

Care Partner Training

Session 7: Sleep, Hallucinations, and Delusions in Parkinson's

Davis Phinney Foundation

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

Polly Dawkins, MBA (Executive Director, Davis Phinney Foundation):

Hello, everybody, and welcome to our session seven in our Care Partner training series. Welcome back, Jori Fleisher.

Jori Fleisher, MDS (Associate Professor of Neurological Sciences, Rush University Medical Center):

Hi, Polly. It's so good to see you.

Polly Dawkins:

Great to see you here. Today's session is for everybody in attendance. We are going to be focusing on some big topics, and we hope to be able to get through all of them. We're going to be focusing on cognition, sleep, hallucinations, and delusions to get us started. How about telling us what we mean when we talk about cognition? And then, we can jump into some basics.

Jori Fleisher:

Sure. So, we really mean all the different ways or different mental abilities to obtain and process knowledge. Whether those are abstract things, whether that's memory, being able to store something as a memory and then recall it later. It's almost like making a file folder and being able to remember where you put it and pull it out later. Being able to understand how we navigate space and being able to use language, all of those things can go together.

Polly Dawkins:

Could you talk to us a little bit about processing speed and cognition?

Jori Fleisher:

Absolutely.

Polly Dawkins:

And what that means.

Jori Fleisher:

Yeah. So, you know, people think about Parkinson's and think that we have a movement that slows down, and that's true. And we use, sorry, do I need to fix my volume? I can try and talk a little bit louder. So, people talk about bradykinesia, which is that, you know, fancy word for the slowness of movement and movement that gets quieter as it goes. There's this idea of bradyphrenia, which is our fancy Greek word for slowness of thinking. And it means the processing speed is a little bit slower. It's not that the quality of the thought is different. It's almost like as you're talking to someone, you can kind of see the wheels in motion. You can kind of hear the gears turning. It just takes them longer to process what you asked and to get out the response, sort of. So, there's a slowness of responding.

Polly Dawkins:

Super. So, for our care partners, so many people want to know what we should be aware of or what we should look out for when it comes to cognitive decline or cognitive impairment. And can you sort of explain what the natural course is and what people should be looking for?

Jori Fleisher:

Yeah, absolutely. And so, you know, we think about it. It's really hard to tease apart sometimes, like what's normal aging, right? So, I'll have people that will tell me, yeah, you know, I struggle to find a word every once in a while, but yeah, so does everyone my age. Right? And that is, that can be true, and it can be Parkinson's. And so, when we talk about cognitive impairment, there are two categories: two steps along the way or levels of severity. So, mild cognitive impairment is the milder right. And it means that there's definitely a change from that person's baseline. There's definitely some decline, and at least one area of cognition could be memory. But for most people with Parkinson's, it's not memory; it's attention concentration. It's decision-making or what we call executive function. It's language, or it's special.

So, there's a decline from where we would expect that person to be, how they used to perform, if we have kind of how they were before. But it's not significant enough that it is changing their daily activities. It's not causing them to leave their job. It's not causing them not to be able to participate in, you know, social activities and in their community when things are severe enough that they are impacting the ability to work, to function socially, to do the things that that person used to do to keep up with chores or activities of daily living that qualifies as dementia. So, dementia, you know, people hear the term dementia, and I think we automatically go to Alzheimer's. We go to this, you know, vision. If you have the same shared vision, right? You hear dementia, and you think someone who maybe no longer knows who is around them, or you know, is repeating the same questions over and over and over.

And I would caution us to actually step back from that because dementia is a much broader term. If that's who you're picturing, if that's what you're thinking of, you're thinking of Alzheimer's. And the analogy here is every migraine is a headache. So, Alzheimer's is a very

common form of dementia, but not every person with dementia has Alzheimer's. Just like not every headache is a migraine. So, dementia is this broad category of some significant change in at least one area of memory or thinking. And so, as people with Parkinson's have the disease for longer, and as they age also, those two things are kind of combining and going in sequence, right? The risk of developing mild cognitive impairment goes up. So, at any given time, if we tested people or asked them specifically enough, 20% to 40%, or maybe higher, depending on the study of people with Parkinson's, have mild cognitive impairment.

Again, change from baseline. It's not enough that it's affecting daily living, but it's noticeable to the person, right? And what we also know in terms of the risk of dementia is if people have Parkinson's for long enough, right? The risk of dementia goes up as people age, and the risk of dementia goes up the longer you have how you have Parkinson's. And so, there's a big study that they did in Australia where they followed people with Parkinson's for just overtime. They just kept checking in, probably sending annoying surveys, right? And what they found was for people who were still alive, nothing else had gotten them, you know, their diabetes, their heart, nothing else, right? They are with us, and they've had Parkinson's for 20 years. At the 20-year mark, about 80% of people had significant cognitive impairment or dementia. And so, that risk is there; it is not everyone's. But it's something that, you know, we want to be mindful of.

Polly Dawkins:

So just because somebody has been living with Parkinson's for 20 years doesn't necessarily mean they're going to,

Jori Fleisher:

It is not a guarantee. Okay. And it, you know, it also means that, you know, could they be living with Parkinson's for 20 years, and they're noticing that they're struggling to find words or that, you know, it's harder to navigate unfamiliar spaces. Absolutely. And that doesn't mean dementia, right? That may be mild cognitive impairment. It may be for a lot of our folks, if you start off and you're really, really high functioning, you know, I've got folks where they will come to me, and family will say, you know, no, we didn't notice anything. You know, all of the cognitive changes just started in this past year, and the person was, you know, super high functioning, top of their field, whatever that is, right? They were a professor, they were a teacher, they were a doctor, they were, whatever it was, but they were really, really good.

And they're firing on all cylinders all the time. What tends to happen with those folks is they have a really large cognitive reserve, which means they can be declining, you know, in certain areas. Still, they're so smart, they're so used to compensating, and if this isn't working, I'll use this strategy that they can hide some of those challenges, even from the closest people to them, for a very long time. And so, it can often seem like things were fine, things were fine, things were fine, boom. But as we've talked about before, right? Parkinson's doesn't just fall off a cliff, but sometimes there's always that level of compensation. And at some point, the compensation, you know, we may run out of compensation. And so, sometimes that decline

can feel more significant, but often when we're talking with people, it's like, oh, you know, well, actually, she did hand over the bookkeeping to her secretary. You know, she was doing all of that as, like, you know, CEO or CFO or something. But yeah, you know, it seems like this person was actually doing this, and this person was doing this. And so, sometimes it's only in retrospect that we're like, you know, people did kind of start to show signs that some things were becoming more challenging.

Polly Dawkins:

You mentioned the term mild cognitive impairment or MCI, and you also mentioned Parkinson's disease, dementia, or dementia with Parkinson's disease. Are those two related, or are they separate issues?

