



The What, When, Why, & How of Treating and Managing Parkinson's Dyskinesia  
with Dr. Irene Malaty  
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Davis Phinney Foundation

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

Hi and welcome everybody. My name is Melani Dizon. I'm the Director of Education at the Davis Phinney Foundation, and I'm really excited to be here with everybody to talk about Parkinson's dyskinesia. We have Dr. Malaty joining us from the University of Florida. We have Amy Carlson, who is a DPF Ambassador, and Sidney Donahoo, DPF ambassador, and Karen St. Clair, who is a Parkinson's care partner. And we're really excited to have all of you here today. This is going to be a great and interactive session where we're going to learn a lot about the medical aspects of dyskinesia, and then also from people who experience dyskinesia on a regular basis.

I'm going to tell you a little bit about Dr. Malaty before we get started. She completed medical school at Indiana University School of Medicine before completing a neurology residency and movement disorders fellowship at the University of Florida.

She devotes her practice to clinical care research and education across the movement disorder spectrum. She specializes in the care of Parkinson's and is director of the Parkinson Foundation Center of Excellence at the University of Florida. Dr. Malaty is a primary investigator in several trials in movement disorders and helps direct the movement disorder trials at the University of Florida. In 2017, she became the first female president of the Florida Society of Neurology. She aspires to advocate for improved care and education and neurological disorders through this role and in her national position on the movement disorders subsection of the American Academy of Neurology. Welcome. Thank you for being here, Dr. Malaty.

Dr. Irene Malaty (Parkinson Foundation Center of Excellence at the University of Florida):  
Thanks for having me.

Melani Dizon:

Great. And Amy and Sidney are here because they have both experienced dyskinesia in different forms, and Sidney has DBS. So she'll talk a little bit about that and her dyskinesia. Amy has not had DBS yet, and she's going to talk about her experience with dyskinesia, and then Karen St. Clair has been a Parkinson's care partner, does a lot of support groups, has lived with people who have dyskinesia. So she's going to talk about what that is like from a care partner perspective.

So I'm going to get started. What is Parkinson's dyskinesia, Dr. Malaty?

Dr. Irene Malaty:

So dyskinesia is the abnormal, involuntary, and excessive movement that can be seen in Parkinson's. So when people have Parkinson's long enough, sometimes it could start in the five-to eight-year mark, sometimes sooner, sometimes later, people can begin to experience when they take their dopamine replacement medication, when it's at the peak of dose, most commonly involuntary wiggling movement. And most commonly there'll be some truncal movement. Sometimes it can be more subtle and be an arm or a leg having some rolling movement. Most people experience dyskinesia when the medicine's at its peak, but there is an a lesser subset of people who actually have what we call diphasic dyskinesia, and those people can experience it when they're wearing off. And when they're kicking in with their medicine. So even when dyskinesia occurs is not the same for every single person.

Melani Dizon:

Great. Cidney and Amy, do you have something to share about like, sort of when it works for you and when you're most dyskinetic?

Cidney Donahoo (DPF Ambassador):

Well, for me, I had the more the diphasic, and so it happens when it, like Dr. Malady said, when it kicks in and when it wears off, it for me is more prominent when I'm wearing off. And it's different, it's not much these kind of movements like this. It's more of a writhing type of movement in my leg and my right arm. And so it's a little bit different than what Amy suffers from.

Melani Dizon:

Okay. Amy, what about yours?

Amy Carlson (DPF Ambassador):

So what I find with dyskinesia is it's typically, I have peak-dose dyskinesia for the most part. I also, I get dyskinesia anytime I eat. It's there. If I'm eating, if there's food, I get dyskinesia. My doctor says that that's very common, and I'm not going to try to explain why, because she tried to explain it to me. It made sense when she said it, but now I can't repeat it because it doesn't, you know, it's too complicated, but in either case what I find for mine is it's not as much of the Michael J. Fox variety, which seems to have this kind of pattern.

Mine is much more aberrant movement, which by that, I mean, it just, things just do, you know, my body does these strange movements that I didn't plan, but there they are.

Melani Dizon:

Okay. And so would you say that you're at peak dose right now?

Amy Carlson:

Yeah, possibly. It also could be, I mean, this is a classic time for me, right around noon, one

o'clock, I just am here in this place. That tends to be that way. And it may just be that I've stored enough. I've taken enough levodopa for me throughout the day that now I've stored enough, that it's kind of hitting that threshold. I often find that if I exercise right now, I can tamp it down a little bit, but I'm not sure that that's really true. I just kind of live with it and work with it.

Melani Dizon:

Okay. So Dr. Malaty, a couple of people asked about if dyskinesia is lessened if you take the brand name of carbidopa/levodopa versus the generic. Is that, is that a thing? Has anybody experienced that?

Dr. Irene Malaty:

I would say that would be unlikely. The reason some people, the most common reason, some people prefer brand is that they perceive there to be more potency, meaning they would, they would think that, although there are requirements for a certain percent bioavailability, meaning the generic has to be close enough to the brand to be acceptable, there are some rare people who feel like that little percent different is relevant for them. Or maybe they had some kind of an allergy that they think may be different in some inactive component of a pill that's made by one maker or manufacturer versus another. Those would be some of the reasons. So really if you're increasing potency, unless you have the exceptional diphasic dyskinesia and you're bothered like Cidney is when it wears off, she wants more during that time; for most people, it would be actually more and it would not reduce dyskinesia.

