we call a Phd. And the way they're using the term Phd is a Personal History of Disease, which trumps any scientific education and knowledge. It's what we are feeling and what we are experiencing. You have to communicate it. And I cannot stress that enough. You have the right, because you're the one with Parkinson's, trying to deal with it every day.

I silenced the group.

Kat Hill:

Mic drop.



Melani Dizon:

Kat, did you want to say something?

Kat Hill:

Yeah. I just want to say, I really agree. I think that if you don't feel good, keep reaching out to your provider. You don't even necessarily have to know why or exactly what's going on, but you know, they send you home and they, if they don't get any feedback about what's going on, they don't know that it's not working for you either. So I keep coming back to that. Communicate, communicate, communicate. You can be a squeaky wheel on email. You can get support from others. Guidance you can find if you're not getting the kind of feedback you want from your provider. You can look for other advice as well. But be a squeaky wheel because you're figuring out a disease process, but you're also trying to figure out what's gonna work for you.

And it's going to be different probably than exactly what works for me or what works for others. And it may also work for a while and then it doesn't work. So then you have to evaluate whether you're going to go up on a dose or whether you're going to add a different medicine. Are there some other tools that you can use, like acupuncture, exercise, you know, you're going to have to figure that out. You're going to have to get your own PhD in your Parkinson's disease. And I love that Kevin, I'm gonna steal that.

Gaynor Edwards:

We're all going to steal that. All of us. Yeah. I just wanted to add, coming up halfway through the call, a little levity to such a heavy topic. I don't know if anyone else has struggled with this, but we're all on medications. And just the simple thing is, I can't get the fucking pill bottle open. You know, it's just like, give me a break! So I found out, and this might help some people, if you go to your pharmacy and fill out paperwork, you can get non-childproof opening medications, which has saved me. And now, granted I have dropped the pill bottle on the floor once or twice and had pills everywhere, but I'll take that any day over trying to open up that child's safety bottle. So you know, it's just the simple thing with medication too. Just even being able to administer them to yourself, right. It's a struggle, it's a challenge. And I'm sure everybody on this call has dropped that bottle at least one time and had a scatter of pills they've had to pick up. And they're rolling under the refrigerator and under the oven and everywhere else. So yeah, I think definitely someone had an interesting sense of humor when they designed the child proof medicine bottles. Absolutely. Yeah, because you just can't do it.

Kat Hill:

I have to ask my kids to open it. I participated in a clinical trial and, and they gave us swag, but I couldn't use it because I couldn't open any of it. They were hard to open. It was worthless.

Melani Dizon:

Does somebody — we have a lot of, I think everybody on this call exercises, and I know that

people are wondering about how to use their medication with exercise, to make their exercise the best for them. Does anybody have any tips or anything that they've used? Tom? I know this was a big thing for you. Do you want to start us off?

Tom Palizzi:

Well, one thing that I was instructed or suggested by my doctor to do was to mix up a Sinemet in a can, in a water bottle where no light can get in — a solid water bottle, and drink that along the exercise routine that you're doing. So like if we were out mountain biking or on a hike or something that for a longer period of time, that one Sinemet keeps things kind of low for you over that time period, it really, really works well for me. I've always done that when, again, when I'm going to be gone doing something rigorous for quite a while. It does work really well. Sometimes it helps if you dissolve it with a little bit of soda water or something like that, or seltzer water.

David Ashford Jones:

Lemon juice does the trick 'cause it's an acid. pH helps help Sinemet dissolve. So we have tried a spoon full of lemon juice with the water. And I like the idea of the water with the exercise as well, because I think the last video was talking about the importance of water as well.

Gaynor Edwards:

Well, the tonic water as well, tonic water, because that'll help you with, or hopefully help you with, the dystonia.

Tom Palizzi:

That does help to help the Sinemet dissolve much faster. But the thing with water is most of the pills that we take, most of the medication that we take is water soluble, and it's supposed to be that way. So common sense will tell you just drinking a good swath of water when you take your pills really helps. And I've heard so many people say, Oh man, that's made all the difference in the world. So there you go. See, Heather's got her water there.

