



Q&A Session: Parkinson's Medication Management for Motor Symptoms
with Dr. Aaron Haug
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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 at the Davis Phinney Foundation. And I am here with Dr. Aaron Haug, and we are going to talk about all things medication. Hello, Dr. Haug, how are you doing?

Dr. Aaron Haug (Neurologist and Movement Disorders Specialist, Blue Sky Neurology):
I'm great. Thank you. Thank you for having me. Hello everyone.

Melani Dizon:

Great. So we recently had a webinar that was all about different types of medication and it was great. And we had so much feedback and people had a lot more questions, and we decided to do this second session so that we could answer as many questions as possible. If you did not happen to see [that webinar](#), I highly recommend looking on our YouTube channel or looking on our website for "medication management and Parkinson's webinar," and you will be able to find that and watch the initial session. That might help you with some of your questions. And then you can either come back to this one or listen to this first. It doesn't really matter, but just know that there is a first part to this.

Just as a little introduction: Dr. Haug was born and raised in Kansas. He attended undergraduate at Creighton University and then earned his medical degree at the University of Kansas. He completed neurology residency as well as fellowship in movement disorders at the University of Colorado, including a year as chief resident. His medical interests include Parkinson's disease, tremor, and other movement disorders, as well as deep brain stimulation. And outside the office, he likes to spend time with his wife, kids, run, ski, and follow Colorado Rockies baseball. What's happened? The baseball, I just found out that the World Series is happening right now. I didn't even know they were playing baseball.

Dr. Aaron Haug:

Yeah. They made it. The Rockies didn't make it, but now baseball carries on.

Melani Dizon:

Yeah, it was good. That's good. All right, let's jump right into it. So the biggest question

that we get is from people who are worried about starting their medication, because somewhere down the road, they were told that it's it will be less effective over time. When they do start to take it, it won't work as well. So can you dispel some of those myths and talk a little bit about when is a good time to start taking medication?

Dr. Aaron Haug:

Yeah, this is a really important foundational question. I think it's a good place to start here. So what the medications do in Parkinson's is all directed at improving quality of life and day-to-day function, whether that's daily activities or work. And so the typical standard currently is to treat motor symptoms—tremor, stiffness, slowness—to the point that they're no longer interfering with quality of life. And there are some misconceptions out there that medications maybe only work for five years or that medications should be saved until your symptoms are maybe worse than they are now. And I would say the truth of the matter is that there's evidence that shows that medications do not work better later if you save them for later. And really all that does is kind of lower your quality of life. In the meantime, Parkinson's symptoms can progress over time. So typically as a person has lived with Parkinson's for more years, they tend to need more treatment, but the medications that we start are potentially medications that will continue to have benefit over how you would be without medications for decades, for a person's entire life.

Melani Dizon:

Great. That's super helpful. A couple of these are, all kinds of questions all over the board because people are, we have all our own issues, right, with the medications that they're taking? And so somebody, a fair, fair number of people actually asked, "Is there an advantage or disadvantage to taking Sinemet at bedtime?" Some people have said they, it doesn't do well. It makes them jittery and makes them, maybe they're wondering if that's Parkinson's or is the medication, but is his sleep impacted by carbidopa/levodopa?

Dr. Aaron Haug:

Yeah. I would say that sleep can be impacted in a multitude of ways, either from Parkinson's symptoms directly and sometimes from medication side effects. As far as the specific question of whether to take Sinemet at bedtime, there are some people who sleep better with it, and some people who feel like it interferes with their sleep. So if a person has significant tremor or stiffness or slowness that makes it difficult to position in bed, or if the tremor is continuing while lying in bed, then a dose of medication at bedtime tends to help those symptoms. And occasionally for better, in this case, some times people have a mild sedating side effect from some of their medications, so that can be helpful at bedtime. But some people have either bothersome, vivid dreams or

nightmares if their medication is too close to bed. And a minority of people do feel kind of amped up if they take their medication too close to bedtime.

So getting to the related question of, well, how should I space my medication throughout the day? I would say the answer to that that during the first few years that a person is on medications, especially carbidopa/levodopa, a person tends not to notice dramatic kicking in or wearing off of their medicine. And so I will often say that taking the medicine about six hours apart with breakfast, lunch, and dinner, or trying to get eight hours apart so that they're evenly spaced throughout the day, any of those things are fine, but it tends not to be quite as critical in the early years. And so I don't mandate that someone take their medicine exactly at 6:00 AM to PM and 10:00 PM, which would be eight hours apart. In the early years, it tends to be more important to get them in.