Jori Fleisher:

So, I would say it's usually that MCI or mild cognitive impairment is kind of the weigh station before dementia. However, there are many people who will one year, if they get like neuropsychological testing or they're doing, you know, testing with their neurologist, they may test in that category of sort of mild cognitive impairment. And they may come back the next year and test back in the normal range. Or stay at that mild cognitive impairment level for quite a while. And often, you know, how could you go back, right? How could you have mild cognitive impairment and then improve? Aha. You absolutely can, particularly if sleep is disturbed, particularly if there are mood disorders that are untreated. So, there's this term called pseudo dementia. It's a terrible name, right? What is pseudo dementia? It means often that a person has depression or anxiety that is so significant that it seems like they're not retaining anything.

They're asking the same questions over and over. You've told them something; it's like it didn't even happen. And it's true because they didn't even store it in memory, not because sort of the memory storage capacity is broken. Still, because there's so much internal chatter from the depression and the anxiety that it's like, it's just in the way of everything. Like, you can't even break through that fog of the mood problems to store a memory or to process correctly because all of the brain's resources are being eaten up by the mood issues or by sleep deprivation. So, I have many folks who I, you know, will test sort of real quick pencil and paper tests and, you know, remember these five words in a few minutes, tell me how many words you can name in this category. We go through all these things, and they'll score not-so-great one year, and they come back the next year, and lo and behold, they've connected with a therapist. We've fixed their sleep; their mood is better. You know, some of the psychosocial stuff that's going on maybe has gotten better, and they will pick up a bunch more points in a good direction, right? So, I don't want people to hear mild cognitive impairment and think that's it, we're done. This is dementia; this is a guarantee. It's not. But it also means that we need to pay attention, and if there's anything treatable or reversible, we absolutely should be.

Polly Dawkins:

And it does bring up that there are just so many things that are connected in our bodies to our brains. And you need to find a specialist who can help you tease those pieces apart for your person. A

Jori Fleisher:

Hundred percent. I mean, it cracks me up when people will talk about, you know, well, psychiatrists think everything is in your head, okay, I'm a neurologist. Your brain is in your head, and everything kind of comes from your brain. So, I mean, I think everything you know is all in your head. And that's all very, very real, right? And very, very connected. So

Polly Dawkins:

Are there Parkinson's meds that can make cognition or increase cognitive issues or cognitive impairment?

Jori Fleisher:

That's a great question. So, most of our usual medications don't. However, some of our older meds can. So, for example, what do I mean? Some of the older kinds of meds that we might use for tremors. So, these are things called anticholinergics: Tri Heil, Artane, Benztropine, or Cogentin. We don't use them very much most of the time. We use them in other diseases for other things. However, they do have this sort of anticholinergic property, which means that they're affecting the acetylcholine system in the brain. And that helps with memory and thinking. These medicines block that system. And there's a lot of good evidence that even short periods of being on those medications can increase people's risk for dementia. So, there medicines that were used a lot in the past when that was kind of all we had, we may use them in very, you know, short durations and in certain circumstances, but usually only in folks, you know, younger, you know, forties, fifties. But I tend to taper people off and always kind of looking for, like, is the risk outweighing the benefit? When do we switch?

Polly Dawkins:

Yeah, good to know. Mary asks, you've mentioned this topic, pseudo dementia. Could somebody get pseudo dementia because of COVID-19 or aftereffects of COVID?

Jori Fleisher:

And apologies for coughing. I'm popping up a cough drop into my mouth. No problem. So, that's a great question. I don't know that we would necessarily call it pseudo-dementia. I don't know. We would call it pseudo dementia. After COVID, certainly, there's a lot of literature on sort of long COVID and recovering from COVID and feeling this brain fog. So, I guess, in a way, that could be pseudo dementia, but when people use the term pseudo dementia, they usually mean related to mood issues. But certainly, if there's something that is, you know, giving you sort of that fogginess absolutely that can make things worse. I saw something else in there

about, you know, UTI, and we want to distinguish dementia and delirium. And if this feels confusing to you, I promise you this is confusing to everyone. So, delirium is an acute issue, meaning delirium is like it, you know, you can sort of say, here's when this started in terms of hours or days.

It is an abrupt change for a person where their level of alertness and, sort of like how connected they are with reality, suddenly changes. And usually, if someone is delirious, there's an infection that's causing that, there's a fever, they're dehydrated, or there's something else going on. And so, it's different than their normal baseline. It's different even from sort of how they might fluctuate from day to day or moment to moment. This is a big change. So, this is, you know, the person who's never had hallucinations, who's never been confused, goes into the hospital, has a planned procedure, gets a surgery, gets anesthesia. After anesthesia is just, you know, things are on the ceiling, and they're just, they're thrashing, and they're trying to get out of bed. You've never seen your loved one like this, and that's delirium; it's often this response to something else perturbing their system.

Polly Dawkins:

Is there a relationship between cognitive decline and motor symptoms? Do people who have worse symptoms tend to have more or less cognitive decline?

Jori Fleisher:

To a certain extent, yes. Both tend to be because as time goes on, we're seeing progression of motor symptoms. And as time goes on, the likelihood of developing cognitive symptoms goes on. There are certainly people who have had Parkinson's for 30 years and have minimal or no cognitive symptoms. And on the flip side, there are people who may have, you know, significant cognitive symptoms really early or significant cognitive symptoms that kind of outstrip their motor symptoms. So, there can be a disconnect between them. But for many people, as time goes on, the likelihood of cognitive change is increasing. And as time goes on, that gets worse. As time goes on, the motor symptoms change and worsen, too.

Polly Dawkins:

That makes sense. Yeah. How about a relationship between age at diagnosis and the more likelihood of developing severe cognitive patients?

Jori Fleisher:

That's for sure, and again, it's not a guarantee, but, and this always seems strange to people, but it seems like folks who have Parkinson's diagnosed symptoms sort of setting in before age 70 tend to do better than people who are diagnosed whose symptoms begin after age 70, right? And so, some of that is, there's a higher likelihood of developing cognitive impairment and dementia in the older group. And it feels kind of counterintuitive because wouldn't you want to have Parkinson's for fewer years? Right? Presumably, if everyone has the same life

expectancy and Parkinson's kicks in around age 75, that should be better. However, those people may decline more rapidly. And so, five years of progression for them may look the same as 15 years of progression for someone who's much younger. And again, not everyone. I saw one of my favorite people in the late eighties, Parkinson's, for a couple of years. So, onset well after age 70 sharp as an attack, and you know, has all kinds of other medical issues going on. And they're asking me, you know, what about this with Parkinson's? What about this with Parkinson's? And I could honestly say, your Parkinson's is the least of your problems, you know, and they're about to go be snowbirds and, you know, go move around and all this stuff. So, I don't want people to come away thinking, oh my gosh, I was diagnosed at 71, you know, dementia's around the corner. No.

Polly Dawkins:

Speaking of other medical conditions or comorbidities, are there other conditions that increase somebody's chance of experiencing cognitive decline with Parkinson's?