Gaynor Edwards:

I know, Heather's doing product placement.

David Ashford Jones:

I would say, I think the mechanics of it is your Sinemet gets absorbed from your small intestine. So it's got to get into your stomach. So the fluid will actually wash the the dissolved Sinemet through, into small intestine. So speeds it through.

Gaynor Edwards:

Just the great fun, you have to keep reminding yourself to drink or to go because actually the thirst has gone for me apart from, you know, other substances. But certainly I used to guzzle water and I don't anymore. So it's, that's part of the education process. And I think it's right. It's about, you

know, keeping your system working as effectively as you can. So that you've got gut health, so that your absorption is good, so that your drugs work as well as they possibly can.

David Ashford Jones:  
Exactly.

Melani Dizon:  
Yeah. I would say that's a real educational piece that, like that video, I literally never looked at water the same. I mean, I have medications for other issues that I have, and it literally has made a huge difference for people. And I think part of it is just having somebody tell you, "Oh, that's actually what's happening." Right? And if you're not doing it, this is what's happening. And then you think, wow, this, this pill is 10 bucks a pill. I better make it, you know, work for me. Whatever it is I'm taking. You don't want to miss those opportunities. And we know people who've literally gone from feeling terrible to feeling great just by doing those things.

And then really quickly, Tom, to just go off of that one, somebody asked you when you're dissolving that pill, is that in addition to your regular schedule or are you adding a pill to your normal regimen?

Tom Palizzi:  
Good question. It's typically in addition to. If it's going to be a long period of time, I'll do a whole Sinemet, but if it's just going to be maybe two or three hours, I'll just do a half a Sinemet. There's two ways. Again, you can grind them up before you put them in the water, or you can use the soda water, or seltzer water, carbonated water to dissolve it. That works really well. You shake the bottle and then it goes.

Gaynor Edwards:  
Could we briefly just have a chat about generic meds and whether the group feels that they differ from the branded meds and how so?

Melani Dizon:  
Heather, go go go!

Heather Kennedy:  
The efficacy of the non-brand drugs is horrifying. David Sangster talks about it a lot over in England. So I'm guessing that it's the same everywhere. I'm guessing probably 65 to 70% efficacy, in my opinion. I've tested this all over the place, but it's very hard not to get the generics, especially in the United States where they're playing all these games with our healthcare plans right now, trying to cheapen things down. It is maddening because the doctors can't even get the original. And I use the NEUPRO Patch. One time, my healthcare coverage didn't come through. I went to pay for it. It was like \$900 out of pocket. So of course we have these choices. We have to

go generic.

Kevin Kwok:

The issue is the absorption on many of these drugs. The generics differ, and for people that are very sensitive to levels, in the generic, the active ingredient may be the same, but it's all the excipients and other things that are happening that affect the dissolution, the absorption. That's what's affecting them. So with generics, one brand is not the same as the other.

Gaynor Edwards:

I mean, in the UK, I get my neurologist and my GP to specify the brand name. Is that a possibility in the States or is it just more money or how does it work?

Tom Palizzi:

I think you can specify it, but you know, you can't necessarily get it.

Erin Michael:

Yeah. And it would depend on health insurance too. So insurance may or may not cover it depending on what gets fulfilled. And if you don't know that you can go pick up a prescription and if you have 90-day supply, you could lose your house at that point. You know? So it's a very convoluted process. And kind of going back to, I think something that was resonating throughout the panel with, you know, doctor's appointments and everything. I think, you know, a lot of people that we see have lost sight of patient care and it's more of a commoditized environment anymore. So you just have to keep going and find, keep going until you find somebody that you are comfortable with and that you trust as part of your patient care team, because it's not just one person, it's a team of people that will be taking care of you.