Melani Dizon:

Okay, great. So this brings me to another question that I thought to myself like, "Oh yeah, I have no idea." So most people are given the prescription to take however many pills. They're going to take it three- or six-hour intervals or that kind of thing. But they also will experience OFF times. So what is the, why would you not just take a pill an hour and you know, every hour, is that going to stop the OFF times or like what's really happening there and is there a way to just spread it out more so that you're not taking it in a bunch?

Dr. Aaron Haug:

Yeah. Good question. So this oftentimes comes down to a matter of logistics. Taking a pill every hour would end up being a fairly high dose, and people tend not to need that much early on, but if somebody has lived with Parkinson's for 10 or 15 years, then it actually is sometimes the case that a person might take a half pill or a full pill, or some combination every 60 or 90 minutes. The true half-life of carbidopa-levodopa is something like 60 to 90 minutes. That's how long it stays in your system. But in milder, earlier stages of Parkinson's, the brain is still making enough of its own dopamine to provide some buffer, which is why I take it in just three times a day, which can be hard enough is often adequate. But if a person is having a lot of peaks and valleys, then taking a lower dose more often, what we call fractionating the dose, can be helpful.

Melani Dizon:

Okay, great. You had talked a little bit about Mirapex, and when you talked about it, you talked about sudden sleepiness, like sleep attacks. Is that something that is common with Mirapex, and if for those of people who aren't completely sure, what is a sleep attack, how would you define that?

Speaker 2 (07:38):

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Dr. Aaron Haug:

Yeah. So a sleep attack or sudden sleepiness, I would say, is this problematic issue that can occur when you fall asleep in the middle of doing something. So you fall asleep in the middle of an active conversation like we're having right now, or you fall asleep while driving operating machinery. So those are all highly problematic if they were to occur, and they can happen with very little or no warning, as opposed to other sleepiness, which can be a symptom of Parkinson's, or it can happen with really any of the medications where you're more likely to fall asleep, but this sudden sleepiness or sleep attacks is kind of its own thing, which fortunately is less common. It is listed as a possible side effect with, I think, just about every Parkinson's medication, every medication, but it's something about the category of the dopamine agonists where it's more, a little more likely with the dopamine agonist. So that includes Pramipexole, which is Mirapex, Ropinirole, which is Requip. And to some extent also Rotigotine, which is the Neupro patch.

Melani Dizon:

Okay. So is this something that if, I mean, it's hard to say, but if somebody is, has that, is it something like, they're probably gonna have it all the time? Well, I had a sleep attack and I'm still going to take my meds, I'm just trying to picture somebody who they had, their first one, they read this as a side effect. They don't really have a life where they can have sleep attacks, like for whatever reason, right? They have to work or drive or whatever.

Dr. Aaron Haug:

Right. So a couple of things about that. It's sometimes it's dose dependent. So if a person is on a fairly high dose of Pramipexole, for example, then potentially that can be lowered somewhat without being stopped. And maybe some alternative medication could be added or integrated to the regimen. Sometimes it is specific to one specific dopamine agonist. So a person might have this issue on Pramipexole and unpredictably not have it on Ropinirole. So sometimes switching within the class can be helpful.

Melani Dizon:

Okay, great. A couple of questions around exercise. So is there a tie-in with how meds function in the body because of exercise or lack of exercise or other factors? So a few people have said, aside from the fact that they might time their medicine so that they're ON when they're exercising, is it something where the body absorbs it really fast? And if you are exercising and maybe vigorous exercising on a regular basis, you should take more.

Dr. Aaron Haug:

Yeah, that's interesting. I'm not aware of a lot of research to guide us in this respect. So it's mostly anecdotal experience. And so if a person finds that they take their medicine at 7:00 AM, and then they exercise from 7:30 to 8:30, occasionally people will feel like that kind of uses up their medication more. And if they are a person who's experiencing on-off fluctuations, then maybe their OFF period comes on an hour or two sooner, later that morning than it otherwise would. And so if that is the case, then the strategy would potentially be to work with your prescriber, to either have extra medication that you can take for exercise or so that you can take your medications a little earlier and still have a bill left by the end of the day. Sorry, there's a fly flying around here. It's like we're on a vice-presidential debate. So I occasionally that is something that people experience where they do need to take a little bit more medication if they're exercising vigorously.