Melani Dizon:

Okay. I want to talk about the different types of dyskinesia in a minute, but is it common for, let's say you have, your doctor has prescribed that three times a day, you're going to take the carbidopa/levodopa, and during your first time of maybe a peak dose or wearing off, I guess it depends on what kind of dyskinesia you have, that it's, it's pretty bad, but that second time it gets worse. And by the third time, during the day, it gets even worse. Is that a common sort of pattern throughout the day that it's just going to continue to get worse?

Dr. Irene Malaty:

Yeah. And again, every person has their own different patterns. So there are definitely no rules. There's always a saying that if you've met a hundred people with Parkinson's and you've met a hundred different versions of Parkinson's, but the truth is it would be a commonality that people might say it gets worse as the day goes on or in the late afternoon, like Amy said, and there are a few reasons for that. One is that as she said, if you've already had some in your system, then each subsequent dose may be building upon that. Whereas overnight, you've commonly gone all night without medicine or with less medicine, and so in the morning, many people are at the low point of how much medicine is in their system. Another thing that's very common in Parkinson's would be abnormalities of the gastrointestinal tract, the GI tract, and how your guts move and how your stomach moves.

And you can have delayed gastric emptying. So your stomach may empty slower, and your guts may move slower and abnormalities in that sense. And so a real common symptom, almost everyone with Parkinson's has experienced constipation. Not every single person, but it's awfully common. I'm sure many people in the audience are probably nodding their heads. And oftentimes it even shows up before the Parkinson's is real obvious. And constipation is a symptom of that slowness of intestinal movement. And that can actually affect how you absorb your medication. So if it's not getting to the part of the intestinal tract where it gets absorbed, and then it suddenly kind of all dumping there at once that can affect certain times of day can result in having more medicine absorbed at those times. The other factor that some people will experience is when they eat their meals, particularly high protein meals, they may experience a reduction in the amount of medication absorption.

So they might say, *After I eat my dinner, it's like my medicine stops working*, or they may say, *I can't eat a whole bunch at once because it'll, it'll negate my medicine*. And that's because your food is getting absorbed also; it's competing for absorption. So it may actually interfere. And some people will have to time their meals to avoid them causing interactions with how much medicine is absorbed. And so an optimal way would be if you took your medicine 30 minutes before you eat, or two hours after you eat, you may absorb a little more out of it. Now in early Parkinson's, I commonly tell people to take their food, take their pills with their food. Because they'll remember what their meal times are in an early Parkinson's case. It often doesn't make enough of a difference to really rearrange the whole day. But if people have had Parkinson's for some time and they're very sensitive to those changes, sometimes they can get a little bit more out of their medicine by separating it from mealtimes.

Melani Dizon:

Okay. I was speaking with somebody yesterday about this idea of gut-stomach dyskinesia, that actually it happens in your stomach. Is that a thing where you can, your stomach is, actually gets dyskinetic and that can cause pain in the stomach and can cause uncomfortable sensations in the stomach? And I was like, Oh, I had never heard that before.

Dr. Irene Malaty:

I think it would be more common to have dystonia affect the trunk. And so that can be involuntary muscle clenching, almost like a twisting or cramping feeling. Commonly people experienced dystonia in their feet. And so they may have toe curling or cramping or their feet trying to turn in. Some people have cervical dystonia and they could have a tilt in their neck or a tension in their muscles and a pulling to one side. And in fact, dystonia can affect the truncal muscles and cause a pulling forward and a pain. We don't tend to talk about dyskinesia in the abs causing intestinal movement prompts or different kinds of muscles in the gut versus in our limbs. But you know, people experience different kinds of discomforts when they have dyskinesia. Respiratory dyskinesia is another rare variant, where when people are at their, most commonly at the peak

dose, they will have a panting or a feel like they can't breathe and that they can have an irregular respiratory pattern. So, you know, every, everybody can experience dyskinesia a little bit different.

Melani Dizon:

Okay. So in speaking to that, is there dyskinesia that doesn't, that is not related to the side effect of medication? Do people have dyskinesia just because their Parkinson's is progressing, for example? Can you, after, let's say you take your last dose of carbidopa/levodopa at mid-afternoon and then you wake up in the morning and all that medication is not in your system, but you are very dyskinetic, what's going on there?

Dr. Irene Malaty:

So I would say that if you never took medicine, you would not have dyskinesia. So the first part of your question is "Can dyskinesia be independent of medicine?" And so the pure answer is no, if you don't take, levodopa, you would just be stiff or slow or shaky. And you wouldn't experience dyskinesia or an overriding, I mean, an overactive muscle movement. You would have underactive movement. And so they've looked in different countries where people couldn't get Sinemet or levodopa early in their disease course. And once they started it, some people are afraid of levodopa or medicines because they think it will bring about dyskinesia, but it's been shown that the duration of how long you have Parkinson's is what predicts dyskinesia, not how long you've been on medicine.

So if you waited until you had really super bad Parkinson's and then you started medicine, you could immediately have dyskinesia because you're in that phase of Parkinson's. But if you're asking me, well, *I know somebody and they didn't take it for many hours and then they had dyskinesia before they took it*, I would say that's really unusual. And it would be hard for me to say, to explain that because it's not typically seen in somebody, you know, aside from fluctuating with their medication fluctuations.