Jori Fleisher:

So, there are a couple of different things. Number one, if you have a family history of dementia, you know, then we certainly worry that you may be at higher risk. And why is that? So, like I said, dementia can be many different things. And unfortunately, what we found and what seems unfair is that just because someone has Parkinson's doesn't mean that they can't also develop other things, including Alzheimer's disease. So, when we look under a microscope, they've found that in many people who had no symptoms of Alzheimer's disease in life but developed, you know, Parkinson's and or had Parkinson's dementia under the microscope, their brain showed signs of both Parkinson's and Alzheimer's. And so, if you have a family history of Alzheimer's, particularly if you have certain genes that are more associated with Alzheimer's disease, you may be at a higher risk of developing dementia.

Yeah. If you have, you know, we know that people who have cardiovascular risk factors, so chronic, high blood pressure, smoking, diabetes, poorly controlled, you know, all of those kidney disease, things like that, those can increase the risk of damage to the blood vessels in the brain. And so, there's something called vascular dementia, which is where people are having, you know, tiny strokes over time in different areas of the brain. And so, certainly, that increases your risk, not of Parkinson's, but of a different kind of brain illness that can sort of go along with it. So, we really want to make sure that we're, just because there's a Parkinson's diagnosis, it doesn't mean that we get to sort of forget about all the other stuff. We still, you know, shouldn't be smoking. We still, you know, should be doing all the right things.

Polly Dawkins:

Before we hop into some stories from the field that you have experienced, Deanna has a question. Is it unusual for, or sorry, is it usual for cognitive confusion issues to be worse in the evening? Deanna?

Jori Fleisher:

That's such a great question. Yes, absolutely. So, it's so common that we have a term for it, which is called sundowning or sundowners. And depending on where you are in the world, right? I don't live in Alaska. I don't have patients, you know, in Alaska, but I can only imagine sundowners is worse. Because as people lose their normal kind of visual input of lights on during the day, they can see things really clearly, and they have a sense of what's going on. And as our body gets more tired as they go on throughout the day, we lose the ability to, you know, think as clearly as we did, maybe first thing in the morning, bright lights, everything else going on. So, people can get more confused, more turned around, and have trouble figuring out what's real and what's not real. Sometimes, in folks who have hallucinations, the hallucinations can get worse around that time. Makes sense. Often, it's because they may see a shadow, and it's hard to tell if it is that a shadow. Is that a person, is that, you know, a bear is, what is that? So, things can kind of pick up as the evening goes on.

Polly Dawkins:

So, let's think about all of your experience meeting people in their homes and working with care partners and seeing how successful care partners or care partners have successfully navigated issues with cognition in their homes and in their relationships. Do you have any stories that stick out for you that might be helpful for our audience?

Jori Fleisher:

Yeah, I was actually just reviewing some transcripts of some focus groups that we did with people yesterday and being reminded of, you know, some of these brilliant suggestions. And one thing that really resonated among several care partners was the purpose. Make sure that your loved one has a sense of purpose feels a sense of purpose and meaning, and especially as time goes on and as cognitive abilities change, right? Previously, they might have been, you know, super high functioning and, like I said, managing lots of different things and all kinds of stuff. And that may be harder, but instead of focusing on what they cannot do, what can they do? What are they really good at? Right? And maybe that's teaching someone else the lessons that they learned. Maybe that's showing someone the ropes of something else. So, I think the, you know, some of the really amazing care partners I know would find ways for their loved ones to serve as a tutor to give a talk to people, right? To show those things, to be in the workshop with kids or grandkids. And maybe, you know, it was harder to kind of plan out a really complicated project, but the care partner might talk through the project with them ahead of time, make sure that everything that was needed was there, and waiting on the workshop bench, maybe kind of laying it out in sequence. So, it's a little bit easier for the person to kind of navigate and say, oh, yeah, okay, this step comes next, this step comes next. So, I've been so impressed by that.

Polly Dawkins:

Yeah. I remember speaking with a care partner, and she said during the pandemic, she, and her husband, who's had Parkinson's for 20 years, would volunteer together. Yes. And they could both purpose and make them feel like they were doing something, and they would deliver groceries. And that's amazing to folks. Yeah. And it, you know, while he couldn't be the driver, she could, but he could still participate and be a part of something a little bit bigger than what they were dealing with in their own lives.

Jori Fleisher:

Yeah, yeah. Absolutely. And just recognizing, you know, okay, here's, if this is a challenge, right? If navigating, you know, maybe the person used to be the driver exactly like you said, and they used to have a great sense of direction, but now you're noticing that that's becoming an issue. Maybe the caregiver is driving, but you're asking them to reminisce about, you know, how's this changed? What do you notice that's different? Right? Just finding ways and recognizing this change might be a loss, but how can we leverage what that person knows? Because there's, you know, for whatever is lost, there's so much more still there.

Polly Dawkins:

Yeah.

Jori Fleisher:

And so, reminding not just you as a care partner, but reminding your loved one, there's so much more than whatever, you know, deficits there may be,

Polly Dawkins:

In addition to ensuring that there's purpose for your loved one. What else have you seen or have; do you have other ideas that you've seen care partners do successfully when it comes to helping manage cognitive impairment or cognition issues?

Jori Fleisher:

Yeah, I think because attention is so often affected, thinking about how do we, you know, if we want the person with Parkinson's paying attention and taking something in, how do we set that up for success, right? So, if you're trying to talk to your loved one, and especially if it's like a significant other, if it's a spouse, right? People are often, you know, yelling from one room to the other, right? Or you're walking and passing, and you're going, did you remember to do this thing? And the TV might be on, or a podcast might be on. All of those things are incredibly distracting for someone who has deficits in attention and concentration with Parkinson's. And it can feel like the loved one isn't listening to you. And that's not the case, right? It's that there literally is not enough attention to go around, and there's all these things.

So, I've been so impressed, you know, I'll jump on a video conference with someone, you know, to do our visit and there, you know, sitting and waiting, and I'm running late, right? So, the TV's on, but as soon as we connect, the care partner is like, oh, okay, so and so, Dr. Fleischer's here. And without me saying anything, we'll turn off the TV. We'll, you know, put the puppy in the crate. Well, you know, ask someone else, you know, if there are other people in the house, can you go out of the room? We're doing this. We'll close the door. We'll eliminate some of those other distractions so that it's easier to focus. I have another care partner who told me, you know, she was, we might have talked about this before. She was noticing that her loved one just wasn't making eye contact,

And she just felt like she was missing this connection, and he wasn't aware of it. It seems like it was kind of a visual-spatial thing that he'd be looking off in one, you know, area. And she felt like she wasn't being heard. And so, she just kind of trained herself to say, eyes on me, look at me. And she would wait until they had established eye contact before saying the plan for today was right. And just, we talk with my kids about whole-body listening, right? Show me that you're listening, and you're not distracted by the TV and the things that, whatever. Where are you? Right? Are we communicating? Okay, now let me deliver this information. Now let me ask you this question. So, I've seen care partners do that in all kinds of ways, but just the simple, like, are we making eye contact? I think that's huge.