Melani Dizon:

Okay. So maybe a practical strategy for somebody would be, if that's the case, maybe do a tracking where you track it over a couple of weeks, the days that you exercise, the days you don't exercise. And then so that you have something to go to your doctor with and say, "Here's what's happening." And then have them be like, "Okay, in this case, it seems to be a pattern. Maybe you take, on the days that you exercise I recommend you take another pill on such and such a time." Tracking over time might be the best way to figure out what's happening.

Dr. Aaron Haug:

I think that's right. Not to get too driven nuts by the details, but keeping track of that sort of pattern of, *okay, on average, my medicine lasts five hours, but after this session of exercise, it seems only last three hours*. Coming to your provider with that type of information is extremely helpful. I was just talking to a patient who said, "You know, I take my medicines four hours apart in the morning and that works pretty good at seven and 11, but then my next dose, I don't take till five, and boy, every day at 4:00 PM, I feel terrible. I can barely move." Well, I say, "Well, thank you for doing such good tracking of that. Now we know exactly what to do by moving your medications a little earlier."

Melani Dizon:

Great. So this is a sort of it's a long question because it comes with a story. Somebody recently reached out to us who is on many medications for Parkinson's. "I've had Parkinson's for a long time." And they were about to get testing for DBS. They went off, they were told, you know, "Here, go off these medications. You're going to come in and we're going to do all of these testing." What happened was, I think, around maybe 48 hours or 72 hours before she went off of her carbidopa-levodopa, 24 hours before I think she went off of her dopamine agonist could have been, it could have been the other way around, but the fact of the matter is she was trying to get, you know,

completely off the meds. And what happened was, you know, she basically just fell apart.

She, she couldn't function; she couldn't move. She was like locked in, but she was also, she and actually someone else talked to us about it that same week, where she had this feeling of just this like intense heaviness came over her, which was like a level of depression and darkness that she'd never felt before to the point of being like, "Oh, I, I think I just, I could walk off this bridge right now." I mean, it was just really heavy, and somebody else told us the same thing. And her concern was, why didn't anybody tell me that this was going to happen? Because she was, she was planning to go alone to the doctor. They never said to her, "Make sure you come with somebody, make sure somebody is with you 24, 48 hours beforehand. And all of those things." What is happening. And then people did ask us again, what if I just go cold turkey and decide to not take my carbidopa/levodopa, what can happen? So there's a lot of questions in there, but you know, what is happening to the body that is creating those sort of locked in and really, and then also that very dark, heavy feeling of, "Oh my gosh, like I can't do this?"

Dr. Aaron Haug:

Oh, that's a terrible experience. Fortunately, when we're doing off-medication evaluations for DBS, a story as bad as that one is uncommon, but obviously here it's possible. So a couple of things to say about that one is that if a person is very responsive to their medications and thus, they have maybe been very good about taking them for years and years, the locked-in, almost total inability to move may just be what their Parkinson's is like untreated. But above and beyond that, people can sometimes experience a dopamine withdrawal syndrome. This is particularly with acute cessation of the dopamine agonists, but also can occur with acute cessation of the carbidopa/levodopa and some of the other medications also to a lesser degree. And I mentioned previously that dopamine agonists, even in people that don't have Parkinson's, can sometimes have an antidepressant effect.

Well, the opposite can also be true, where abrupt withdrawal of dopamine agonists can cause depression and it can be profound. And so approaches for handling this person specifically in the context of off-medication evaluation for DBS — practices will vary among providers, but typically we will say for short-acting medications, like carbidopa-levodopa, stay off it for 12 hours would be one average practice. And for longer-acting medications like Rasagiline or extended release agonists or the patch, to be off those for 24 hours. And that's usually enough to see the big difference that medications make for a person. But this is also a, I think a cautionary tale to know that your symptoms may be pretty bad off of medications. And so when you get to that appointment, you may need someone to bring you bring your medications with you so that you can then take them once you're there. So those would be some of the things to learn from that.

Melani Dizon:

Great. Yeah, absolutely. Even if you don't, yeah, you're not going to know, probably, how much it's going to impact you. So probably safety is assumed that you need to take somebody or that somebody needs to be with you during that period before and hope that you don't need them, hope that you just have a friendly face that's with you as you go. But if you do need more help that, that you have it.