Amy Carlson:

I wanted to talk a little bit about diet because I think that Dr. Malaty brought up some really great points about eating. And one of the things that I noticed is that I know a lot of people with Parkinson's love sugar and and so, and I found myself for a long time kind of regularly taking my dopamine, but then I'd also hit the caffeine sugar button at times. And I finally decided that that was a bad idea one day. Actually there's a long story about that, but in either case I kicked out sugar and out of my diet for quite some time. And I, I went, I'm not going to say that I went keto. Okay. I'm not, I'm not advocating that, but that was how I know that I was not intaking any sugar, no carbohydrates.

And it, and people are like, *Oh, did that really?* I think what it did is it made me tune into my need for dopamine, much cleaner because the sugar kind of, you know, gives you that high. And then you crash and then your dopamine cycles over here and all, and you're very confused. Your diet can help you, but it can also make you make it difficult for you to feel what's going on internally in

your body. And so by eliminating sugar and that sugar rush and in also a little bit of caffeine, caffeine can be good and in a different way, but it helped me home in on when I was feeling ON and when I was not feeling ON much cleaner. And that really helped me control my dyskinesia, because I was feeling very dyskinetic a lot of the times.

And when I got rid of the sugar, I was much more able to dial in. And I wasn't experiencing nearly as much dyskinesia when I was low on sugar. Now COVID has kind of like killed that. And I'm all about the cherry pie and the ice cream now. So as you can see, I'm a little bit dyskinetic, but my feeling is that the, that sugar can be an enemy and it can be a way to tune into your dopamine needs. And so again, you know, what you feed your body is really important.

Melani Dizon:  
Right. Food is medicine.

Dr. Irene Malaty:  
I would comment that, you know, for you, Amy, it sounds like sugar is a major variable. That's important for you, and for someone else that may or may not be. But I would say that each person can tune into their own special triggers. So for some people they go, *Every time I'm stressed, every time I'm around, that's almost everybody, every time I'm around people or I'm excited or I'm like answering the phone, suddenly something I wasn't expecting.* And so you kind of tune into your own triggers. And if you know, *This situation always makes me a little worse, or This makes me a little better,* try to use that to your advantage or at least plan that. So, you know, you can sometimes make adjustments that are personal, that are actually helpful for you.

Amy Carlson:  
Absolutely what the doc said. I mean, I can't advocate enough for trying to explore that and understand that about yourself. And sometimes it takes doing a little bit of the hard work, you know, like what happens if I give up sugar? What happens if I alter my diet? So I'm only eating protein when I'm not really being rigid, rigid with yourself and trying some of these things and seeing how it affects your body, I think is something I would encourage people to do.

Melani Dizon:  
Thanks. Thanks, Amy. Great points.

Karen St. Clair (Parkinson's care partner):  
Yes. When Rob's dyskinesia was particularly bad, we actually kept a chart with all the hours of the day along one side, and then his meds — he was taking medical cannabis at that time — and just really, you know, like what was happening at that particular time to get a feel for what could be impacting it more than something else. And, and actually we were also tracing you know, kind of keeping track with the medical cannabis helping the dyskinesia, and was he getting longer periods of without being dyskinetic by using the medical cannabis? So sometimes keeping a chart can be

real helpful to figure out what is happening. And it also helps your doctor to figure out what's happening with you.

Melani Dizon:

Yeah, absolutely. I mean, if you can go to your doctor armed with that information, that's only going to make the best use of your time with your doctor since it's so limited. Anyway, Dr. Malaty, we've spoken about a couple of different types of dyskinesia. Are there any others that we need to address that would be helpful for people to know? And then I'd like to talk about Cidney's diphasic and then how it has to do with her DBS and that kind of thing.

Dr. Irene Malaty:

I noticed one comment come up on the chat that said, "Can tongue thrusting be a kind of dyskinesia?" Absolutely. Yes. So pretty much head to toe, you can experience dyskinesia. Some people have head movements. Some people have a lot of facial movement. Funny facial movement. Some people have just a subtle moving of their arm when they walk, or maybe it pulls behind them when they walk. Some people, their foot will kind of take a little extra wiggle on the way forward. And so that's one of, sometimes dyskinesia of the foot can actually impact your balance and your gait. So here you're ON and your medicine's working better, but sometimes if the dyskinesia is too much, it can actually impact your balance. And so those are some of the more common ones, pretty much anywhere from head to toe, you can experience it most commonly. It will be more on the side. That's a little more affected. So most people with Parkinson's have a bad side and a good side. It usually kind of starts on one side, kind of picks on one side more than the other you could say. And usually the side that's worse when it's bad is also the side that has more dyskinesia.

Melani Dizon:

Okay. So actually bring up a point — so for people who are, let's say they're motor-symptom dominant and they have tremor as well, are those people more likely to then have dyskinesia than, let's say, people who maybe don't have tremor or, you know, that's not part of their, symptomology?

Dr. Irene Malaty:

I'm not sure that anybody has looked at whether people with tremor are more prone to dyskinesia. I think pretty much every subtype of Parkinson's could have dyskinesia. I think tremor predominance is the most common and so it also is a common category that doesn't experience dyskinesia. And if I had to guess, I'd say, yeah, it's probably maybe a little more than people who are really akinetic rigid, meaning more stiff and trouble moving at all, compared to people who experienced tremor as a prominent part. But I'm not sure if that's been scientifically explored or not.

Melani Dizon:

Okay. Cidney, can you talk a little bit about the type of dyskinesia that you experience and then also, what role did DBS play? In your decision to get DBS, and then how is your dyskinesia now?