Polly Dawkins:

That goes both ways, too, because you're the person tasked with doing all the things in the house and remembering all the details that you yourself might get; you yourself might get distracted and not be able to focus on the conversation and pay attention to somebody who might be processing more slowly and

Jori Fleisher:

Absolutely. I mean, so I'm a big list maker, and I'm sitting here, you know, with my pen and paper, and I have a lot of our care partners who will come in and, you know, we're in a visit, and they are frantically scratching down notes, or they're flipping through to something else that they wrote down before, right? And the person with Parkinson's is trying to say something, and the care partner is so, you know, so wrapped up in the, but I need to tell them this, and I need to make sure that there was a list. I wrote down this thing. There's a checklist, let me make it, and I'm like, you're right. They may be having trouble communicating, but you might be having trouble hearing it, right? And it can be coming from that caregiver strain and all the things that are going on, but if they have trouble paying attention and focusing, you are going to kind of model that same behavior, I think. Yeah.

Polly Dawkins:

Jane mentions to us that this concept of eye contact is especially helpful and is needed for both partners who might have hearing loss.

Jori Fleisher:

Yes.

Polly Dawkins:

Yeah,

Jori Fleisher:

Absolutely. The number of times that I have people sitting, and again, it's often spouses significant, others where the person with Parkinson's is going, you know, they say they can't hear me, but I think they've got hearing impairment. And you know, the person is going, I've had my ears checked, it's not me. You know, they don't speak up. And I'm like, could people, could people, you know? So, and you know, hearing loss, there's a lot of research more recently, and I feel like this is one of those, like, we had to study this really, but we had to study this to prove this, I guess, and to get more attention to it. It turns out that if you have untreated hearing loss, you are at a much higher risk of dementia. And if you already have cognitive impairment or dementia and you have hearing loss, you are going to do far worse if your hearing loss is not treated than if it was, which is really simple, right?

We know we've talked about social isolation, right? If people are not connected to other people, they do worse. Imagine if you already have a hard time paying attention; you're trying your best to pay attention to the conversation as someone with Parkinson's. And maybe your processing is already a little bit slower, but now you can't hear, right? That is just too many things stacked up against you. And if enough time, you know, goes on like that where you can't hear, people are talking around you, they're talking past you, you're going to withdraw. And so, we see that also a lot is because it can be hard just to keep pace with busy conversations. I see a lot of people with Parkinson's kind of withdraw. They will sit quietly, and the conversation goes on around them but not with them. And when I see, you know, I see caregivers, and they will make a really conscious effort.

So, you know, as we're coming up on big holiday dinners, right? Instead of putting the Parkinson's, the person with Parkinson's right in the middle of the table where there are a thousand things on the table, you know, if you're fortunate enough and people are reaching and getting up and moving and talking and there's, you know, 20 different conversations that you could be picking up parts of, position them at the end of the table with one person who you know, you know, that they will connect with, who can speak up, who will make sure that they're making eye contact with them so that they will be part of the conversation, not sort of drowning in all of the conversations and unable to participate in any and if possible, if there's, you know, events like that, talking with kids with grandkids, you know, people and saying, you know, so and so, can't wait to hear about what's going on with you. They can really, you know, focus on you better. There's so much going on. It'd be awesome if you could go sit in the living room. It'd be so like, go sit, you know, go sit over there and so, and so, cannot wait to hear

about whatever, invite them, invite other family members and friends to help sort of, you know, pull the loved one aside so that they're in a quieter, more contained environment and can focus.

Polly Dawkins:

Great strategy. We've got so many topics to cover today. I wonder if anybody in the audience has a cognitive or question or question on cognition before we move on to sleep. And probably sleep is pretty interrelated with cognition, too.

Jori Fleisher:

And I see someone I brought up, Carol Roberts, mentioned afternoon-evening challenges with imposter syndrome. We're going to get to sort of the imposter syndrome in kind of hallucinations and delusions. So, we'll get to that.

Polly Dawkins:

Somebody asked Earl, much earlier in the chat, we were talking about the slowness of thinking. Is the slowness of reading affected? Is that something related to Parkinson's?

Jori Fleisher:

Yeah, so it certainly can be. So, we know that there's trouble with the special process. So, even if you know the light and everything is coming in, okay, through your eyes, the back of the brain is still responsible for figuring out what you're looking at. And so, even if attention was fine, sometimes people can have a really hard time sort of gauging what's going on the page. And so, people may spend a long time sort of reading the same paragraph over and over, or visual-spatial may be okay, but attention is affected.

And so, the doorbell rings, a puppy barks, you know, something's going on. And we go right back to the, you know, first sentence, right? And so, it can be really, we can see people who were avid readers, you know, and going through books at Rapid Clips, and now they still enjoy reading, but it's taking them so much more time. I would say make sure you're seeing an ophthalmologist and go see an eye doctor. There are a lot of different things that can affect vision in Parkinson's. Some are treatable, so many people have dry eyes. And that can lead to some double vision. It can lead to some blurry vision. Because they're just not making as much as many tears. And so, things can get a little bit wonky that way. That's very easily fixable with drops. It's annoying to put drops in. But it's very fixable, right? And that can restore something that a person loves and a great way for them to process information. So, we always want to look for those low-hanging fruits to see if we can fix this and get this activity back for them. Absolutely.

Polly Dawkins:

Sheila asked us if stress affects cognition.

Jori Fleisher:

Oh, absolutely. I would say, Sheila, if you're stressed, do you feel like you can think straight? I know that I don't. And so, you know, yes. In everyone, yes to the nth percent in people with Parkinson's. So, you know, a phone call comes in, and there's bad news about something or someone, and the person may just really have a very rough time, have a really hard time focusing on anything else. You know, and get kind of stuck and perseverate, you know, kind of fixate on that thing, that thing, that thing, that thing. And have a really hard time, sort of like, getting out of that rut.

Polly Dawkins:

Super. Let's shift into talking about sleep. Can you talk about how common sleep problems are for those living with Parkinson's and those may be sleeping next to or sleeping with those with Parkinson's?

Jori Fleisher:

Yes. Yeah. I mean, if we added up all of the different kinds of sleep disorders that can affect people with Parkinson's, I would say it's hard to find someone with Parkinson's who doesn't have at least one way in which sleep is affected, right? That the prevalence of some kind of sleep disturbance in Parkinson's has got to be close to a hundred percent, maybe not all at once, right? But people can have trouble falling asleep. People can have trouble staying asleep. People can have trouble when they wake early in the morning, at 4:00 AM, and have a really hard time going back to sleep. People can have a really unrestful, fitful sleep. People can have extremely vivid dreams. Sometimes, they're pleasant; sometimes, they can be work-related. I have people that will have, I mean, they can describe a conference that they went to and like the keynote speech that they were listening to in 1967, and they just relived the whole thing in their dream, right?