Dr. Aaron Haug:

I would maybe interject, the reason we subject people to that when we're going through the DBS evaluation process is that for most physical symptoms, DBS can help as much as medications help when they're working for you at their best. And so to determine if someone's a really optimal candidate for DBS, we want to see that when they have no medication versus whatever medication can do best for them, that there's at least a 30% improvement in their symptoms. And so it is often an unpleasant thing at best to have this off-medication evaluation. But we're considering an advanced treatment option in DBS. And so it's a standard part of the evaluation.

Melani Dizon:

I guess, and going back to the other question that people just say, like, "What happens if I stop my medicine cold turkey?" Especially for those people that seem to come with the caveat that they don't think it's working. I guess if they stop it, they're gonna know right away if it's working, right? I mean, what are the other real disadvantages? Is, is any, is there any other expectation of what's going to happen if they stopped? I mean, aside from the fact that they could show some of their symptoms that they didn't realize was actually working?

Dr. Aaron Haug:

Well, there's maybe three ways that could go. And it depends on a number of factors, including how long they've had Parkinson's and how much medication they're on. If this is someone who's on a fairly low dose of medicine, they've been on it for maybe a year or two, and they're not impressed that it's making much difference—if they were to stop it acutely, then maybe nothing would change. Maybe it's really not helping very much at that dose. Maybe they would find, Oh, wow, look, this tremor that I haven't noticed at all for a year; it's back. So it turns out it *was* doing something. And the least likely would be that they would have some of the terrible dopamine withdrawal syndrome symptoms that we just discussed. But if someone has had Parkinson's for longer or is taking a lot of medication, if you stop a higher amount of medication, the likelihood of having a really bad withdrawal syndrome is higher.

Melani Dizon:

Okay. So somebody is asking, his nighttime leg cramps, can that be associated with

Sinemet? With too much or too little?

Dr. Aaron Haug:

Yeah. The answer would be yes. Nighttime leg cramps are sometimes a symptom of Parkinson's that we call dystonia. And so this is sometimes just a tightening in the calf. It can sometimes even cause the foot to turn in or the toes to flex or extend. And usually, well, it can just be a Parkinson's symptom. Sometimes increasing the amount of carbidopa-levodopa or other medications can be helpful. Less often, those types of movements are actually a manifestation of dyskinesia, in which case it would be possible that it's from too much medication. But most often it's a symptom of Parkinson's, and either a higher amount of medication or addition of other medications can possibly be helpful.

Melani Dizon:

Somebody asked—their person was Parkinson's was diagnosed about seven years ago and his hands are freezing all the time. Is this something, freezing cold? Is this something that can happen with Parkinson's progression? Is this just, is this a circulation problem related to Parkinson's or is this just maybe getting old and the circulation system isn't as great?

Dr. Aaron Haug:

Yeah, I would say that cold extremities are something that I see in my patients. It's not the most common symptom. It can sometimes be associated with orthostatic hypotension and drops in blood pressure. If cold hands happened very early on as a symptom, it can sometimes be a red flag for one of the Parkinson's plus syndromes like multiple system atrophy. But it's also possible that this is just a separate thing. People that have migraines are more likely to have cold hands all the time. Colorado's cold. It can just be cold. Raynaud's phenomenon is a thing that's separate from Parkinson's and it can be environmentally sensitive.

Melani Dizon:

Okay. Is there any evidence that carbidopa/levodopa can cause cognitive confusion?

Dr. Aaron Haug:

Yeah. Here again, this is something that cuts both ways. I would say what I see fairly often is that if someone's undertreated or a treatment naive and they start carbidopa-levodopa or maybe other medications, that they can sometimes have kind of a mental awakening where they feel like not only is their body moving better, but their mind is moving better. On the other end of the spectrum, it is possible for carbidopa/levodopa to cause often a mild confusion in a couple of different ways. One of the side effects is that

it can lower the blood pressure some. And if somebody is very sensitive to that side effect, not having enough blood flow up to your brain can make a person kind of foggy and confused. If, if that's what it is, then lying down should pretty quickly make it better. So that's a quick test for, "Is it just a blood flow to the brain issue from low blood pressure?" But less often, carbidopa-levodopa can cause other symptoms, including rarely hallucinations or delusions or other kind of false sensory input. And that's more likely in more advanced or later stages of Parkinson's. But it is possible with really any of the Parkinson's medicines that dopamine could have some risk of those hallucinations or other side effects like that.

