



## Living Well Today Webinar Series

### Parkinson's Disease Psychosis Q&A

Davis Phinney Foundation

*Note: This isn't a flawless, word-for-word transcript, but it's close.*

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

Hello and welcome everyone to the Davis Phinney Foundation's Live Well Today webinar series. My name is Melani Dizon. I'm the Director of education and content at the Davis Phinney Foundation, and I'm really excited to be here today with Dr. K to talk about Parkinson's disease psychosis. Dr. K, first of all, let's talk pink. We both got on the thing, and I was like, oh, we're matching. This is great. So, Dr. K, can you share why you're wearing pink today?

Cherian Abraham Karunapuzha, MD (Medical Director, Meinders Center for Movement Disorders):

Well, I promised my daughter, and I mean, it's, you know, cancer awareness, breast cancer awareness, and so she raises, she's 10 years old and she does bake sales quite a bit, and she, I promised her I would wear pink for a whole week if she raised like \$500 or more. And she raised about \$600 for the Susan G Komen Breast Cancer Awareness program. And there was a walk and everything. And so, this is my last day of wearing pinks. I've been wearing different hues of pink all through this whole week.

Melani Dizon:

Well, this hue is perfect because we're matching. I love it. Okay, so let's get started. So, you're currently a practicing movement disorder specialist at the Meinders Center for Movement Disorders in Oklahoma City. And I did share your full bio, but I'd love to have you tell us a little bit about how you became interested in this field of work and working with people with Parkinson's, and then, specifically, your work related to Parkinson's disease psychosis.

Cherian Karunapuzha:

So, for neurology as a whole, I think it has always been ingrained in me that I was going to be a physician. But I've had a couple of relatives who've had really severe neurological disorders. Some of them are very devastating to the point. They were pretty much just in a chair day in, and day out, spastic stiff, and could barely speak. And it always irks me to think, why is it that we can't do more for this person? There's, there must be something which you could do. So much so that this poor person who is, who is extremely intelligent, and you know, could not communicate effectively could not get a lot of things done by himself and would quite help for all bodily functions. And so that's where it started. I started to think like, you know, maybe this

is where I need to focus as a physician and get into, and of course, through medical school, we see tons of great professors.

They help mold you essentially and make you sort of gravitate towards their field of sorts because they're great teachers. And I've had several great neurologists, and professors who helped kind of shape my movement disorders per se for almost the same reason because Parkinson's is one of those disorders where you could get into that sort of scenario, which I just described about my own relative. But if we intervene early and strategically, we can keep people functioning for very long stretches because it is a long disease if appropriate intervention is done. And I always like to use an analogy of cars and gasoline, and it's like, you don't wait for a car to break down to do an oil change. And it's that same principle. A lot of these things are preventive management, and I think Parkinson's really fits in that mold.

And so, for me, movement disorders were a natural extension of what all I could offer to a patient. There are a lot of interventions that we can do in Parkinson's, like a lot of the patients who are on today, and you yourself know this, that we have deep brain stimulators, we have pumps, we have injections, we have Botox and other related injections that we can do. So many things that we can offer at every juncture. Like there's something going on, there's always something I can pull out of my ad and go, Okay, let's try this. There's never a scenario where we go, That's it. I mean, that's all we can do and you're going to live like this. So, there's all this hope. And so, I wanted to be in a field where I could really offer a lot of different options for patients.

Melani Dizon:

That's great. Yeah, and I think, you know, it's probably satisfying, right? To have somebody come in and you know, they're not living well, they're maybe not taking advantage of the different medications, different surgeries or even, you know, non-pharmacological things like exercise and drinking water and doing all of those things. And they can come in and you can say, hey, let's try this and this. And then you, you see it is.

Cherian Karunapuzha:

It's very much so, but it's also, again, it is a process, right? So, when you explain a lot of these things, it's a lot of information many times for patients to digest in one go. Like our new visits with our patients, we go over every element including medicines, exercise, psychosis, bowel movements, you name it. But it can be very overwhelming for patients. As many times we sort of jot down and give them a full copy of our notes, which we do for every patient, every visit. They get full copies of our notes, and we also put in a quick blurb and line with links to free books. Like the Davis Finnie has a great manual and we say, look, you're going to have a lot of questions, or you may have this one issue, which we talked about, and you didn't have, but not, it may happen between our next visit, and you start to develop constipation.

He mentioned it, what do I do about it? There are like three pages worth of stuff in this book. So, we would leave things like that too, so that there's a lot of reading education, and I think Parkinson's patients are great about that. In some fields within the scope of neurology, they, these patients just because of the way they get the injury to their brain, they're very resistant to either accepting new therapies learning about new things, and it's just because of the damage they accrue in their brain. They just become like that. Parkinson's we always have seen, they're very motivated for the most part. You don't get the unmotivated patients and there are always some like that, but for the most part, they're always eager to like, what's this next tweak that I can do to my day to make things better?