They're very vivid. And some people, you know, always remember their dreams just lifelong. There are other folks who tell me constantly, "I don't dream at all. I've never had dreams." So, as a neurologist, your brain is always dreaming. Everyone does dream. It's a question of whether you remember the dreams. But people with Parkinson's can have very vivid dreams, very vivid nightmares. And they can have REM behavior disorder, which is when you act out dreams during sleep, that kind of switch that should turn off the ability to dream about playing basketball. And if I'm dreaming about playing basketball, I am lying quietly in bed. But if someone with Parkinson's is lying in bed dreaming about basketball, they may be going like this. They may, their legs may be running, they may be moving all about.

Polly Dawkins:

And what causes sleep? Parkinson's and sleep problems in Parkinson's. And how does that differentiate from just sleep changes that happen when we're aging?

Jori Fleisher:

So, each of those different things that I described, those are all coming from different areas. So, there's an area of the brain that, you know, almost acts like a switch to kind of turn off that connection between what you're dreaming about.

And it is activating your skeletal muscles during sleep. And so, that area of the brain, those neurons can be affected in Parkinson's so that they just don't switch off, right? And that REM behavior disorder where people are acting out their dreams that can be going on for years, decades before someone ever has slowness, stiffness, tremor ever gets diagnosed with Parkinson's. So, that's one thing. We also know that normally our brains produce melatonin, right? And it's a chemical that helps you fall asleep. That helps kind of shift your brain from wakefulness mode to sleepiness mode. It's the like equivalent of like, okay, we're turning down the lights in the cabin, we're getting ready, you know? And in people with Parkinson's, they don't produce as big of a melatonin surge in their brain to get them ready for bed as people who don't have Parkinson's.

So, you know, does that mean that melatonin can be a good treatment? Absolutely. Talk with your doctor about, you know, dosing and which kinds and stuff, but similar to how we are missing dopamine and Parkinson's and can replace it. We can be missing melatonin and Parkinson's and can replace it. Some of it can also be that people are waking up for various reasons. So, I have folks to tell me, you know, I wake up in the morning, you know, I wake up multiple times a night and go to the bathroom. So, the question is always, are you waking up because your bladder is waking you up, right? You are waking up with the, oh my gosh, I going to pee right and running to the bathroom or attempting to, or are you waking up for some other reason and I'm up, I'd probably like wake up in another hour to go to the bathroom anyways, so I might as well get up now and go to the bathroom, right?

If you're waking up for some other reason, we need to think about that. And there are all kinds of reasons people can be waking up. Sometimes it can be stiffness or slowness, sometimes it can be meds wearing off. Typically, we think about we don't usually need our Parkinson's medicines overnight during sleep because you're not moving around, you don't need them. But if you're still prone to waking up and you're very stiff and you have trouble turning over in bed and getting comfortable, that can be a reason why people have trouble falling back asleep and have really disrupted sleep and can be missing out on a lot of sleep. So, there's any number of different reasons. I see somewhere in there someone said like cramps, absolutely. Charlie horses, whatever we want to call them, that, you know, calf muscles, toe cramping that can go like this, toes that can go up like this.

Jori Fleisher:

Very, very common. Can off usually it's sort of, you know, early morning like 2, 3, 4 am that people may be waking up with that. Sometimes that's a sign of dehydration. So, sort of one of the easy things to try is can you try hydrating better? Ideally hydrating better during the daytime and to tapering off your fluids in the two or three hours before bedtime because someone out there is going great if I hydrate and that makes my cramps go away. But then I'm waking up to pee all night long. She's not fixing anything. You are correct. I'm heading you off the pass. Hydrate early. Something that I was told actually so lots of pregnant folks will have a lot of leg cramping. It's a very common thing during pregnancy. And so, I had had that with my first kid.

Jori Fleisher:

I could not find anything that made it better. I mentioned this to one of my colleagues who's a neuromuscular specialist and said, is there anything that really works? because You're really not supposed to take anything when you're pregnant. And she said, try coconut water. So, coconut water is, comes in those like aseptic boxes, sort of juice boxes for grownups. There are a thousand different brands. Some of them are flavored, some of them are not. It does not matter. It's basically water that has a lot of magnesium and some other minerals in it. And the thought is, probably the hydration and magnesium may help some people. So, I've had some folks where that really, really helps with their nighttime cramps. They'll drink, you know, four ounces or so of coconut water on the nightstand right before they go to bed. It helps some folks does not help others. But hydrating better during the day can help.

Polly Dawkins:

Let's talk about some pharmacological and non-pharmacological ways to treat sleep issues that somebody in the audience might be able to try right away.

Jori Fleisher:

So, you know, making sure that you are trying to get your brain on as close to a normal schedule as possible. What do I mean by that? This is not, are you a night owl? Are you a morning person? This is awake during sunlight asleep during the night and Parkinson's has a tendency to try to shift people's schedule. So, every week I have someone who goes, well, I've always gotten five or six hours of sleep my whole life. What does it matter? If the five to six hours are between 6:00 AM and 11:00 AM, it matters. Your Parkinson's is doing that. It's trying to shift you. And we also know that the more that that happens, the risk of dementia goes way up. Your brain does better when you are sleeping at night and awake during the day. If your loved one has shifted their schedule like that didn't happen overnight and you are never going to succeed going like, I listened to this webinar.

She says, you can't do that. We going to shift it right and go to bed by 9:00 PM No, it's not going to work. They're going to be very angry with you. They're going to be miserable. They're still going to sleep the same. Anytime we try to shift sleep schedules, I mean, just think about which

direction is it with daylight savings? If you are in a state that does daylight savings fall back, you get the extra hour. Lovely. Right? In the spring you lose an hour of sleep. It's just one hour. Everyone is miserable. Everyone complains, right? And everyone is like, ah, it's never been this bad. It's terrible. Right? If you are trying to tell your loved one, you must shift your sleep cycle by 2, 3, or 4 hours. They're not going to do that overnight. 15 minutes. 15 minutes, like every week, every two weeks. Slowly trying to walk back that time to try to keep someone on a more regular schedule can be really helpful.

And are you thinking about how can we get light exposure during the day? Can you get outside? And if you can't get outside, if you're a place where it's not safe, if you're a place where it's too cold, whatever that is you know, people talk about the sort of happy lights and the lights that kind of approximate daylight sitting in front of one of those lights. You can even purchase them online, right? Sitting in front of those lights. And they usually come with instructions about, you know, what's setting and for how long and approximately when during day can be really helpful. I have a colleague who's studying this and looking at melatonin levels and you know, light exposure and making sure that we have good sleep hygiene, which I think is a funny term. And people think that means like sleep hygiene. Well, my sheets are clean, I wash them every, that's not what it is.