Melani Dizon:

Okay. A couple of people asked about OFF times related to the gut. So somebody said they'd been diagnosed with small intestinal bacterial overgrowth, SIBO, and whenever this person is bloated, their carbidopa/levodopa doesn't work. And they said that this is like very reliable and frequent. So it seems like this person has been tracking it and they'll have an OFF time, like when their stomach is loaded from, I'm guessing, the small intestinal bacterial overgrowth. He's tried different diets, but he hasn't found a reliable way to manage this. Is there anything that you have experience with that that helps with the gut and OFF times?

Dr. Aaron Haug:

Yeah, this can, this can be a real challenge. I don't have much to speak to specifically about small intestinal bacterial overgrowth. But I, I do hear this fairly often that people that are very sensitive to bloating, which actually can be kind of a vicious cycle because sometimes they feel like their carbidopa/levodopa process, some bloating but separate from that, if somebody has a lot of bloating issues, then sometimes they feel like their medication isn't working as well. The main angle from which I say it's important to address at least one aspect of that is to ensure that constipation is not a compounding factor. Because if a person is significantly constipated and everything is just sort of moving through the gut more slowly, that can impair absorption of the carbidopa/levodopa. And constipation can relate to bloating, obviously. And so if constipation is a part of it, then managing that as aggressively as possible can be helpful.

Melani Dizon:

Okay. And that actually reminds me of something I wanted to make sure that I mentioned. I think I mentioned it on the other webinar about this, but one of the things that we learned with our community is that if you take your medication with a large glass of water, your carbidopa/levodopa, every time you take it with a full glass of water; we've had a couple of people who have said it's absolutely changed their life and changed the way their medication works. So in this instance, if bloating is an issue, sometimes in the constipation, the more water you drink and the more you're moving around that might,

that might also help. But I think it's a good rule overall to take your medication with water. So we're, we're big fans of making sure that we give people that information every time we can, because we were surprised. One of the people that told us is a physician she's had Parkinson's for a really long time; she's been very compliant, always doing what she's supposed to do with taking her medications and on time. And then one of our doctors said, take it with water. And she said it really just changed everything, which is pretty amazing.

Dr. Aaron Haug:

Yeah, that's a great tip, definitely worth trying.

Melani Dizon:

Somebody said that her husband was diagnosed with Parkinson's just a year ago and his medications have been increased just over the last year, five times. Plus they've added a request. Is this, is this normal? Is this a normal progression of medications to get to the right point? Is this an indication that the Parkinson's is progressing really quickly? What would you say to that?

Dr. Aaron Haug:

It's a good question. And it could be either of those things. One thing that I see quite often is that a person has had fairly subtle symptoms building for multiple years, and it can sometimes take multiple medication adjustments upward to kind of catch up because a standard starting dose may not be enough if the symptoms have really been brewing for several years, as opposed to truly just having come to be visible in the past few months. And then the other thing is that people with Parkinson's have very different paths to walk. You know, we're doing these webinars to try to answer as many questions as possible, but there is huge variability from one person to another. And there are some people that really just have had their physical symptoms first come to prominence in the last six or 12 months, and pretty quickly need to go up to a high dose of medication. That's a situation where using multiple medicines from different categories and even working up to the highest tolerable dose within each category is going to be the first steps. And considering some of the advanced treatment options like deep brain stimulation may be another consideration as early as within the first four or five years of symptoms.

Melani Dizon:

Great. A couple of questions about drug interactions. Somebody with Parkinson's also has diabetes, and they said that "I've read where diabetic medicines, Diabeta, I don't know if I'm saying that right, was being used or tested for use or Parkinson's. Actose was previously pulled for diabetes because of heart impact. And do you, do you have any information on crossover meds contrary to date and contra indications or

interactions with other Parkinson's needs, like comorbidities, things like obviously diabetes and other issues that people are dealing with?" What are some of the like more tricky cross crossover meds that you've dealt with?

Dr. Aaron Haug:

One of the things that's nice about Parkinson's medications is that most of them have few interactions with medications that are used for other health conditions, like high blood pressure, high cholesterol, diabetes, even blood thinners. You know, I'm just thinking through the categories—levodopa; dopamine agonists; monoamine oxidase B inhibitors; COMT inhibitors, A2A antagonists, the anticholinergics; and amantadine—and there's not a lot of big interactions through metabolism in the kidney or metabolism in the liver. I think it's maybe, and we mentioned this in the other webinar, one of the red flags that pops up most often is between the monoamine oxidase inhibitors, like Rasagiline or Selegiline and antidepressants. There is a boxed warning about the potential for too much serotonin when those things are used in combination together. And I would say that in clinical practice, we use that combination with good effect and without intolerable side effects, thousands of times. So that's one of the things to theoretically be aware of, but tends not to be much of an issue in practice. Looking at it the other way, in terms of some of the diabetes medications that were studied for possible disease modifying effects in Parkinson's—I'm not aware of any evidence that those things have panned out to a large degree. So at this point I would say it's a kind of a boon that Parkinson's medications don't have a lot of interactions with medications taken for other health conditions.