Cidney Donahoo:

Yeah, so like I said, I have biphasic (and I've heard it called diphasic and biphasic, both). Both things, it is kind of hard to get some information on, and I didn't really realize, I didn't know what it was until I actually went to Washington D.C., to the NIH and they said, "Oh, you have, you know, you have biphasic dyskinesia or diphasic." Anyway it, before I had DBS, it really got to the point where I was going ON and OFF. So I mean, the, you know, the, the ups and downs were so, so consistent so often. And when it was happening, because it was primarily in my right foot and it was writhing around; I had to be very careful about what I was doing. I mean, there were times when I was driving my car and I had to pull over because I was not safe.

And so when I had DBS, it did help, but it's been a real challenge to program for, with the biphasic. And I have heard several different people who have said that with the biphasic, you really need to go in more often. So you, after you get your DBS, you typically will get your first program maybe a week a month later, and then a month after that. And then they'll, they'll keep, you know, making the intervals bigger. With biphasic, they really like you to go in far more often, just because it's a little bit trickier to program. I'm, I haven't found, I've never really found a place where I don't have dyskinesia with the DBS, but the dyskinesia is much less invasive, I guess, in my life. You know, it's not as powerful, so I can still drive.

I can still do a lot of what, you know, I couldn't do before. I've had to also use it with medication regimen. So I started Rytary a few months ago, and that's really helped because that kind of spreads out my ON time. So I guess if somebody is looking into DBS and they've got biphasic or diphasic, I would just make sure that your doctor and your surgeon know that this is an issue because it's going, you know, it's going to be, it's going to be affected by the DBS.

Dr. Irene Malaty:

It looks like from the comments coming on the chat that maybe it'd be helpful if we just take a minute to side step and explain what DBS is. I see some questions, "What is DBS?" And some of us have taken certain words so much into our vocabulary that we forget. They may be new terms for other people who are newer to the family. So why don't we just take a minute and just talk about what — and I saw "Is that the pump, what is that?" So let's take a quick minute to talk about medicines versus the pump versus DBS. What does that mean? And then we can jump back in. And Cidney, I'm sure everyone appreciates you sharing your experience because some people have the surgery and it's just like magic and their dyskinesia is gone and they're so happy. And then other people have more of a struggle.

And it's worth knowing that both are both are possible abilities. So when people have dyskinesia,

most commonly, it relates to fluctuations. And when having Parkinson's long enough that there are certain changes in the brain that relate to low dopamine and less neurons that use dopamine, and then replacing that to relieve the symptoms, but in a way that is not the natural way where we have dopamine all the time, but we're replacing it and it runs out and we replace it and it runs out. So we call that pulsatile. When that happens, it's not the total natural state, and that results in some side effects. And one of those can be dyskinesia. So some of the things we do with medicines are either taking less medicine more often to avoid dramatic ups and downs; using slower release forms of levodopa; and somebody in the audience probably heard Cindy say Rytary and said, "What's that?" Rytary is a form of carbidopa-levodopa that is kind of a mixed; it has beads inside, so some of them are immediate release and some are more time-released so that it spreads it out. And some people find that instead of having ups and downs, that having a more smooth ups and downs for some people can alleviate some of that.

There are add-on medicines like amantadine preparations that can sometimes offset dyskinesia. So sometimes we're adding things that try to smooth out the ups and downs. And then we also can talk about surgical therapies that Cidney brought up. Deep brain stimulation means putting in a wire or an electrode in the brain, into the areas that are most involved with Parkinson's, and attaching it to what's like a pacemaker in the chest. Sometimes it's implanted in the abdomen, but most commonly in the chest, and that battery pulse generator generates electrical pulses that change the firing pattern in the brain and alleviate the symptoms.

So deep brain stimulation is that electrical stimulation in the brain that can be part of somebody's therapy regimen for their Parkinson's and for some other conditions, too. And for some people, it can be really effective at reducing dyskinesia. For some people, it gives them some motor benefit that lets them reduce their medications, and that can avoid some of the peaks. And for other people it may be less of a complete home run. Most commonly it's quite good at reducing dyskinesia.

The other surgical option that somebody asked about in the chat is the pump or continuous carbidopa/levodopa enteral infusion, meaning a small little tube is implanted in the belly that goes through the stomach and an inner tube goes into the intestine. And so the levodopa goes straight into the intestine. They wear a small pump, well not a small pump, it's about the size of a brick. They wear a pump either on their waist or in a bag or in a vest and that little pump they put on in the morning and take off at night. And it just continuously infuses the levodopa continuously all day long to avoid ups and downs. And to skip the stomach for some people who have problems with, with that affecting their absorption a lot.

And so sometimes when people, Cidney said she was up and down all day long. And so when some people are kind of feeling like a yo-yo all day long or taking really frequent doses, they may prefer to just have it go right into the intestine continuously. And they can give an extra dose when they need to through that. And it has to be programmed, just kind of like the surgical stimulator

has to be programmed and adjusted to try to control symptoms.

So I just wanted to put out there what those therapies are. So people in the audience were going, "What are they even talking about? Can I kind of have a little intro?"

Interestingly, there's some research going on now that's looking at continuous subcutaneous levodopa infusion. That means instead of going in the gut, it kind of goes right under the skin. And it's infused that way so that it's not a surgical procedure, but it does involve some little needle-like prongs that you just kind of put a patch on that lets it infuse that way. So a lot is going on and a lot of research trying to look at more continuous delivery. Those are sort of some of the current things that are being done.