Sleep hygiene is like, are you doing all the right things to help you sleep well? So, the bedroom should be for sleep and intimacy and that's, it should not be for tv, should not be for any other activities. Ideally, you shouldn't be exercising in the same room that you're sleeping. Because your brain is like, oh, are we doing yoga or are we sleeping? Are we doing, you know, cardio or are we sleeping? What are we doing? It could be up for anything because the environment is the same. It's getting the same stimuli, right? We want the brain in every possible way to go, oh, this is a dark room. Or, you know, this is a calm room. There's no sound or there's white noise. The shades are drawn at night. So, sleep environments should be cool. People do better sleep in a colder room, better to have a few layers of blankets. And if thermos regulation, heat regulation is a problem, the person can toss them off, but better to start in a colder room, darker room, quieter room, or you know, white noise. Then have other stuff going on and really wind down. So, as much as possible, turning off the screens, doing something that is calming in that 45 minutes before you get into bed, that tells your brain like, Nope, this is, this is our routine. We're getting ready.

Polly Dawkins:

You talk a little bit about light exposure. You said that if you can't get outside, there's some lights if you can get outside. I've, I've heard that just getting outside for a mere 10 minutes in the morning. Yeah,

Jori Fleisher:

Even 10 to 15 minutes in the morning can be enough for many people. Plus, it gets you good vitamin D, which is good for your bones. But yes, get outside if you can use that as part of, you

know, look, we're getting outside and we're walking, we're doing our exercise. Multitasking. You just got a twofold, right? But absolutely daylight really, really helps.

Polly Dawkins:

What are some strategies that you've heard care partners use? Obviously, you've talked about many of them here, but to help with sleep or to sort of combat some sleep challenges. That they're maybe stuck in a vicious cycle with their person or their own sleep around it.

Jori Fleisher:

So, one very common one is I don't sleep while at night. So, I take a lot of naps during the day, or I take long naps, especially during the afternoon. The person's brain, you know, is trying to get as much sleep as it needs. And if it's filling that quota during the day with napping, then you're not going to be tired again at night, and the cycle will continue. So, I'm not saying no naps; naps are okay if we need them, but power naps no more than 45 minutes to an hour and no later than like two o'clock in the afternoon.

Right? Otherwise, trying to keep the person with Parkinson's active, right? If you know that well, okay, but like they're just going to sit down in front of the TV and they're going to doze off. Okay, well then, we going to be doing something else. So, we need to kind of, you know, be active and be moving around and try to, you know, tire out the person's brain during the day with activity so that they can sleep better, longer, more sound or sleep at night.

Polly Dawkins:

I'm looking to see if we have questions that haven't been addressed. Oh, what about restless leg and sleeping.

Jori Fleisher:

Yeah, so, and I want to distinguish restless leg from a couple of different things because I spend a lot of time with people going, I got restless leg and then there's certain meds that we use to treat that. But sometimes the person's using the term restless leg and they mean something else. So, what is restless leg? Okay, restless leg is this uncomfortable feeling. So, the person has to be able to say, my legs. And it can sometimes involve other parts of the body, but typically legs. my legs feel uncomfortable. They feel I have a creepy Crawley uncomfortable sensation in them. And if I move them, it goes away even briefly. It typically is something that happens at night. Usually when a person is sitting when they're, you know, sitting down on the couch when their feet might be up or down, but they're kind of reclining. They might not even say anything at first, but you see that person and their legs are just kind of, it's usually bothering the person next to them as well.

Because they're like, what are you doing? They're just, they're just wiggly and jiggly. But this is different from dyskinesia. So, dyskinesia is often when they'll, levodopa medicine is kind of

peaking in the system. People kind of have those wiggly jiggly movements. They're not doing it in response to feeling uncomfortable. Often, they are not cognizant. They don't, they're not aware that they're making the movements, right? We've talked about how someone could be sitting there like this and I'm asking them as their doctor, do you ever notice any involuntary movements? Right? The person with restless leg is very aware that their legs feel uncomfortable and that moving the legs helps at least momentarily makes stuff better and is preferable to just trying to stay there with this yucky feeling. Often if they get up, if they move around, if they exercise, that can make it better.

Yes, dehydration, cramps and restless leg can go together. Common triggers for restless leg would be dehydration. Many people are very sensitive to alcohol. And that can be a trigger for their restless leg. So, you know, half a glass of wine and they might just be all the time, right? So, everyone's a little bit different, but those are kind of common things. There are some medicines that we use for Parkinson's that double up and are decent treatments for restless legs. So, for example, those would be the dopamine agonists. However, some people have restless leg and levodopa makes their restless leg better, but some people have restless leg and levodopa makes their restless leg worse. So, it's always a question, you know, the meds are not causing restless leg, but the meds could be helping or hurting, and it really depends on the person. So, that's a very individual thing.

Polly Dawkins:

Tracy asks us what if the care partner has frequent REM sleep behavior disorder? Should they be checked for Parkinson's?

Jori Fleisher:

They should at least. I would say they should be followed. For sure. You know, see a sleep physician, there are actually a lot of different studies like that enroll people now with REM behavior disorder trying to follow them and, you know, see are there, you know, could this person have very early Parkinson's, or could this person be at risk of Parkinson's? So, not everyone with REM behavior disorder goes on to get Parkinson's, but the risk is pretty substantial over time. So, I think one study followed people out for about 14 years especially men with REM behavior disorder. And around that 14, 15-year mark, most people, 70 to 80% had converted to having some Parkinson's or something like it Lewy body disease or multiple system atrophy. So, definitely, you know, be following with a sleep doc, it may be worth seeing a neurologist and saying, you know, I'm aware of this connection. Let them examine and see if there's anything. And you may be very eligible for clinical trials as they come out saying, you know, we really want people at the very, very earliest signs of Parkinson's. That's kind of who they're looking for is the person who's got REM behavior disorder and maybe nothing else.

And there are other meds and treatments that can help severe restless leg syndrome. So, probably the most effective is a medicine called Gabapentin. And relatives of that medicine, they're sort of a long-acting gabapentin that's very effective. And a newer cousin called Pregabalin. That can be very effective. There are some other medicines that we can try. Sometimes a medicine called methadone, which is often like our third- or fourth-line treatment when other things have failed. But there are things that can be very effective. So, talk with your neurologist, a sleep specialist, or your neurologist for help with restless leg.

Polly Dawkins:

I wonder if anybody in the audience has suggestions for Deanna or do you Jory, she says often a struggle to walk to the bedroom at bedtime. So, how to make a more calming pre-B bedtime routine. Any questions or Jori? Do you have some suggestions?