Melani Dizon:

Going back to, well, actually somebody asked about taking Gabapentin for restless leg syndrome. Are there other medications that are often prescribed for that?

Dr. Aaron Haug:

So restless leg syndrome is common in the general population and even more common among people with Parkinson's. And sometimes the medicines that we use to treat the core motor symptoms, including carbidopa/levodopa and particularly the dopamine agonists like the Neupro patch or the Pramipexole, Ropinirole can also be helpful specifically for restless legs. And they are sometimes given to people with restless legs that don't have Parkinson's. Gabapentin. Is that also on the list of things that can be helpful in for restless legs that doesn't really help the other physical symptoms of Parkinson's. A note of caution about some of the medications like Sinemet and the dopamine agonists is that when it comes to restless legs, those medications can sometimes lead to a phenomenon of augmentation over time where the symptoms of restless legs can be worse with prolonged use of those medications, which creates a dilemma because they may be necessary for the treatment of the Parkinson's motor

symptoms. But I would say that those are some of the most commonly used medications for restless legs. Some less frequently used ones are an old category of antidepressants called tricyclic antidepressants, like amitriptyline, occasionally benzodiazepine, such as clonazepam, can help restless legs as well as helping some other things like insomnia. And sometimes the cramps that we talked about earlier. So those would be probably some of the most commonly used medications.

Melani Dizon:

Okay. Yeah. So are his restless leg at all related to dystonia? Is it often if you have restless legs, you often have dystonia, or is it just totally separate?

Dr. Aaron Haug:

I would say that they're separate. But they're all common symptoms of Parkinson's. So a person's could certainly have all of the above.

Melani Dizon:

Okay. What about high protein diets? A lot of people are talking about timing, and I know we've talked about the timing of protein and carbidopa/levodopa and absorption and that kind of thing, but is there, is there any evidence that keto or a high protein or carnivore diet is ideal for somebody with, and is it, is it just the timing that they have to think about or are there other things that a high-protein diet might influence Parkinson's symptoms or progression?

Dr. Aaron Haug:

Yeah. I would say there's unfortunately not a lot of strong evidence to guide us about what type of diet is optimal for a person living with Parkinson's. Protein in particular does have this potential for decreasing the absorption of carbidopa/levodopa. And so I will typically say that if you're going to have a high-protein meal that the levodopa should be at least half an hour before, or at least an hour afterwards, but in terms of other, a carnivore or high-protein diet has specific benefits for Parkinson's, it's not something that I've seen much about at this point.

Melani Dizon:

Let's see. Freezing of gait is a very common symptom for people with Parkinson's. And is there anything medication wise that helps with that?

Dr. Aaron Haug:

Yeah. Freezing of gait can be a real challenge. So when we talk about freezing of gait, we mean that when a person is initiating walking or turning or going through a threshold, like a doorway, that the feet feel like they're frozen to the floor. And I would say that sometimes the medications that we use to treat other motor symptoms like Sinemet, like

the dopamine agonists, can have benefit for freezing as well, but freezing can sometimes be refractory to standard treatment options. So there's not a lot of science to guide us about what other tools deeper in the toolbox are clearly helpful for freezing, but there are some small amounts of evidence for Rasagiline potentially being helpful. There's interestingly some research that shows that anxiety and freezing can create a vicious cycle. And so sometimes treating the anxiety with SSRI medications like Prozac or Paxil can have a benefit for anxiety, and in turn that helps the freezing. And the last tool that I will sometimes pull out the toolbox is methylphenidate, which is Ritalin, which is a stimulant use for other things like ADD. And sometimes that, medium or higher doses, that medication can provide an improvement in freezing in ways that are not clearly understood, maybe by increasing attention and concentration. That medication, which we haven't mentioned in another context, has a couple of specific side effects of which to be aware, including feeling jittery and the potential to raise blood pressure sometimes to an unwanted level.

Melani Dizon:

Okay. What's the difference between amantadine and Rasagiline?