Karen St. Clair:

And subcutaneous one, that's been used in Europe now for some time, hasn't it?

Dr. Irene Malaty:

They've had subcutaneous apomorphine. I'm not sure that the subcutaneous levodopa is already being used there outside of trials. Yeah. I'm not sure about that.

Amy Carlson:

I think they have it in Israel.

In Israel, one of the companies — there are two companies that are working on that pump and one of them is from Israel. My understanding is that it's still in a trial and not already approved there, but I actually don't know. I'm not sure if they have it in Israel already.

Amy Carlson:

It's just rumors that I'm hearing. So don't, don't rely on me.

Dr. Irene Malaty:

Well, they've been doing these studies there for a few years now, so it is possible.

Melani Dizon:

Great. So a lot of people have asked about, "Is it, is it going to progress?" Is that just a natural thing that the dyskinesia is going to get worse over time or can do some people just, you know, they have it and it just kind of stays at that level.

Dr. Irene Malaty:

I would say that it's common that it can be more bothersome over time that in the beginning. It can be sort of mild and not too, not too much of an interference, and many people would rather have just a little bit of dyskinesia and feel like they can move and do what they want to compare to

feeling OFF and feeling really trapped. Most commonly if you have Parkinson's long enough, then things that are bothersome can be a little more bothersome. So that probably the most (but I never say always. And I never say never, except just now.) So I would say that, you know, there might be someone who says, well, I've had it 10 years and it never got worse. So everybody's a little different again, but I would say commonly, it could start out as a really mild nuisance and it can get a little more irritating over time.

Melani Dizon:

A bunch of people wrote in about distinguishing between tremor, dyskinesia, and even dystonia. Can you give them a quick, you know, thing to help people identify what, what is what?

Dr. Irene Malaty:

Yeah, sure. I'm so glad somebody asked that because again, we forget how important it is to explain the words that we're using. And if you ask someone, sometimes people come in and they just say, "I'm wiggling," or "I'm moving at night and I can't sleep because of movement." And it can be hard to kind of be a detective and figure out which kind of movement. So tremor, you know, to use a non-helpful word sort of oscillation. So it's kind of like a jerking movement. Most commonly, it looks like this. And it used to be called a pill-rolling tremor cause pharmacists used to roll pills like that. And so usually a tremor is a regular oscillation. So basically like a back-and-forth kind of movement. And you can have tremor in your jaw. You can have tremor in your arm and your leg, different body parts.

Dyskinesia is kind of more of a dancing, like wiggling sort of movement. It's a little bit more of an irregular kind of movement. Dystonia most commonly is a tensing up of muscle. So tensing or twisting of muscle. So somebody, I thought I saw a comment go by that said something about "My toes are drawing back." That would typically be dystonia where there's an involuntary activating of muscles that should sort of be working in coordination. But instead they're just tensing at the same time. And those would kind of be the differences. And sometimes if you don't know, the very best thing you could do would be pull out your cell phone, if you have a smartphone, and take a one minute video or a couple-minute video, have someone take it over the movement, the bothersome movement, cause it's very common.

You could have all three of them. And we want to know which one's annoying you because the strategies can be different for the three different types of movement. If you're having tremor, the same kinds of therapies, the multiple types of medicines we have for Parkinson's including the surgical therapies may be helpful. If you're having dystonia, you may need an adjustment of your medicine timing, but also we have botulinum toxin injections. Some people refer to those as Botox, although Botox is one of four brands that are available for botulinum toxin injections. And that can be done in relaxed muscles, for instance, the toe curling and the neck pulling. It lasts about three months at a time. And sometimes if the medicine's doing really great and that's the

only bothersome thing that might be a good strategy to augment the oral medications.

Amy Carlson:

I was going to jump in a little bit on, on how it feels, like, because sometimes it's hard to, it's a little bit easier to understand what it feels like from the inside for. So I want to talk about that for a little bit. I mean the tremor, to me tremor is very you know, it's pretty distinct. You can see it in, in the beginning, you can't. And the thing about tremors, I almost always know when it's tremor. If I use that muscle in intention, the tremor tends to go away for a short amount of time. So if my hand is trembling and I purposely make a fist or I go to do something with that hand, I can stop the tremor for a second or two, sometimes longer. So that helps me know that that's a tremor because tremor only happens when you're at rest. Tremor will not happen, my understanding is when you're sleeping, which I find interesting but whatever,

Dr. Irene Malaty:

Oh, it does tend to go away with sleep, but it can keep happening with action for some people. But you're definitely right, that the most common is at rest. And that many people like you will say, "Well, it'll go away for a minute. If I tend to sit up or if I move it." So that is the most common type of tremor, but of course, some people are not quite that lucky and they actually have tremor with actions, too.