Melani Dizon:

Right? Yeah. I, I think I probably get emails every day from people that are in the community and say, hey, have you seen this? Have you seen this? Like, they're, so, I love it. They're just very much into the research, want to learn everything they can, and want to share it with everyone they know. And that's, that only helps the community. So, I'm sorry, if someone does you, if you hear an echo, let me know. Then, I think Parkinson's disease psychosis is definitely one of those things that probably comes up in between appointments. It's right, it's something, especially when people are initially diagnosed, they're not thinking about this. And I know that many people that come to us say, I, my doctor never told me I, it scared them so much because they hadn't had any information about it. So, first of all, can we, especially for the people who weren't able to see the first one, can we define what Parkinson's disease psychosis is? And then can you talk about sort of the three main elements of it?

Cherian Karunapuzha:

Fair enough. So, for people who are relatively new to the Parkinson's space, they make the assumption that Parkinson's is a very physical disease. Like, hey, I'm going to start to get slow. I might get stiff, my tremors are going to get worse, or I might start to shuffle because I've seen that one person or my grandpa had this, or I've seen this TV personality have it. And we're assuming this is a very physical disease. The funny thing about this disease is that it spreads many times, it has to hit these non-physical circuits first before it gets to the physical circuit and vice versa too. And eventually, as the disease spreads, it blooms out in your brain to all these different, different little sections of your brain. One such section, which is almost shared space with your Parkinson's circuit, is your mood and hallucination circuits. So, it's one of the first things that the disease creeps into is your mood circuits and your hallucinations.

So, this is why people find it odd sometimes, like, I thought this was a physical disease, why am I feeling depressed or anxious? So just to get a baseline is that lot of non-physical aspects will occur in a Parkinson's patients. It's just pure random as to how it spreads in your brain. So, one person may have more of mood issues, another person may have more of blood pressure issues, and another person may have psychosis. It's very random. And so, if you had to define psychosis in Parkinson's disease, it's basically two major things which happen, which is either

hallucinations and or delusions. So, what is a hallucination? Hallucination is your brain cooks up information about something that you sensed when there was never such a sensation, to begin with. For example, your brain cooks up a sensation that you saw something, there was nothing in the environment for you to have perceived that, but it cooks it up.

This is in clean speak a hallucination. So, hallucinations are with all your five senses. So, seeing, hearing, touch, smell, taste, it can be any of them. But in Parkinson's predominantly it tends to be a very visual form of hallucinations. And we'll go into more detail as to the flavor of those visual hallucinations. What is a delusion? A delusion is a false fixed, usually very irrational belief, that the patient cannot shake despite being given evidence to the contrary. So, you can tell them a hundred times, you can show them all the evidence saying this is not true, but you are still stuck with that notion. No, I know it's true. And so, there are various flavors of delusions too, which you can break out in detail. So, these are the two major criteria to define psychosis in Parkinson's disease. However, most people with Parkinson's disease don't start off with decent symptoms.

They start off with more subtle or what we call minor phenomena. These are major two phenomenon's, which is the hallucinations and delusions. The minor phenomenon includes one illusion. Illusion is a false perception of something which actually happened in your environment or on you. So, for example, I see something with a flickering of the lights, and you look very quickly to the side, and you go, was that lightning outside that I saw? No, probably that was my light bulb. So, you see something in, but you misperceive it, that's an illusion. So, for example, like what magicians do, they play tricks on you, which is your eyes play tricks on you with what they do. That is an illusion. For example, you're sitting there watching tv, you know, a sock, a rolled-up sock, falls from your laundry hams on the floor, and you very quickly look both, Is that a mouse?

No, wait, that's a sock. So, you don't see, you assume it's a mouse because, in the corner of your vision, it almost appears like one, when you look carefully at it, oh, it's a sock, it doesn't stay as in a mouse. So that's an illusion. And so those are many times early in the game along with this, another phenomenon, which is extremely common, which we catch many times very early, as long as we ask the question, is the wig fleeting shadow-like movements or what we call passage phenomenon. Whereby, let's say again, it usually happens in the evening when there's more dim lighting, you're watching TV or something right at the edge of your vision, there's wig shadow, like movements either hovering right there or something do's spiral really quick along the side or under you and you like, huh, if somebody just walked by, did the dog just run across, did a car drive by my window?

Now here, there was no actual phenomenon happening in the environment. It's not an illusion, it's a false cooked-up sensation in your brain, but it's the earliest form of visual hallucination. It's what we call a wig shadow-like movement, a fleeting shadow-like movement. So, this is another extremely common phenomenon. Another minor phenomenon, which tends to

happen, is the feeling that there is somebody next to you. So, you're sitting there again, reading a book, watching tv, you get this feeling like, is that my, is my wife behind me? No. So you keep feeling like there is somebody next to you. And this can expand. The radius of this can expand over time. Like initially it is just next to you, then it's somebody in the same room, then you feel it's in the closet, then you feel like there's somebody downstairs, then it's somebody out in the packet, Honey, go check.