Jori Fleisher:

I mean, one thing I would think about, and I see this a lot. Sometimes this is our doing as the physicians is, you know, I've mentioned that usually we don't need levodopa, we don't need medicines while we're sleeping, but that means that we're often timing the medicines. So, we're like, okay, when do you wake up in the morning? When do you go to bed at night, we're going to space out the medicines. So, you know, the first dose of the day kicks in, lasts you a couple hours till the next one lasts you a couple hours till the next one, and then that last dose of the day, you take a few hours before bedtime and it should carry you through. And if you're coasting on the last fumes, that's okay because you're getting into bed and for many people that can be okay for a while, but if you are running outate steam and the bedtime routine hasn't happened yet, absolutely that can be, you know, it can make bedtime take four times as long. It can be really stressful. So, that may be as simple as telling, you know, whoever is prescribing the medications and going, look, the bedtime routine is taking this long and it's very stressful. Can we adjust the medicine at all? Is it worth having a dose closer to bedtime to just get us over that hump or a slightly longer acting version as, you know, the last dose of the day to maybe just carry us through that time.

Polly Dawkins:

Great suggestion. We've got two people asking the question about going back to too much sleep and can too much sleep add to a risk for dementia or increase dementia?

Jori Fleisher:

It's a, that seems like a really simple wonderful question. It's an incredibly complex question. So, it's hard to know exactly what's cause and effect and it may go both ways. So, certainly people with dementia often will have what's called excessive daytime sleepiness, and we'll just see that they are sleeping more and more and more hours of the day. So, I have some folks where they're asleep 16 or 20 hours of the day and you know, we get a two-hour chunk here and a two-hour chunk here. And that's an extreme and that's not everyone. But it is the case.

You know, I want to balance the, if that is happening to your loved one, you are not doing something wrong. And sometimes I see care partners struggling so hard to try and get their loved ones awake and it's just kind of the course of the disease and it's very, you know, it's, we're not going to make a lot of headway there.

But absolutely if someone has swapped their sleep cycle, you know, and they're sleeping all day long and then they're up all night, that does tend to increase the risk of dementia. So, that we do really want to be careful of and wary of and setting reasonable sleep and wake times. And I see a lot of struggles sometimes when, you know, we have the morning person married to the night owl because, you know, the morning person is like, I'm getting you up at 6:00 AM and that's just, it's going to be a recipe for disaster for the night owl. Right? So, meeting somewhere in the middle recognizing, okay, maybe there is a first wake up and there's, you know, one snooze allowance and then there's a getting up out of bed. Another thing is if the getting up out of bed is so difficult because the person is so stiff or so slow, yeah.

Sometimes something that we'll do is say, you know, even though it's not convenient, I will have people, you know, the care partner will often be up a little bit earlier and maybe they give, they wake their loved one up, they give them their first dose of medicine for the day in terms of their Parkinson's meds. And then they intentionally, you know, make sure that they're sitting up or angled up so that they can swallow, okay, they're not going to cough on a pill, wash that down, and then let them go back to sleep. Give them 30, 45 minutes to let that first dose kick in so that when you're trying to start the morning routine, they've got some gas in the tank. You're not just trying to, you know, push them, but they can actually kind of mobilize as well. So, sometimes that can be really helpful.

And I saw the getting up frequently at night for the bathroom and feeling really frustrated. If you're not seeing a urologist, it's worth seeing a urologist whose specialist and sort of, you know, kidney and urination and things like that. They may be able to look and see, you know, is this prostate, is this bladder? If it's prostate, probably not Parkinson's related. If it's bladder, probably Parkinson's related. There are meds that can be used for either or both. Sometimes they coexist and some meds are better than others. So, you know, maybe see if that urologist will consult with the neurologist or ask your neurologist if there are medicines that they would feel more comfortable with than less comfortable with in terms of urologic. The other very simple thing, if we haven't talked about already, is this idea of double voiding.

Which is, I feel like what I do with my children when we're about to go on a long road trip, which is like, all right, we're starting to pack the car, everyone goes to the bathroom, right? And everyone goes to the bathroom and 45 minutes later because we've forgotten all the pieces and everything else, right? It's like, go again. I don't have to, I just went, I know, but just try. Because there's not going to be a stop, right? For the next 90 minutes. Like, you're stuck in the car and I'm not pulling over the side of the road, right? Just try. Okay. And so, it's this idea, which is before you change into pajamas, before you do the teeth, before you do anything else, go to the bathroom first and then do everything else. And literally before you're about to turn

off the lights, try to go to the bathroom again, even though it doesn't feel like you have to go try a second time and you're training your bladder and being like, Nope, last call.

Last call. Right? and the urologists tell me like, really, you know, if people do this, it really does work. And often what they'll do during the day, they'll pair that with bladder training, which is, if someone is going really frequently, you know, they'll say, how often are you going to the bathroom every two hours? Okay, we're going to make a schedule, we're going to set a phone alarm and say every two hours you go to the bathroom, and you may realize actually like it's two hours, I actually don't have to go, go, but then you cannot go again for another two hours. And then they stretch out that time and say, okay, now it's every two and a half hours, now it's every three. The bladder is a muscle, so you're doing reps like you're, you're conditioning that muscle to get stronger and to be able to hold things better. And so, you know, there may be some non-pharmacologic, non-medication things we can do for bladder. And there are medicines out there and some medicines are better than others for people with Parkinson's. Great,

Polly Dawkins:

Thank you. That asks you and me an important question, and then I'd like to copy that part of that question here. Do other care partners have trouble? I'm going to put it out for everybody else to see. Do other care partners have trouble because they are not allowed to sleep at night because of the partner's needs? And then Pat asks any ideas?

Jori Fleisher:

Oh, Pat, you are not alone. So, many people. I was just talking, I was giving a talk to neurologists about care partner strain in people with Parkinson's and Lewy body and talking about this big study and this guy came up to me and he said, are you measuring care partner sleep quality? And I went, oh my God, I didn't think to put that questionnaire in there. And he started trying to explain his rationale and I was like; you are a hundred percent, right? Because if you are being woken up frequently throughout the night, that has a huge toll. Sleep deprivation has a huge toll, right? It actually increases your risk of high blood pressure. It increases the risk of mood disorders. It, you know, leads to people are more socially isolated. They don't have the bandwidth to go out and try and socialize or call someone because they're running on fumes.

And it makes it so much harder to have that relationship because you're just exhausted. So, what can you do? So, I have some people, you know, number one, what of the person with Parkinson's sleep issues are treatable. Many of them may be right? So, talk with a neurologist, talk with a sleep specialist. Maybe they have sleep apnea. Sleep apnea is more common in people with Parkinson's and can be a reason why they're waking up. No one wants the CPAP. Okay, I know it sounds like Darth Vader. No one will possibly ever be able to get used to it. I promise you people do. And once they do, it can make a world of difference in their sleep if they have sleep apnea. And it's kind of like a white noise machine, so it's sort of a twofer for the person in the room with them.