Amy Carlson:

Right. And so the whole thing about squeezing your hand or something that, this makes your children and your husband excited because they feel like they can control your tremor. And it's a fun game to play, but there's only so long that you can make that happen. So the meds are good for me to get rid of my tremor. So that's one thing I know about tremor when I'm feeling aberrant movement or dyskinesia, which it, you can see it right now. This is not my normal state. I'm pretty excited here because I'm on a panel. I get to talk to a lot of people. So that makes me excited. And it's later in the day, so you see kind of this I'm, I'm moving around a lot. You know, everybody else is sitting nice and still, and I can watch myself and go, "Oh gosh, she's all over the place." She being me. This kind of dyskinesia doesn't bother me too much. It's not the, dyskinesia can actually be a little bit painful if you fight it. Okay. So like if I'm in a bed, a big fight with my dyskinesia, if it's rocking pretty hard and I'm trying to hold it still and try to, if I fight it with my muscles, this can start to become, I don't know if painful is the right way to say it, but it can be, it can cause my muscles to get very tired and sort of achy and not very comfortable. One thing I've noticed sometimes I have dyskinesia the jaw and I will actually come out of that where my lower jaw is jutting out past my upper jaw, like an underbite, I think that's called. Yeah. And that feels very strange. And, and these, these kinds of things are kind of odd.

The difference to me with dystonia, dystonia is this almost always painful. I mean, it's almost always, I mean, sometimes it can be really painful. Like it's going to grab your attention because you're, and if you look at your body in that moment, like my toe curling or my hands sometimes

get this demonic, my hand is doing something it's not supposed to do. It's not supposed to look that way. You know, like my fingers are curling back in a position that is not at all normally achievable, same with my toe or my leg. My foot will curl up into like a, a bit of a ball. It'll be off center. That is dystonia. I mean, when your muscles cramping so hard that you can't get it to relax and you can't get it to feel comfortable. That to me is dystonia. I had dystonia before I ever took meds.

Right. It was one of my, so dystonia can live without, with Parkinson's without meds. Yeah, my experience. And I think most people's experiences that dyskinesia there's a lot of confusion about it. Dyskinesia, yes. It's caused by the meds, but it also like Dr. Malaty said, comes on after you've had Parkinson's for awhile. And so the thing is, and there's a lot of interesting research about it that says, yeah, you can't get dyskinesia without meds, but sometimes there's some people that are talking about it. It's the way the brain uses the meds. And so, and it's habituation of certain neuro pathways. There are some theories that says, if you don't take the meds, your brain starts learning really odd neural pathways and building neuro pathways for movement to adjust for your Parkinson's that then when you start taking the meds, don't know how to handle the meds and can cause aberrant movement. Now these are all theories and hypotheses and whatever else. But I constantly run into people who are under medicated because they are afraid of dyskinesia. And I feel like I want to communicate to people really rethink that feeling because I, somebody said this to me once and it made so much sense. I like to pass it on along.

The more you can make your body behave normally and move, normally the neuro pathways you're writing down in your brain at that time are the closest thing to normal. The more your body is doing something aberrant or strange or slow or whatever. And because you're not taking medication, you're building neuro pathways that are not necessarily maybe what you want. And so I think our goal is, people with Parkinson's, is to try to get our medications as well, modulating as possible so that we can 1. exercise, which we know is the only thing that we currently have to help slow the progression of disability with Parkinson's.

Melani Dizon:

Thanks. Yeah. That's great.

Amy Carlson:

And so you really want to stay in that place where you can exercise and you can be as normal as best you can be, because I think that that's going to help your brain and help you become as best as you can be and enjoy your life.

Melani Dizon:

Thank you, Amy. Cidney, do you want to jump in there real quick?

Cidney Donahoo:

Yeah, I was just gonna say, this is kind of a perfect example. You've got Amy, who's got kind of the, you know, the peak dose kind of moving around and you can't see my leg, but if you could see my leg. If you look inside my shoes, see my toes going like this. And if you see my leg, it would be going like, it's going like this. And that's because I'm, I'm starting to go into an OFF time. I will go, my meds will completely wear off, not completely, but I'll go through this time where they're wearing off and then they'll, the dyskinesia will stop and I'll have a little bit of time before I get really bad, need another dose where it will settle down. And then when I take my next dose, my next dose kicking in, my dyskinesia really isn't as bad. It kinda is kinda tells me, Hey, you're kicking in, so yay. But it's the wearing off that gets a little bit more difficult for me.

Karen St. Clair:

I did see someone question about medical cannabis. And my husband got, his dyskinesia was similar to Cidney's. His legs would just be this incredible twisting, turning cramping of his calf muscles. And his calf muscles would literally just be like hard as a rock from all of this twisting and turning of his legs. So we used medical cannabis, tinctures, and Rob got some relief with that for probably a couple of years. And we kept track of it, like I said, with with a chart to take into the doctor to show when he was using it and when that was working. But over time that lost its efficacy. And it, it just, you know, kind of wasn't doing the job like had been before. So in March or April of this year, I think it was April, Rob went on some new medication and it has dramatically decreased his dyskinesia and he's back writing songs and playing his guitar and playing the keyboard.

So it's made a huge difference in his life. And the other thing that I noticed from it is, he had REM sleep disorder at night and his bed would be just a torn up mess. And now when I go in there I can literally just kind of like pull the sheets up and make the bed, cause it's not a torn up mess anymore. So he's getting a lot more restful sleep. And I don't know whether that's from the GOCOVRI or whether that is from the melatonin that he's also taking at night, but it's definitely made a big difference in his life.

Melani Dizon:

All right. Thank you so much for that. Dr. Malaty, can we actually talk about some of those treatments for dyskinesia, some of the most common ones right now?