I think the kids are out there. No, there's nobody there. So that expands over time. But in the initial stages is that feeling we all get when we are really tired. Like I'm at the end of the day of my shift. At the end of the day, I kind of get a sinking feeling. My nurses come with one more thing to sign, and I look and turn. There's nobody there. We all feel this, right? The same thing just happens more and more frequently. The problem with such a minor phenomenon is that most people chalk it off, Oh, that's just my thick rim. I'm just catching the edges of it. Oh, that's my cataracts, that's my glaucoma. They poo-poo it off as something else. And this goes underdiagnosed for years. So, this sort of minor phenomenon will occur for 2, 3, or 4 years before you bloom into the real deal stuff. So, in hindsight, when we ask patients this when they come in complaining like he's seeing stuff and we ask about this, they go, oh, that I've been doing for about five years. Ah. And so, this is why we always make it a point, especially movement disorder centers, we will ask this question as part of the screener, and as part of our regular follow-ups is sort of a tick box that we ask the fleeting shadows. It always almost gives us the most mileage in terms of one question if I had to ask.

Melani Dizon:

Oh, wow, that's interesting. I've never, I've never heard that before. Is anybody watching have any experience with these early signs that, that you want to share? If anything is resonating for you? And then also, can we, so these might occur over a course of three to five years, maybe, obviously depending on the person, but it's not unusual for them to go on that long. And then can you talk about the different flavors that you said of hallucinations and delusions?

Cherian Karunapuzha:

Definitely. So, starting off with hallucinations, let's start with visual hallucinations. So, the earliest bit of that is what we just talked about, the shadow, like flickering movements along the edge or darting bind. Eventually, it becomes more well-formed to where it's not just a shadow. There's, it's almost like a figure, like it's a person or a kit or an animal and it's there or it's moving, and you can catch almost like a full-fledged image. There's no color to its shadow. Like, then eventually it becomes fixed and within your full vision space, not just at the edges. This is how it usually evolves. And more often than not, it tends to be in the latter half of the day when your brain is tired, the more tired you are, the more your brain is susceptible to these sorts of hallucinations. This is why a lot of people see it in the late night or in the middle of the night.

They wake up and they wake up from their nap or they're asleep and they look in the dark, in the shadow. They see a brief image form and it goes, so they're very quick, they get scared because they think somebody's standing there next to them while they're sleeping or in the corner there. So, you can see how this can be very disconcerting to people, especially if your loved one with Parkinson's is in a facility, is in a, is in nursing home setting, what happens the next day when you talk to them, they're saying, somebody was standing in my room. Oh, it could have been the aides. And then every day it happens. So, then it starts to get confusing, like, and you start calling people going, Who's in my dad's room? And so, this is how many times it evolves, and we still think there is no hallucinations going on.

He's waking up and seeing somebody there. So, this is how it starts to happen. A lot of people are extremely predisposed to seeing small objects, either inanimate objects or small things like animals, babies, and kids kind of just walking around too. So, these are all things which slowly start to evolve over time. It never is extremely bizarre or morbid. There's and it's not extremely developed hallucinations. It's usually very static. Like there's a person is standing there or maybe barely walking and conversing to them or anything. Doesn't usually you don't get a big interaction there. Hallucinations can take on also minor flavors, like lines on the floor, or on the wall. And all of them still start to merge and separate out and emerge back in. They ate and they go in waves. You can see sometimes creepy crawlies along the floor, like bugs and stuff.

Or the bugs start to come on you so that you're constantly seeing them touch and move things when there's nothing there. Or did you tidy up the space? There are a lot of bugs in my room. So, these are all usual things that start to happen from a visual perspective. Number two is hearing. So auditory hallucinations, again, tend to be very subtle. The classic psychosis that we think about when people hear things is schizophrenia. But there that's it's much more developed forms of hallucinations where they hear commands, and people have conversations. This is not how it happens in Parkinson's. In Parkinson's, it's more subtle, vaguely. They feel like there's music being played in the background or somebody calls out their name and like, huh, did you call me? No. So they think it's a hearing issue. They're not assuming there are auditory hallucinations. Vaguely they hear bugs or birds chirping.

These are the usual phenomenon that happens with auditory hallucinations, and tactile or skin-based hallucinations. As I said before, people feel bugs, and creepy crawlies on them, like they feel like hair. The hair's fallen onto their skin and they're pulling out stuff. Sometimes this gets very, very severe. This concept of having bugs on them. So, they're constantly feeling like there are lice, there are ticks, there's, and they will bring things in their old pill bottles many times saying, Doc, I know my wife is half blind so she can't see. But you see it, right? You see the bugs in here and all. I see some lint and dead skin. So, it can get very severe for some the tactile hallucinations, usually bugs. But another flavor of tactile hallucinations is people grabbing at their legs or their arms. So, this happens in the middle of the night.

So, they're sleeping. Let's say you feel something crawl up the bed under the sheets and you think, oh shoot, I live on a farm. Is it a snake? Or somebody yanks the leg or somebody's crawling in the bed? You get a feeling like that, and you look, there's nobody there. Again, you can see how this is going to go really wrong if the person was in a facility and the next day on the phone with the daughter, she says, somebody was kind of messing around with my legs yesterday when I was sleeping. And then everybody's calling and trying to figure out what happened, who was there. So many times, it's stuff like this. So that was tactile hallucinations. So, then you can also get an olfactory, sense of smell. And so, sense of smell for hallucinations. It's again, remembers Parkinson's patients lose their sense smell for the most part. And especially when they go years with this, they've definitely lost their census smell.