And you just gotta find that right fit. So you'll find them. It took me, I think, three or four doctors that I went through before I found somebody who I, you know, I don't trust them a hundred percent. You know, it's not their life that they're taking care of, but I do trust her. And you know, she'll give me as much time as I need. I have spent hours with her in the office. Where some people it's, "Here's your prescription," and they walk out the door and you have no idea what you're taking, why you're taking it, what the side effects are, all of that type of stuff.

And to add onto that, Joe was asking something about impulse control disorders. So when I first got put on medication, they put me on Mirapex, and you know, at my doctor's checkup, they're like, "How are things going?" I'm like, "It's great. I walked 11 miles today." And the person that was with me, they were like, "No, you walked 11 miles around the island in the kitchen. That's not normal." And I'm like, "Oh." You don't even realize these things are happening to you. But I was like, so proud of myself, like I've walked 11 miles today. And then I'm like, no, that's crazy. It's around the island in my kitchen. So it's a very sensitive subject when you start talking about

impulse control, because a lot of times it's very hard for the person that it's affecting. They don't realize it's an impulse control thing that's happening to their body or what they're doing until somebody else points it out. And then you kind of go back to your normal way of thinking. "That's not a normal behavior for somebody to walk 11 miles around a circle on their kitchen. That's, that's just plain nuts." Yeah. I'm like, "Okay, I know you're right. This is pretty crazy."

Melani Dizon:

Real quickly, Leigh's going to put a link to our post about formularies. She did put up the post about impulse control disorders as well, but formularies is, you know, definitely for the U S something to look at in terms of your prescriptions and how you might be getting the medications that you're getting and why sometimes you can get the medication that you want and sometimes your insurance covers it, and then the next month they don't. That's a really great topic. So check it out. She just put that link in there. Does anybody have any other experience?

Gaynor Edwards:

Sorry. I think Kevin wanted to jump in. Did you Kevin? Oh, is he frozen? Oops. Okay. Someone asked me about my glass of red and apparently if you are going to drink alcohol red wine is the stuff to drink, and this is your finest organic. Moving on. Oh. And by the way, it's 8:30 in the UK. So perfectly normal, I didn't just get on with jammies and down a glass of red.

Amy Montemarano:

I just want to say that I am learning so much from all you guys. And I consider myself to be someone who, it's important to me that I educate myself about all this stuff. And I thought that I had, but I'm learning a lot about my particular cocktail of drugs. And I'm on three. I started on Rasalect, and then I started with ropinirole — Requip, which I saw someone in the chat also uses. And that's the agonist. And then about two or three years in, I started with carbidopa, but my neurologists, all three of them that I'd been to said "Stay on all three." I'm wondering if that's a good idea, and I'm going to I'm definitely gonna go back and do some research about all this. I really appreciate this. And this is one of the reasons why I enjoy being on this panel is because I learned so much every time from all of you.

Kat Hill:

I think agonists can be effective. I started on an agonist and I knew full well the potential side effects, and I didn't have side effects for a very long time. But I'm struggling with some now and I've been really proactive about it. And I'm gonna start tapering with the cooperation of my provider, but it was my husband and I who had a dialogue, at the opportune moment, kind of about some behaviors, a lot of not sleeping, a lot of being the computer compulsively, some eating stuff that I don't want to be doing. And you, those are things that — there are other people that have reported other, you know, really scary side effects. So it's important to aware of them and communicate them. But not everybody has side effects from these medicines. So it's important to be aware of them if they happen and that you communicate and you do not stop the medicine

suddenly. That's really important. We already said that. There can be some terrible side effects. So it's important that if you decide you are having side effects that you work with your provider to come off of it.

Kevin Kwok:

Yeah. So I'm about to check out here, but I want to make one public service announcement. I'm often asked, you know, by other patients in our tribe, why does it take so long to develop medications? And it is maybe one of the hardest industries to be in. David can speak to this as well. But the thing that I would say is, for all of you to think about, is to be active in your drug studies and get involved as a patient subject in the areas that ail you. Because by getting involved as a patient subject, we are helping all of our tribe. So that's my PSA for today. I've got to sign off, guys.