Dr. Irene Malaty:

Karen brought up GOCOVRI, which is a formulation of amantadine. Amantadine was invented to be a flu medicine many years ago, and it's not effective against today's flu, but it turned out to have some anti-dyskinetic effects that were helpful in Parkinson's. Sometimes it's used for Parkinson's as a symptom medicine for other symptoms, too. But most commonly it's used for the dyskinesia. And regular release amantadine is called that. GOCOVRI and Osmolex are two more recently released long-acting versions. So they just have a different pharmacodynamic properties about when they reach a peak and how long they last. So those are medicines that are used

specifically for dyskinesia. Otherwise, the interventions we do are kind of what I said before about trying to have really high peaks and low troughs. So we might be moving doses closer together. So instead of every five or six hours, maybe we're dosing every four hours or every three hours over time.

And it may involve taking less medicine all at once, lower doses, more frequent. It may involve incorporating some longer acting medicines like Cidney brought up, Rytary or Sinemet CR, or combinations of those. We have other medicines for Parkinson's called dopamine agonists, and they come in long-acting forms. There's one that's in a patch form that's 24 hours. And so sometimes when people are on one formulation, we may try to switch to one that has a more even spread.

And then we talked about the surgical therapies like pursuing continuous levodopa or deep brain stimulation. Lesional therapies are a different kind of surgical approach; instead of stimulating in the area where the electricity is actually burning a hole in the area. And some people have heard about focused ultrasound or in the old times just ablation. And those are surgical therapies that have also been used for Parkinson's.

But specifically for dyskinesia, it usually comes to changing the timing and the regimen. And when you're becoming, when you've had Parkinson's long enough that you're having troublesome dyskinesia is, and the timing is difficult, it's very helpful if you have access to a movement disorder specialist, certainly a neurologist, preferably a movement disorder specialist, because some of those things you know, require some expertise and it can be challenging to even things out, but it's not one right answer. It's always looking at, you know, what Karen did is very helpful, which is, she really got a good picture of what are the times of day that we're having troubles? You know, what are the times of the medicines and the times of the symptoms, because sometimes we can figure out if it has to do with dietary fluctuations, does it have to do with timing of medicine? Are you having bowel motility issues and what else can we do? So those are kind of all different strategies.

Melani

Great. Thank you. I think your microphone is doing a little bit of like staticky sounding. I can hear you, but it's just sounds a little staticky. I don't know if there's something on your shirt. It was totally great at the beginning. I think it's okay. It's just maybe if you're, if it's something's being touched, move it farther.

Oh, that's, that's a little bit better. It's still a little staticky, but we can hear you. I don't wanna, I don't want to mess up with that too much. And for those of you, who've asked some, several people have asked about the names of the different medications and wanting, you know, to have things spelled out for them. We will provide a transcript. We will provide the audio, the recording, and

show notes. So everything that we talk about here, we will provide a more detailed fashion, so that you'll get that in the email. Can you speak a little bit about exercise and dyskinesia?

Dr. Irene Malaty:

Well, exercise. Is the sound okay?

Melani Dizon:

Okay. But it's really staticky. Okay. I'm not sure what happened because it was totally clear in the beginning.

Amy Carlson:

Yeah. I can talk a little bit about, I mean, I know we want to hear from Dr. Malaty, too, but I feel like exercise can help. Not with, it can help with dyskinesia. I mean, along with just sort of keeping a generally stable routine of your day. A lot of times for me, dyskinesia is a lot about timing. It's just how much dopamine I have on board, how much exercise I did, how much stress I have on board. There's a lot about balancing and managing. And one thing I would say about amantadine is it for me worked really well with dyskinesia. Unfortunately I had some hallucination-type side effects, so I can't take amantadine. And sometimes I like to mention that because sometimes people don't really like to talk about hallucinations. It's not on top of our list of fun facts, but and, and hallucinations are very strange. They're not just like what you see in *A Beautiful Mind*. There's my hallucinations were actually tactile, which I didn't really realize could be a type of whose initial, which meant I felt like pins and needles and rolling waves of, of prickliness. And it was very strange experience. And I didn't realize that was a hallucination until later. And so I like to talk about it now, because I want to share that experience. I want you to know if you hear things in the fan, like you have a fan on or white noise on, and you hear things that's an auditory hallucination. You're not maybe imagining that that might be something that's actually happening.

Visual hallucinations can be things skittering along. Like you think you see a mouse running along the corner of the baseboard. And olfactory hallucinations. You smell things that are not there. You smell cigarette smoke and nobody's smoking. And then the tactile ones are freaky. Just that you feel things that are actually not happening. Like you feel really hot or very cold. And it, there's no real reason for that. And if those things are happening to you, please talk to your neurologist. There's nothing you can't tell your neurologist. There's no reason to hide hallucinations from the world because there is help for that. And so I encourage anybody if it happens, talk to somebody.

Melani Dizon:

Yes. Thank you, Amy, for sure. You know it's, it's definitely something that this is, you have to go to your doctor, you have to talk to them about it. You don't have to suffer over time, you know, I can't get to my doctor, so I'm just going to wait and suffer. You don't, you don't have to do that. Right. Karen, it looked like you were going to jump in about something. Did you have something to say?

Karen St. Clair:

No. I was just gonna mention that go along with Amy and the hallucinations, almost every drug that you use for Parkinson's can have a side effect of hallucinations. So you really just have to be aware of that. And as a care partner you know, you have to be able to ask the right questions and you want to stay on top of it. So, I mean, if you have one occurrence of it, that's one thing, but you know, if you start having regular occurrences of it, you really need to mention that to your doctor.

Melani Dizon:

Great. Dr. Malaty, were you gonna say something before?