And all of a sudden now they start saying, hey, did you burn something? And it's almost always at the same time, in the evening, did you burn something? It seems like I smell smoke. Or they're always looking for that dead rat in the closet. Like, what are you up to? There's something smelly here. It's always at night that he's trying to figure it out. Why? Because it's that time when the hallucinations pick up. So, these are all the different flavors of hallucinations. What about delusions? Delusion, as I said, is a false fixed, usually irrational belief. So, the most common one is paranoid delusions. People are just paranoid, they're upset, they're worried that people are ganging up or plotting things around them, usually to your detriment. That's how they think. It's like why are you telling Dr. K all these things, you know, I know what you're up to.

You want to throw me in a nursing home, right? So that's how they think. So that tension is there. And we see it sometimes in our clinics that you have the patient sitting there and you have extremely uncomfortable family members all kind of keeping quiet and kind of darkening their eyes and looking at each other. Nobody's saying anything. And anytime I ask a question, he, the patient's like making sure that you don't do better, not say anything. And that's when you know there's some tension going on in the background that there is, this conflict has been going on for a while. So, this can happen with their own kids, it can be with your aide or she's all those guys are always stealing stuff from my house, or I don't want to be left alone with them. Because I know they're up to something. The neighbors are up to something.

Why is he turning his dissent and not this faith? There's, there's nobody there is, the house is empty. No, no, no, there's something there. And they're always stuck on that notion despite giving evidence of the opposite. The second kind is delusions of infidelity or jealousy. So, they're jealous that their spouse probably married to them for 40 years, is cheating on them. Or sometimes are delusions where they feel like their kid or, or somebody close to them is cheating. And they come in talking to me about a dog. I'm so upset. I thought I raised my son better than this, but I said, What's wrong? He's, he's been cheating on his wife and it's no good. And so, you know, on the next visit I remember, and I ask, and at that time happens to be that his wife is there with him, and he goes, she goes, no, none of that stuff actually happens. What

are you talking about? And that's when I realized, oh shoot, he was having a delusion. Because it seems very plausible to me.

Melani Dizon:

Right?

Cherian Karunapuzha:

So, these things all, so those are all variations. And finally, there's a third kind of delusion, which is not terribly common, but it can happen in delusions of reference where they infer themselves into situations that have no bearing on them. Like let's say he's watching the evening news and very quickly jumps and says, I told Joe that that wouldn't work, that we shouldn't pass that. What are you talking about? Who's Joe? Joe, Joe Biden. Huh? That that bill would not be passed. I told him. And so somehow they interject themselves into a situation which has no bearing on them. Those are less often, but it happens to, these are the two subcategories within this space which predominantly it tends to be very visual. Okay.

Melani Dizon:

Gosh. I wish that I could talk to you for four hours about all of this. There's so many great, so much great information and lots of great questions coming in. A couple, a couple I want to address immediately because I got a lot of them via email and then people are talking about them here. But can you talk about the relationship between hallucinations and Lewy body dementia? And if people are getting hallucinations, does it mean they have L v D? This is a common question we get. Like what, what's that relationship?

Cherian Karunapuzha:

Lewy body dementia is a subtype of Parkinsonism whereby you get something very similar to Parkinson's disease. You have the slowness, stiffness, and tremor even. But at the same time, in parallel, you're also getting cognitive decline from the very beginning itself. You having cognitive decline thinking issues along with it. The classic nature of that thinking issue is they have inattentiveness, forgetfulness, difficulty with directions and they hallucinate. But this is from the very beginning, they're having a little bit of tremor in 2020. At the same time, he started to have thinking issues by 2021, the tremor is worse and he's trying to hallucinate, Okay, that's the story. Parkinson's,

Melani Dizon:

No, the big deal with the big deal for that is timing,

Cherian Karunapuzha:



Is timing. That the history reveals the diagnosis. Almost always whereby you are having a very similar form of Parkinson's like movement problems along with simultaneous cognitive decline and hallucinations. Parkinson's patients too can get cognitive decline and dementia. But in the lag end of that disease, we're talking 10, 15 years into that disease, they start to get cognitive issues and in turn hallucinations then too. And which means what? The same story is given by the Parkinson's patient who's brought in, he's coming in with his walk or both sides are affected. He's pretty obviously affected physically. And he says, stops the last six months. My thinking is not good. I mean, having difficulty with directions, been starting to see things. That's the story for Parkinson's patients. So, Parkinson's disease patients, that's the guy who comes in and tells me this same story for the other person who barely has any physical symptoms and says the exact same thing about his thinking and hallucinations from in, from the get-go. That's the difference. So just because a Parkinson's patient gets hallucinations down the road doesn't mean he is converted to Lewy body dementia. It's a separate disease,

Melani Dizon:

Okay?