All:

Thank you, Kevin.

Gaynor Edward:

So on that "patient, heal thyself" message, David, did you want to jump in? You had your hand up earlier, sorry.

David Ashford Jones:

No, I was just going to reiterate I think what Kat was talking about with coming off the ropinirole. So my experience was I was up at 24 and I came down to 16 and that was actually too much trouble and then dropped again to eight from 16, which seems like not too bad a trip. It was actually quite horrendous. And I suppose if you think about the relative change, the first one was 30% and the second one is 50%. So there's a question about being able to come off it. Yes, you can come off it. And it's not everyone, it's only about 10 or 12%. But when you get it, my experience is quite significant. So I think your approach, Kat, was exactly right. Thank you.

Tom Palizzi:

Yeah. It seems like a slow decrease has been good for me too. Just coming down a little bit at a time. And you know, I may not ever get off all of it, which is okay because it alleviated some of my problems and life goes on and it's worked out pretty well.

Gaynor Edwards:

Yeah. I think you're right though, Kat. For a lot of people. I mean, I was on just Requip for seven years and it worked mostly okay. But when you hear the horror stories, they far outweigh, I think it's massively underreported. You know, most of the people you speak to about agonists have had some kind of issues with them. I think it's very rare not to. Would you say the people that you've spoken to, that obsessive compulsive behaviors, et cetera, are under reported.

Amy Montemarano:

To that point, Gaynor, the first thing I did when my doctor prescribed the agonist is, I went to do some legal research to find out any products liability lawsuits that were filed. And there are a good number. And they're pretty scary to read about. It took me a long time to sort through that information, but they have been sued for various types of obsessive compulsive behavior and the damage that it's done to certain families.

Heather Kennedy:

So I just wanted to add, not only are people maybe unaware of how they are changing because it is working with chemistry in the brain, right, and nothing happens in a vacuum. We're all very busy. It's not like we are observing ourselves, you know, like under a microscope or something. So we're not sure that we're acting funny or not. So it's not only that, but we don't seem to recognize our own shame either. So a lot of people are ashamed to say what's happening. And my very first Parkinson's jam was the World Parkinson Congress in Portland. And the reason I'm telling you about this real quick is that I misunderstood the behavior of an older gentlemen there. And I was so put in my place by someone in the Parkinson's community and I thanked him repeatedly for doing so, because I was about ready to say about this gentlemen, "Wow, he's a little handsy, what the heck's going on with him? That was a little inappropriate." Now that I'm on these drugs, and I hear myself reaching out and saying really weird things to people in the grocery line, I give that guy a wide berth. And anybody that comes at me that way or any way, actually, I just give them a break and say, "Hey, how, how are your agonists?" You know, because it's not really our personality. And we get crucified for this behavior even in the Parkinson's community. So I just wanted to add that part.

Gaynor Edwards:

Yeah. Very good point, Heather, thank you.

Kat Hill:

So basically what we're saying to everybody is everybody's unique. We don't have anything really tangible to share. No specific advice, but we've shared a lot of unique perspectives. So maybe that's helpful. I hope it's helpful, but also that you need to communicate and be aware. I guess, that those are really the only pearls we have.

Gaynor Edwards:

And good luck!

Kat Hill:

And I'm just sort of cracking up inside and I just had to let it out. Forgive me. I'm on agonists.

Gaynor Edwards:

Recently a speed camera got me for speeding. And you know, I'm an Essex girl on the agonists. Of course I was speeding. That's what we do. Anyway, what about genetics? And the

route was maybe individual medicine, on the basis that we were saying, you know, one person with Parkinson's is one person with Parkinson's. But I thought we have a similar disease. Everyone is unique. Yes. Are they, or are there just lots and lots of genetic types?