Dr. Aaron Haug:

Yeah. Good question. I would say one of the ways to ways in which they're similar is that they both have some anecdotal evidence for maybe providing a little bit of activation or alertness. They've been studied for fatigue and showed maybe some mild benefit for fatigue. And they're both medications that can be used in mono-therapy for Parkinson's that don't need to be combined with anything else. But otherwise they're from separate categories of medications. So Rasagiline is one of these monoamine oxidase inhibitors. This slows down that MAOA enzyme and thereby allows more dopamine to remain in circulation in the brain. Amantadine is a medication that we don't fully understand the mechanism of. It seems to potentially lead to an increase in dopamine release from cells and also modulates some pathways related to another neurotransmitter called glutamate. And amantadine has the special role of being the only medication where you can get more Parkinson's treatment and potentially bring dyskinesia down. It is one of the only medications used to treat dyskinesia.

Melani Dizon:

Okay. You said monotherapy. So in what instance, so we know carbidopa/levodopa has been the gold standard for 50, 60 years, and it's typically the first line of medication. Under what circumstance would you not take that and go for a monotherapy of something else? What prompts you to do that?

Dr. Aaron Haug:

This really gets into the art of treating Parkinson's and living with Parkinson's because different Parkinson's specialists would even give different answers to this question. One of the reasons to potentially consider carbidopa/levodopa as first treatment would be that for most people, it is the most powerful medicine. So if symptoms are either causing significant embarrassment or difficulty with activities of daily living or interference with work, then often starting with the most effective medication first, and keeping it at as low of a dose as possible, maybe one tablet of 25/100 milligrams three times a day is a reasonable place to start. And that's where I often start my patients.

If a person has maybe really mild physical symptoms, enough to be diagnosed, but they're causing much functional interference and they say, well, you know, my symptoms are a little bothersome, but I don't really feel like I need to treat them, that's a situation where I will sometimes start with Rasagiline as initial therapy. It tends to be kind of a small tool in terms of how powerful it is for treating tremor, stiffness, and slowness. But it has a putative disease modifying effect. This is controversial. There's not strong evidence that Rasagiline has any disease slowing effect, but there was some research in the late nineties and two thousands that showed maybe it has a disease modifying effect. And I will often use that medication either early on in that situation for this possibility of disease modification or it is often one that I will add second or third for that same reason, in addition to the fact that Rasagiline has this booster type effect, where it can make each dose of Sinemet, for example, lasts longer, it works stronger. Amantadine as an initial monotherapy is not something that I really do, but it is something that other practitioners will sometimes do, and that may just be to postpone initiation of carbidopa/levodopa.

And we talked some about that in the other webinar, but just to mention it here as well, carbidopa/levodopa is the most effective medicine for tremors, stiffness, and slowness — the core motor symptoms. But the more years that a person has been on it, the more likelihood that there is of developing motor complications and those complications can be either the on-off fluctuations or dyskinesia and other medications can lead to those issues as well. But carbidopa/levodopa seems to shorten the timeframe for some people at which those complications occur. So one reason to use either Rasagiline and/or amantadine or a dopamine agonist first as part of a so-called levodopa-sparing strategy would be to push off those complications maybe to a somewhat later time than they would otherwise.

Melani Dizon:

Okay. So the carbidopa/levodopa orally disintegrating tablets, do they have a quicker effect? If yes, what is the, what, what is the downside of taking those? Why wouldn't anybody just, just take those?

Dr. Aaron Haug:

Yeah. So the oral dissolving tablets, their old branded name was Parcopa. They are also carbidopa/levodopa, just like the regular, usually yellow tablets that a lot of people take that are quite a bit more prevalent. I would say that the oral dissolving tablets, their main clear advantage is if someone has trouble swallowing, then the tablets can dissolve and they're easier to get down that way. And that's why, that's probably the most often the reason that they're prescribed. One of the reasons that they're probably not prescribed as often as that there was initially some costs differential. It became available after regular carbidopa/levodopa, and was a branded medication for a longer time. It was quite a bit more expensive for a time. Currently, I'm not sure if there's a significant cost differential looking at a source like goodrx.com might be helpful for comparing. But I would say that there likely is a slightly faster onset. I don't know that it's been studied. I'm not aware of any data that it has been, and it probably tastes less bad than chewing up or crushing regular carbidopa/levodopa, but you can do that as well. So I would say it's probably slightly faster. And the fact that it's not used more broadly may be an issue of cost, or may just be an artifact of the times at which medications became available.