Cherian Karunapuzha:

Parkinson's disease patients, the odds of getting hallucinations are about 50% in their lifetime with Parkinson's. So, with Parkinson's you can get hallucinations early in the game, middle of the game, or toward the end as well. More often than not, it is in the middle and the end middle where naturally as part of your disease spreading or blooming in your brain, it hits the hallucination surface towards the end. Eventually, when it starts to hit the thinking part of your brain and you start to get a cognitive decline or dementia with Parkinson's, the natural characteristic of that dementia is also hallucinations. So that's the another scenario in the early stages where Parkinson's can get hallucinations, it's usually drug-induced like you give them a certain drug and it tends to kickstart hallucinations temporarily. That's the early scenario where Parkinson's suspicions can get a drug-induced phenomenon of hallucinations.

Melani Dizon:

Great. So that is a super important part because I think that there may be people on here that had an early diagnosis and then had early hallucinations and they're thinking they have Lewy body when it was really an induced situation, which is a totally different situation, right? Right. When if it's drug-induced, yeah, okay, that's great.

Cherian Karunapuzha:

And if their cognitive issues do not last because let's say they are offending medicines also pulled out and on the formalized testing, which we call neuropsychological testing, they do

great on the testing. They don't show a decline or perform in the performance of all those testing.

Melani Dizon:

Okay, that's great. What about people who are, you know, young onset diagnosed, do they, what is what happens to be there as the same progression? Usually as somebody who's diagnosed later in life when it comes to hallucinations.

Cherian Karunapuzha:

So, people who are much older when they develop Parkinson's, they already have a little bit of baseline cognitive decline just from aging, just 75, my brain's not going to be as healthy as somebody in their forties. So, there's already a little bit of cognitive lapse naturally as part of aging. Those folks tend to be more predisposed towards an earlier onset of hallucinations because as I said, you know when your brain's fatigued, that's when it plays tricks on you just because of age, your brain's a little behind on the game and on top of it you add Parkinson's and some of the medications which are potent, they tend to get more predisposed to its hallucinations. There are certain subtypes within Parkinson's disease. Again, this is more academic than really for patients where we go and talk about tremor-predominant Parkinson's or akinetic rigid forms of Parkinson's and so on and so forth. Within that, there are certain subtypes we do tend to gravitate towards cognitive and hallucinations earlier than the remainder of Parkinson's disease patients, they don't, we don't call them Lewy Body dementia, it's just Parkinson's disease blooming into Parkinson's disease, dementia, and psychosis earlier.

Melani Dizon:

Okay. Just a couple of comments. A lot of people have said, I have early illusions, especially in a darkened room, my husband sees rows of ants in rows on the floor. At one point they, this person had the husband take a picture of it and he was like, See, you can see them now. And she couldn't see them. A lot of times I'll hear a small chatter like talking or a TV is on comes, it seems to be like one side of the ear. I don't know, is that common for it to be just coming?

Cherian Karunapuzha:

So that's an important point. Remember as I said with the brain, the more damaged the brain is, the more susceptible or more fatigue the brain is. It's the same goes with your sensing organs as well. So, if you tend to have cataracts or glaucoma, your vision itself is impaired, and you're more predisposed to some of those illusions and hallucinations more. Same way it goes with hearing issues too. If you tend to be deaf on one side more than the other, these sort of things tends to factor into body parts which are more damaged. You have neuropathy in your hands and feet, you're more apt to feel things on you.

Melani Dizon:

Okay. So, let's say somebody is starting to experience this. Is the expectation for sure that they're just going to get worse? Or is there anything people can do to stop the progression of them?

Cherian Karunapuzha:

So, let's assume that the hallucinations which are happening currently, let's say it's just vague shadows, or they get a feeling like this person next to them. And we've, we've chalked it off to that. It has happened more than a couple of times and it's happened at least for a month or more, which means it's gone past the point of something being secondary to let's say a UTI, an infection, or dehydration. These are all these extra things that can insight hallucinations temporarily. So, we know it's not any of that. As long as we've excluded all of that and we've excluded medications as being a possibility, we just keep tabs on them and we tell them, make sure you keep tabs on these things because this can bloom out as the months or years go by, especially during summer months. Make sure you stay hydrated because that can amplify the process.

Or come the covid season, you're going to get bronchitis again, an infection's going to amplify it. So, they tend to stay slow progression, slowly over the course of, I would say two, or three years even slowly picking up. But there's going to be these disruptions, which are completely unpredictable. We can't predict when the next time is you're going to get bronchitis. But we can help offset it quite a bit if you keep practicing your speech therapy and making sure you don't have swallowing issues. That's why some of these extra things we keep harping on, it's, for this reason, is that make sure we don't get the infection if we can avoid it because my throat is stronger, I'm not aspirating my saliva into my lungs. Those are the kind of measures we take. So, we tell them ahead of time, you're riskier for hallucination, so I need to know not in the next visit before that I need a call saying I'm trying to see more of that stuff you're telling me about so that I can nip it in the bud with certain medications before it blooms out and becomes bad.