Dr. Irene Malaty:

I was, but I don't remember what the question was at the time. Oh, exercise. Sure. And I do remember one thing I was going to answer that was a while back, but I don't want to interrupt anybody. Somebody asked about tremors with a definition of tremor, which is. Do I sound any better now?

Melani Dizon:

It's okay. Yeah.

Dr. Irene Malaty:

Sorry for that. I'm not sure what it is. Well, a tremor is a shaking and somebody asked, "What is the frequency? Or does it match the heart rate?" No, it's actually slower than that. Most commonly it's four to six hertz, which means per second. So it's, but it's, it's not the same frequency as some other thing in your body that you can see. It's just a little bit variable. Exercise is always good for everybody. If there's anything that we think can maybe slow down Parkinson's or have a positive long-term effect, it's going to be exercise. And that's the same true for cognition. Everybody, including me, wants to know what can I do so that I don't experience dementia or severe cognitive impairment. And if there's anything besides living a good life, sleeping, and eating well, it's exercise. And it seems that that may even slow down worsening of memory and individuals over time. There's a lot of research looking at that.

And of course you have to do what you can safely do and what you can, what you're going to stick to. So it's not that everyone should dance or everyone should run. Some people may bicycle. Some people may go in the pool. And I always say, it's what you can do safely and what you enjoy enough to keep doing. And, and sometimes you need a physical therapist to kind of help you craft a plan that you're going to be able to do. Okay.

Melani Dizon:

Right. So do dopamine agonists cause dyskinesia sort of at the same rate that like just carbidopa/levodopa would?

Dr. Irene Malaty:

Well, I would say anything that has an impact on Parkinson's in terms of replacing dopamine can contribute to dyskinesia. And that includes dopamine agonists. There is a study that showed people who took them first before levodopa may have had a later onset to dyskinesia, but it appears that's also because they had less dopamine replacement going on. And so levodopa, as the most effective replacement of dopamine, and so when you have replacement of dopamine, you're going to be at risk of dyskinesia. So the answer's yes, they can cause it too. And so that's why you have to look at all the medicines that are being taken and make adjustments to try to avoid those.

Melani Dizon:

Okay. Going back a couple, a little before, people were asking questions about tremor, and we had talked about resting tremor, which is more common in people with Parkinson's, but do people with Parkinson's ever have essential tremor? Is that, or is that just a lot of people will get diagnosed? And they say, "Oh, I was told I had essential tremor for years and I actually had Parkinson's." So what are the differences, and can people with Parkinson's have it?

Dr. Irene Malaty:

Yeah, I can explain that. So in short, they are two different conditions, but they could co-occur in the same person. And in fact, the co-occurrence is actually a little more, it's more than predicted by chance, meaning having essential tremor and Parkinson's happens more commonly than you would predict just based on the frequencies of the two things. However, most people with essential tremor, there's no expectation they should develop Parkinson's, the tricky thing is that if you're young and you look pretty healthy and you have a little shaking, then a doctor who doesn't see a lot of tremor and is not an expert in tremor, especially, but really any doctor could mistakenly diagnose essential tremor, because they might say, well, you walk fine and you look kind of fine. And you're too young for Parkinson's, which I'm sure there are people in the audience spitting and laughing about that one because we know it can affect young people too.

But if you look young and healthy, you're not walking like what people perceive Parkinson's looks like, they commonly may get misdiagnosed as essential tremor until enough symptoms show up to help build a case that convinces the medical community that this is actually Parkinson's. And so that's super common in young people with Parkinson's who are tremor predominant, especially because what I said is people, even doctors, some doctors may mistakenly believe the old adage that if it's a resting tremor, it must be Parkinson's. And if it's during action, it can't be Parkinson's. There's nothing in life that's black and white. To that extent, people with Parkinson's can have tremor. That's still present when they're doing things. And in fact, they may complain about it when they're doing things, because that's when they notice it. And sometimes that'll lead people to think it must be essential tremor because it shakes while you're still moving. So that's the reason is there may be some overlap, and also there may be some confusion about the diagnosis in the early stages. And so you can, you can see why it can be hard to separate because it's very difficult

just looking at a tremor for, for everyone to know exactly what the future holds.

Melani Dizon:

Right. Great. Well we're almost out of time. And I would love for people to continue to email me your questions. We might be able to do another Q & A session on this super important topic. But Dr. Malaty, is there anything else that I haven't asked that you think is really important to share with this community about dyskinesia before we end?

Dr. Irene Malaty:

I think the most important thing is that it often can be managed and it can often be worked with, and really you always, I always say Parkinson's is like playing a game where the rules keep changing. It's like, just when you have a regimen that seems to work at that moment, then you may have a change over time and it needs to be adjusted. So it's really, there's a constant adjustment process and the medicines have to change. The way you react to particular medications changes over time and with age and with having Parkinson's longer. And so you really have to have an ongoing relationship with a doctor and a health care team that can help you kind of work around the symptoms to manage them as best as they can and let you live the best life that you can.

Melani Dizon:

Great. Thank you so much. I'm so grateful, Dr. Malaty, that you've taken the time to be with us today. Thank you, Karen and Sidney and Amy. You brought so much to this webinar with your experiences and insights. We really appreciate it. Thank you all for joining us for this hour today. And again, email me at [mdizon@dpf.org](mailto:mdizon@dpf.org), and we will be in touch very soon. We will send the recording, the transcript, the audio. You can listen and watch as many times as you need to, and hopefully we'll get all your questions answered. Thank you so much.

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