Melani Dizon:

Okay. Three people wrote in about having trouble breathing, panting, shortness of breath, just breathing, but from taking carbidopa/levodopa. They can't take the full dose because then they just start this panting. And is there anything that can be done with that? Somebody said that their doctor told them to have coffee, and that actually helped a little bit, but then it really messed with their stomach. But is that, is that a common, common thing that, that people have that shortness of breath?

Dr. Aaron Haug:

Yeah, it is not common, but it is possible. And the reasons for it are not fully understood. One of the things that it makes me think about would be if this is a person who has any physical dyskinesia, those that are visible, like had a neck dyskinesia or extremity dyskinesia is the diaphragm sometimes can develop dyskinesia is as well. And if this is, you take the medicine and then 30 or 60 minutes later, you're having this trouble breathing, that may be that you're having this unfortunate symptom of diaphragm dyskinesia, which are difficult to diagnose. And some people it wouldn't even occur to, but if that is the case, then taking a lower dose and fractionating it, like we talked about earlier, maybe helpful because the dyskinesia is, tends to be worst at the peak of the dose. Likewise, changing from regular release carbidopa/levodopa to one of the controlled release formulations, maybe helpful, or potentially adding amantadine as a treatment for dyskinesia. This may be helpful. But that would be the thing that I would mostly think of in that circumstance.

Melani Dizon:

Okay. What is your first line of defense for pain, for people that have, you know, really bad stiffness and just all over pain and maybe, you know, maybe dystonia, but just all different types of pain?

Dr. Aaron Haug:

Yeah. Pain is an under-recognized symptom of Parkinson's. And I think sometimes I'm even guilty of not recognizing it to the extent that I should for my patients. I think the first line of treatment is making sure that dopamine replacement therapy is optimized. So making sure that, "Oh, yeah, you're, you're stiff as a board. I think we need more carbidopa/levodopa," would probably be first. If we seem to have the medications optimized and it's just kind of an all-over total-body pain or aching pain, I'll have to have them see their regular doctor, or maybe even an orthopedist to make sure that there's not some separate joint related issue, but if we rule that out and it seems to just be pain related to Parkinson's disease, then some of the other tools in the toolbox would be a medication like Gabapentin that we mentioned earlier, or more of a recent cousin, pregabalin, which was only available as Lyrica until some recent time.

And then beyond those medications, we will occasionally get into the use of opiate or narcotic medications. And that's something that doesn't come up, doesn't come into play very often in my experience. But that would probably be the kind of next and last line of treatment. Okay. Oh, just to say, also typically over-the-counter pain medications, like acetaminophen, which is Tylenol, or ibuprofen, which is Advil or Motrin. Those are usually okay. Although you would want to make sure that you're not taking them too often where they could cause stomach upset or even ulcers, or they could cause your kidney function to change in a way that would only be observable with routine blood testing. So if those were being used often and at a high dose, then some amount of blood monitoring may be necessary.

Melani Dizon:

Okay, great. Well, I am through all my questions, my many pages of questions. Is there something that I shouldn't have, I should have asked that I didn't ask about medications that you get frequently from your community that I didn't touch on?

Dr. Aaron Haug:

No, I think between this webinar and the other one, which I've encouraged people to check out if they ended up seeing this one first, I think we've really covered the bases pretty well. You know, there are so many people living with Parkinson's and the path is different for everyone. So we can't answer all the questions here. But I think that this



hopefully has answered some of the questions you might've come with. And I hope that it's been helpful.

Melani Dizon:

Yeah, absolutely. Super helpful. And also just, you know, go to your doctor. If you learned something here that you didn't know, and you've been wondering about go to your doctor and say, "Hey, I learned this, like, what can we do about it? How can I change this? This doesn't feel like it's working for me. Are there a couple of different combinations we can try to, to help you with symptoms?" So don't be afraid to go to your doctor. And if you can track something, even better. The, your doctor will appreciate if you go to them with information. Like Dr. Haug said, you don't have to get so crazy that you're, you're monitoring every single solitary thing that you take when you take it. 'Cause that's not a life, very fun life. But you can track a little bit to get, to get more information. Thank you to everybody who listened. If you have any more questions at all about medications, feel free to email me at blog@dpf.org. And we will see you soon. And Dr. Haug will be here to answer more questions in the future, I hope

Dr. Aaron Haug:

I will be happy to. Thank you very much.

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