Because the FDA-approved medicine that we have for psychosis, which is new plastic, doesn't kick in immediately. It can take anywhere from two to six weeks to kick in and fully change the chemistry in your brain. Which means that if you wait till the lag end and it's now really bad, you're seeing things, and you're paranoid about your spouse at that time. If I give you something like this, it's going to take another six weeks to kick in. So, which would require what many times hospitalizes you for the hallucinations. And that many times we do not want, we do not want hospitalizations if at all, we can avoid them because anytime you get put in a bed not moving, you will decondition and daze your muscles, right? And you will come out looking worse off physically. So, to avoid such scenarios, we like to preemptively nip it in the bud when it's time to bloom up, we correct it with many times medicines which are made for this condition.

Melani Dizon:

Okay, so let's, let's go to the medication piece. So, we talked a little bit earlier how sometimes it can be medication induced. Are there certain types of medication that make it more prone to get hallucinations? And then if they are in that situation, they're on medication but they're starting to feel it and you want to give them Nuplazid, what, how does that work? Is there anything they shouldn't be on if they take Nuplazid or, and what is the success rate? Like what are you seeing in your clinic?

Cherian Karunapuzha:

So first off, in terms of medicines par within the Parkinson's space, which can amplify hallucinations, all dopamine-based medications have a potential for amplifying hallucinations. But within that, the ones which are probably the highest culprits are drugs like amantadine and its derivatives. They tend to predispose patients much quicker. The second tier tends to be dopamine agonists. These are drugs like, you know, Exelon, Aricept, Razadyne, all of those guys. And then of course we have levodopa. And so many times we will back off some of these drugs first to see if the hallucinations disappear or strategically change your levodopa dose for less in the evening because that's when you're seeing the stuff. So daytime, you're great. By evening you're starting to see stuff, we back off that evening dose a bit of your levodopa, sure you'll be a little bit slower, but you'll be more lucid.

So there those sort of, those sort of small tweaks we can do early in the game. There are medications which is not within the parking space, which can still impact you like opioids, right? You get a dental procedure and they've given you a dentist, you know trying to do the right thing gives you pain meds, and it messes with your hallucinations and perks it up. There are medicines which are what we call anticholinergic medications. These are medicines and multiple different classes of medicines will have that property, including good old Benadryl. So, you're having problems sleeping and you decide to take a Tylenol pm anything which ends with PM has Benadryl in it and Benadryl will knock you out. But the next day because of its an effect, you're goofier, confused, and you can hallucinate. So many drugs have that potential as a lot of antidepressants can do that, and antihistamines can do that of which one is Benadryl.

So, we make sure those sort of meds is out of the equation, if at all possible. Then we get into treatment options. So, one such as we mentioned was Nuplazid. And so, when we give Nuplazid, we do want to make sure that because all antipsychotics can enhance a certain form of arrhythmia, which is abnormal rhythm in your heart we always want to double check and make sure that you don't have that specific form. It's a rare thing, but if you don't have that specific form of arrhythmia, so we'll ask questions regarding that or if you already have an EKG in the system or in the chart, we can easily look and pull up and see if you factor in from that perspective. So that's, that's the big thing when we look at from Nuplazid standpoint and we start, it's a simple dose. It's a once-a-day dose of 34 milligrams, any time of the day with or without food.

And as I said, it just takes time to build in the trials, one in 14 people had complete resolution of symptoms, but in the majority of patients, what we were, what we saw was a reduction in either the intensity of what you see or hallucinate or the frequency, meaning how often it happens. And some people got a mishmash of both, like introducing the intensity sum and then also how often it happened. The frequency also dropped, but one in 14 will get it completed, just knocks it out there. There's nothing there. From what we've seen anecdotally, I can tell you that the earlier you treat this, it shaves it off much better. When it gets to the stage when you're having delusions like that false belief, it'll drop it down but not shake out the complete delusion. You will still have some and at that juncture, that's usually very advanced psychosis. We do add other antipsychotics. I don't know if all the other antipsychotics are off label, but we can add some just to give us extra control along with the Nuplazid.

Melani Dizon:

Okay. Okay. So bet between medications and some lifestyle choices. We talked a little bit about things that people can do to minimize their hallucinations. You know, hydration is important, making sure there's no other infection involved. Making sure your medications are right and that your timing is right. We talked a little bit, although we didn't talk about the actual like the thing to do, but the shadows and the time of day and the lighting can be a big thing. So, a lot of times you just can turn the lights on. If you're a care partner, you can, if they're in a room that has a lot of shadows, you can make the light brighter, so you get rid of those shadows and stuff like that. And I think that that would be, you know, for people who have a hall, someone said people who have hallucinations during the day they could be maybe some of these other things are at play that is making it happen earlier in the day and lasting the whole day, I'm guessing.

Cherian Karunapuzha:

So, hallucinations all, all across through the day tells us that, you know, it has progressed. It has got to a point where if the person is able to get these false perceptions throughout, then it has progressed to where we do need to tackle it whatever way that is. Either take away some of the offending medicines and or adding a specific medicine to suppress it. For the earlier scenarios where in this time to see just in the evenings or in the dark, these sort of things like keeping automated lights in your hallway or in your closet so that the minute you get up or move into the hallway, the lights come on. And so, there's never a fear of there's somebody standing there as you're trying to get to the bathroom in the middle of the night and then reflexively turn because you thought somebody who was there and has a fall. So those kinds of things definitely make, makes quite a bit of a difference. Lighting especially. So,

Melani Dizon:

Okay. We talked, and you said something about insight, and we definitely talked about this last time where if you're having a hallucination, but you kind of know you're having a hallucination, that means you have some insight. If you don't know it and even looking back upon it, you don't

recognize it. It has a hallucination. It means you didn't have the insight. So, I'm curious and you talked a little bit about being in the clinic with family members. What does somebody do and what do you do when you're in the presence of a person with Parkinson's who had a hallucination and the care partner and they don't know how to deal with it, the care partner doesn't know what to say, they don't know. Do they go along with it? Do they, what do they do?