Kat Hill:

You know, my dad had Parkinson's and I have uncles on both sides of my family with Parkinson's and the medicines that work for me also worked for my dad, for what it's worth. But my dad presented really differently than I do. He didn't have a tremor. He had a lot more bradykinesia and shuffling. But I can't help but wonder if perhaps there — I have no genes; I've been tested for all of the known genes — but certainly there must be something, right?

Gaynor Edwards:

Right. Someone help me out. What else haven't we covered?

Melani Dizon:

Does anybody want to talk a little bit about any medicines they take for depression or anxiety or anything that they've found that has been helpful for them in those areas?

Gaynor Edwards:

My Requip had been working for me as far as that's concerned, but because I'm now edging down, I think joy issues are coming to the full.

Erin Michael:

Yeah, I'm on venlafaxine, but I think that for me manages more of the horrendous anxiety that I had that kind of led to depression. My anxiety was through the roof. I mean, I just felt like I was going to jump out of my skin and nothing would calm me down. But it's weird, so they accidentally filled the venlafaxine that wasn't extended release one time, and it didn't work. And so I'm like, "Oh, something has changed." So it's only the ER that works for me. But that has helped me quite a bit. I, I totally am lackadaisical. "Oh, no big deal. Just keep on moving." When things happen at work, I'm like, "Oh, well, let's move on, grab a book." It's funny how it's done wonders for me.

Tom Palizzi:

I experienced some pretty heavy anxiety at the very beginning. And the first medication I actually took related to Parkinson's was Citalopram, which I'm still on today. And that has been a lifesaver because I never had much anxiety to begin with as a kid. As I got older, it started to build a little bit, but about a year before I was diagnosed, it hit really hard. So Citalopram was a big life changer for me.

David Ashford Jones;

That's interesting, Tom. That's exactly my experience as well.



Gaynor Edwards:

So I was put on Citalopram pre-diagnosis on the basis that, you know, it just looked like depression. And it didn't touch it. And I thought that was because it was Parkinson's and it was a dopamine/serotonin thing maybe, but I don't know. I mean, this is the thing, it is different for everyone. And so you do have to keep kind of pushing back and asking the question.

Tom Palizzi:

Yeah. I think to that end, Gaynor, the more you know about what it is you're taking and how it interacts with the other things and what each thing does mechanically in your body, I think that the better off you are, and the more enabled you are to communicate with your doctors and your pharmacists to help put you on the right path. Because it could, you know, some of the things I hear today are, well, I take that and I do just fine and other people don't take it and they don't do just fine. So again, going back to what Kevin said at the very beginning, we're all different. When you meet one person with Parkinson's you've met one person.

Kat Hill:

One thing I'd love to say, though — if you're experiencing anxiety and depression, please bring it up with your provider. Because there are treatments. And sometimes they think that where our brains had collect all of those, where it affects us, our Parkinson's center, it also may affect where we produce, our serotonin levels too. So they often goes hand in hand. And a lot of us, I was diagnosed with depression and anxiety years before I was diagnosed with Parkinson's. So definitely bring it up.

Gaynor Edwards:

Absolutely. Just quickly, just to say also Tom's point about how it reacts with the medicines. That's not just Parkinson's medicines. It's other medicines, generally. If you're on a course of antibiotics, check them out just in case they are contraindicative.

Tom Palizzi:

Absolutely. And antihistamines and some MAOB inhibitors are pretty dangerous.

Kat Hill:

And they can be over the counter. They don't have to just be prescription. So anything you pull off the counter, check with the pharmacist. They're great about that.

Gaynor Edwards:

Yes, make friends with your pharmacist. Absolutely. Mine's called Stanley, and he's lovely.

Steve Hovey:

And on more of a holistic level, just avoiding things that cause stress. If you can. You know, if you

have to work and work causes stress, then you gotta figure out if that's the right job. But I know that it's easier said than done, but I know for me owning a business and having Parkinson's was not the greatest combination, and I felt a whole lot better after I sold it.

Gaynor Edwards:

It would be interesting to know how many business owners or how many people with Parkinson's have owned their own business. Because I think that is massively stressful. I'm looking at probably half a dozen people on this call.