Cherian Karunapuzha:

So first off, insight is almost always preserved initially, and it's slowly lost over time. And what happens is because we don't catch the initial face because it's sort of blind, nobody knew about it. Nobody was keeping tabs on it. People only keep their milestones of when their hallucinations started. When did your hallucinations start? Oh, it was last year. And what did you see then these people, but it happened way before he saw people's, nobody recognized that. But by the time he's starting to see such detailed hallucinations inside many times could be lost, but almost always it's preserved. So, where we, we tell them ahead of time or we tell them, look, you know, those shadows keep tabs on them. They tell you proactively. I still see them. I don't, I'm not bothered by it anymore. Now that you told me what it was. I sometimes, occasionally get a vague feeling like there are bugs, creepy crawl.

I don't stare at them anymore because I know it's not real. That's insight. But even with insight, it can get irksome after a while because it almost feels like a person. And it is like, you have to look. So, it's intrusive even though you have insight, it's intrusive to where you have to pause and confirm no, okay, and go back to what you were doing. And so even if it, if you have insight and it's intrusive, we still treat it. Now if you have family members who are blissfully ignorant of that, this is a hallucination and they're having it every day, let's say usually their most lucid moments are early morning, if at all possible. If that is there. That's such a scenario there. We usually tell our family members, and the patients like, hey, you guys are going to do like a quick sit-down check.

Like when you're starting to have your breakfast every day, you're going to go through this. All right honey, all right. Like we talked about with Dr. K or like we talked about yesterday, we're going to run through a day. And if you start to see those same things as you do, I know you never remember them, but if you start to see kids or people, you're going to take my word for it that it's not there. If you do not feel com, if you're not feeling comfortable, call and I will check. And if I say it's not there, we're going to agree that it's not there. And sort of reaffirming the same storyline every day that this is what our plan is, this is what we're going to do. It's not always successful, but there is some element of that programming that sticks later on to where, okay, I trust you, it's not there.

So, they're able to kind of get past that very intense hallucinations because I kind of remember discussing and agreeing to this that I want to listen to her. So, this is one approach. The second thing is, do you go along with the hallucinations in the sense that we tell them, look, it is not

there? I look, but it's not there, you're done. But we never encourage these, I had patients come in and say, I don't really care too much about my mom's hallucinations because she thinks she sees angels. I said she sees angels now next month it's going to be something else. And then don't come back to me and say, we should have treated this before. So, no hallucination is a good hallucination and so we always have to tackle them in some manner. Nothing's benign about these things. And so, we try not to reinforce the hallucinations by saying yes, let's put a cream for the bugs on your skin.

Yes, let's go see a dermatologist for the bugs. There are no bugs on your skin, but let's go check. Let's get a second opinion. And I say this, I'm not making this up. These are actually live cases of where this has actually happened when they go, again and again, just enabling the delusion when all parties know it is not real. And even asking me for a third referral to make sure it is not there. And so, I tell folks like, we should not, because that sort of drives it into their mind that it is a fixed phenomenon, and it prevents them from seeking appropriate care. They will refuse active treatment, let's say like with Nuplazid because they're assuming this is real. No, I want to see the dermatologist, that third guy, he, I'm sure he will catch it. I don't want to start the new plastic,

Melani Dizon:

Right?

Cherian Karunapuzha:

The final thing which I tell them is, look guys, because I've done this long enough, your story is not unique. It is the same old stuff I've heard all along. And while what you say or do could be potentially plausible, I don't think that your neighbors working in your backyard and messing with you. I think this is what it is. And if you gimme an opportunity, we can tweak your medicine within a couple of weeks you will see that it's different and it does. And we get that buy-in. Give me a couple of weeks and I will show you that it is different and that this was not really there, right? And so especially for family members who are jealous, who are suspecting they are wanting a divorce who's paying for private detectives to keep an eye on the other guy. So, these sort of things I tell them, look, this is while it's possible he's cheating on you. Let me try this. Because this is a better alternative for all parties. Like if it turned out to be not real, it's best for you and best for everybody, right? So gimme that opportunity so we get that buy-in like that.

Melani Dizon:

Yeah. I want to go back to that cheating piece really quick, but curious about people using CBD for like pain and sleep and all of those different things as you know, dealing with Parkinson's. Has this been known too also?

Cherian Karunapuzha:

Yes, very much so. Okay. Very much so. So, CBD especially in certain states, including Oklahoma has medical marijuana is legalized. And so, a lot of people use it for sleep, for anxiety control sometimes when they have a lot of tremors and the anxiety makes it worse, they use it and it helps for pain, it helps. And so, it's not a bad choice except the problem with C B D is that this is not regulated in terms of manufacturing. There is no FDA regulation on how this is done, how this is synthesized, or what is the exact milligram there, it's just up in the air as to who cooks and makes this batch and is sold in the dispensary. And so, what happens is, one, you can get a blend of other chemicals in it like potent psychoactive chemicals like THC, which can make people paranoid and even activate hallucinations.

And so, if you take something which is an even a bit of a blend and it provokes that the problem, the second problem to that is if it does something wrong, it's going to stick in your system for very long because it's CBD, THC, all these things clear very poorly from our system. This is why we're still able to trace cannabis use for up to three months in an individual because it sits in, so the same gummy which worked for you this Monday, you keep taking it all the way till next Monday. Next Monday you take the same gummy. It's not going to be the same effect. All the previous doses are still kind of in your system and they're going to piggyback along with what you took. So, you got to be extremely judicious with using CBD for any of these things because you can many times tip yourself too much and you can get really drowsy or apathetic.

These are the most common problems we've seen happen. But it can activate psychosis too. In fact, we had a patient two days ago who decided, and again rightfully they tried it because patient, anytime when they get anxious they would give him a C, B D, he calms down and goes to sleep. This person had a combination of meds which made him extremely dyskinetic and manic. Remember levodopa can make you manic. And so, they said, okay, let's calm him down with some CBD and they gave him the C b D and he gets paranoid and wants to call the police or Dr. K, there's only two people he will talk to because he's paranoid that everybody else is lying to him or doing so. And he knows in between he knows that's not real. That's not real. But then he again goes back. So, you can very quickly tip over people with c d especially if they're having hallucinations, we tell them no do not do this drug.

Melani Dizon:

Yeah, that is such a good, that's such good advice. And then also it's not even, you know, some people will say you know, it's, you can have one bottle and then you buy the same type, same bottle, and it's totally different. But it's even pill to pill, right? Like it's in the same bottle, one pill, nothing. Next pill you're completely used. It's like you've taken 10 doses, right? And that's the scary part about lack of regulation, right?

Cherian Karunapuzha:



That's right. I mean, and the cooking batches from a low from something which is sourced from a plant. And so, it's like picking an apple and going, wow, this is so sweet. All the other 10 apples on the street are going to be the exact same thing. Not every flower bud is going to feel, have different components or percentages to this and whatever you cook from this, a little bit of gummies came from those flower buds a little bit. Gummies came from this one. All from the same blend are going to still look different,

Melani Dizon:

Right? Great. And I, the other point that you made in there that is super important is that some people will probably tend to not bring it up or definitely not call and make an appointment if the hallucination doesn't bother them, like it doesn't seem that big of a deal. Like it just doesn't bother them. They're like, Oh, okay, no big deal. So, I think this is, that's a really important point to make that no hallucination is a good hallucination.

Cherian Karunapuzha:

Exactly. Because it might seem relatively benign to you now, but it is one more thing that can fail quickly. If you fail broke your bone, had to go into the hospital and you needed anesthesia. Anesthesia does not only make you sleepy, but it's now going to provoke your hallucinations. Yeah. You had a bronchitis come to this winter, covid flu something again, what could have been just a cold has now become a bigger problem because it activates your hallucination. Your summer, you decided to work in the backyard, and didn't drink enough that day. Dehydrate that day and night you start. So, there's a lot of there is a lot of insecurity when you have something like this floating around and we tell folks, look, it is your choice when it is this mild and non-intrusive. I get it. You don't want to take one more pill in this big med list that you're already on but understand the risks of doing that over the course of the next several months. So, we can either wait and watch and treat it when it gets severe or we can treat it early, but in between if we wait and watch, understand that you may have these, these risks, and some people decide to take that risk, that's a philosophical choice of taking less meds. Some people are at least, once they get that part to go away, I want to start taking meds early.

Melani Dizon:

Right? Great. So great advice for people. If you're starting to experience any of this, even if you don't think you want to go down the medication route, talk to your doctor about it, and make sure that you're sort of noting it. Maybe your care partner can help you with it to track these things so that you can talk to your doctor about it next time. You can talk to your daughter about your doctor, about your current medications, and then what you might be able to do to slow this progression or make it not so severe that you, that you get yourself in a bad situation. Thank you so much Dr. K for being here today. Like I said, I just want to talk to you forever. So helpful. Does anybody have any questions? You can always email me@blogdpf.org and we will look forward to having you guys back on another webinar very soon. We will send the



recording, audio, video transcripts, and all of those things. And thank you so much for being here and tell your daughter we said congratulations on her fundraising. Very good job. And we will hopefully talk to you very soon. Dr. K

Cherian Karunapuzha:

Thank you, everyone. Stay safe.

Melani Dizon:

Thanks, everybody.

### **Want More Practical Articles Like This?**

Much more can be found in the Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action.

[Request Your Manual Now](#)

Thank you to our Peak Partners, Amneal, Kyowa Kirin, and Sunovion for making it possible for us to print, distribute, and ship the Every Victory Counts manual.