Heather Kennedy:

May I just add to that? It's not like we can just take a pill and everything's fine. Right? I mean, we know that we have to do a lot of work to maintain this. Meditation or prayer or whatever it is that brings you to that point of witness. I want to echo strongly what Steve just said. It's very important to look at this holistically, like a bigger picture and pull the lens back. Because those pills alone don't do much. And also a love.

Gaynor Edwards:

And support and honesty.

Steve Hovey:

That's really true, Heather. I mean, learning to appreciate the good that's in our lives and trying to dwell on that. And that's a learned behavior. I mean, for me anyway, it was like switching from just like, go, go, go to like, Hey, you know, life isn't so bad, you know. My beautiful children, my grandchildren, you know, the 32 inches of snow we got this morning, you know.

Tom Palizzi:

That's some special love.

Kat Hill:

Well, having all of you here is a gift, you know, and having people that show up and let us share our stories a little bit is a gift. So yeah.

Tom Palizzi:

Yeah. I think Heather's experience with the diggig into support groups is really good. And then that's a great source of love and companionship and friendship. And that just goes miles. It goes hundreds of miles.

Kat Hill:

There's a point that just got brought up about pain. I'd love to touch on that, cause that that's a probably pretty under discussed and, and significant Heather and I had just had a conversation

about this last night.

Heather Kennedy:

Yeah, apparently I'm a pain in the neck.

Gaynor Edwards:

You have a pain in the neck.

Kat Hill:

Pain is real for a lot of us. I've struggled with a hand dystonia, but bilaterally and I get Botox for my fingers every three months, which helps. And I've got a lot of neck and subscapular back behind my — in my back, in my neck, not just since I met Heather, but you know, muscles are doing weird, uncomfortable things. And I think we have to admit it, address it, be honest with it, and try to find tools that work for us. And not all of those things have to be medicines, but they might need to be. But I think we need to report it also to our providers because I think more of us haven't been reported. We don't want to go in and complain about everything, but it's a real challenge. And again, mindset helps. Meditation. Exercise.

Tom Palizzi:

Yeah. So too, Kat, that's really good to point that out. I think your care partner, your care team includes a lot more than just a doctor, you know, pharmacists, physical therapists, chiropractor, massage therapists, on and on and on. You know, make that group big and make it work for you. And I think life can be better without just taking a pill.

Gaynor Edwards:

Your YOPD Council buddies.

Kat Hill:

Foam roller. I swear by my foam roller. It's like a rock and it works great.

Melani Dizon:

Hold up. We have a special guest. Hang on. A little birdie is talking to me. Hang on. Wait, I'm moving over. I'm going to move over here. Bring it on.

Steve Hovey:

Santa Claus.

Davis Phinney (Founder, Davis Phinney Foundation):

I love you guys. I was so thrilled to be able to be here and listen in on this.



Gaynor Edwards:  
Did we make any sense?

Davis Phinney:  
Oh yeah. You guys have such a good camaraderie going, and I love the mix of seriousness with humor. It's really, really awesome.

Tom Palizzi:  
Thanks for joining us.

Kat Hill:  
Thanks for watching us, Davis. That's great.

Heather Kennedy:  
Thanks for connecting us.

Davis Phinney:  
That's Mel and Polly.

Kat Hill:  
And Mel, thanks for giving Davis a chair.

Well, I would just like to wish everybody a happy holiday season, no matter what you might practice and, and gosh, it's so lovely that you tune into us and I just feel very honored.

Davis Phinney:  
I want to wish everyone happy holidays as well. Especially Steve and his massive shoveling.

Steve Hovey:  
Davis come out here, bring a shovel, you can help me.

Gaynor Edwards:  
Will you be with us for the next one, Davis?

Davis Phinney:  
Sure. Thanks everybody.

Melani Dizon:  
See you back in January.



All:  
Thanks. Thanks, everyone. Bye.

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