But if it's sleep apnea, that's treatable. If we can treat what's going on with them that's causing you to wake up, that will help for many people. I mean, this is kind of the, you know, the thing that I tell my med students is they'll tell me, oh, I asked the person if they had REM behavior disorder and if they're, you know, kicking and thrashing during sleep and the person said that they didn't know and I asked their loved one and the loved one said, no. And I come in the room and go, do you sleep in the same room? And the care, you know, the spouse or the significant other goes, no, we haven't slept in the same room for 15 years, you know, since he started punching me in sleep. And the med student's like, oh. I'm like, yeah, you going to ask if they're in the same bed because the person who's having rem behavior disorder, unless they smack the wall or something else, they don't know you guys as the care partners, you know, what's going on.

So, a lot of people will switch to sleeping in a different bed, sleeping in a different room. I have some folks where, you know, they might set up like a, an audio monitor, a baby monitor, or a video monitor because they still want to have eyes or ears on their loved one, but may turn it down so that they're not, you know, as frequently disrupted. This is also a time where, you know, if there really is so much other stuff about, you know, we cannot get that person sleeping better sometimes getting someone to be a night shift person, right? If you have the bandwidth financially, if that is possible getting someone who can just be eyes and ears and help your loved one overnight. And it may feel like I am paying for someone to sit and stare at the wall in a dark room because most nights my loved one is fine.

You're right. But you can sleep soundly. You can have that respite of sleep, which is a human necessity so that you can function the next day. And you know that if they get up, if they start to go to the bathroom, there's someone there whose sole job it is to try to help them. Right? And that may not be a paid person. That might be, you know, an adult child, that might be a neighbor, that may be someone else. You know, maybe there's someone in the community who is already a shift worker, you know, maybe you know, a nurse who takes, you know, night shifts and things and all that and is okay with, you know, even just being there for a couple of hours to give you that break so that, you know, you can get a few hours of solid, uninterrupted sleep. I think it takes a lot of creativity and it's hard.

Polly Dawkins:

We have many resources on sleep, sleep primers, podcasts, articles, interviews about sleep on our hub. So, for those of you who might be left with more questions about sleep and strategies and what people have found to make sleep easier and work please go over to our hub and check them out. But it's time for us now to shift to talking about hallucinations and delusions. Once again, we have given you many resources on the hub, so if you haven't had a chance to check those out, please feel free to go over there after we meet today and check those out. It's a really difficult topic is, is hallucinations and delusions. And let's talk Jerry, about the impact of these symptoms on care partners and strategies our care partners can use for managing it. Yeah, I think that's what we run into so much. What do I do? Yeah. So, just to really quickly, can

you tell us what hallucinations, Parkinson's disease, psychosis, hallucinations, but just a primer really quick and then we can Yeah.

Jori Fleisher:

So, hallucinations are any, any sensory way that a person is feeling, seeing, experiencing something that is not really there. So, in Parkinson's, most commonly this is a visual hallucination, seeing something that's not really there, but people can also feel things that are not really there, a tactile hallucination. They can smell things that are not really there. They can hear things that are not really there. So, any sense that you have something that that person only is experiencing, and a delusion is a fixed, false, persistent belief. So, it's not, you know, oh, I think today's Wednesday, oh, okay, I was wrong. Right? I get over that. It's, I am convinced that despite all evidence to the contrary, the following conspiracy is real, right? or I am convinced that, you know, my loved ones are stealing from me and no amount of what you show me, don't show me those bank statements.

Jori Fleisher:

You know, you've doctored those, right? It is a, it's something that despite all evidence to the contrary and a lack of evidence to support it, that person's brain is telling them that this thing is true. And so, Parkinson's psychosis refers to when people with Parkinson's have recurrent either hallucinations or delusions. And often when they've lost insight into that. And so, the insight piece is so fascinating because you would think, okay, well if someone is, you know, seeing something that's not there, then they really think it's not there. There's this continuum of reality, which is fascinating to me. And so, people can often have a hallucination in Parkinson's. They can go, oh, I'm seeing, you know, a little bird on the windowsill. I know it's not real. They know it's not there, but their brain is giving them information both that, here, here's this thing, and also that it's not real. And they can hold those two things at the same time. As time goes on for many people with this, they lose that insight. And so, they lose the ability to say what's real and what's not real. And that's when we really get into the Parkinson's psychosis is we don't have insight into it, and we're sort of spending more time with the hallucinations, more time with the delusions.

Polly Dawkins:

Why, why does Parkinson's disease psychosis, hallucinations, delusions, why does that happen for people with Parkinson's? And is there an increasing risk for developing that? Something we can avoid.

Jori Fleisher:

So as time goes on, the risk increases, but it's certainly not everyone. So, depending on the study you read, you know, it can increase to over time, right? At all. We told everyone who's had Parkinson's at any point in time, what percent have had hallucinations or delusions upwards of 50%. Some studies will go higher, 60 to 70%. So, it's not everyone and not every

hallucination or delusion is scary. They can be benign. So, there can be pleasant hallucinations and we can talk about those. But why do they happen? It's, we think at least the hallucinations, the visual hallucinations seem to be related to the Parkinson's affecting sort of the back of the brain, the occipital lobe, and back areas of the brain that kind of tell you where things are in space and what things are in space. There's sort of different pathways in the brain.

Jori Fleisher:

There's what pathway and where pathway and when Parkinson's starts to affect the nerve cells along those pathways. You know, I almost imagine it's like you have these old film reels of memories that have happened or things that you've seen. And it's like the brain spontaneously is like, today we're going to be playing the following and it's just, here's a film reel of your cat from childhood. And you're just kind of seeing that cat move the way that that cat used to move, even though that cat's not there. So, sometimes they can be familiar things, but sometimes they can just be spontaneous things that a person is seeing. The really fascinating thing is there's a lot of similarity across all people with Parkinson's who are all so different. People see similar types of things, which is very fascinating. So, they can often start with what we call minor hallucinations.

Jori Fleisher:

And people don't usually describe these, and families don't usually describe these, I have to be the one to describe the reaction to them, which is do you ever see your loved one just kind of like dusting off some invisible dust or schmutz on a table that they're like kind of gathering crumbs that you don't see? Or are they ever like reaching down to pick something up off the floor or they're picking it like lint on their clothes that you can't, see? It can be very subtle and but often we think of those as minor hallucinations. They're seeing something tiny. I have a lot of times where people will not complain about that. They're not upset about it, but people who might be sitting in a chair or sitting in a wheelchair and are, you know, falling because they're going to reach something that they're seeing on the floor.

Jori Fleisher:

And over time these can evolve to seeing like patterns. So, you know, looking at like a wallpaper pattern, but seeing kind of something in it, seeing something in the pattern that's not actually there—or seeing kind of splotches of color. Flashers, floaters, which we always say, you know, okay, well could they be eye floaters? So, always getting vision checked to make sure that it's not that but can evolve to seeing little animals can evolve to seeing children, people groups of people. And while they tend to start off not scary, if they're kind of left unchecked in some people, they can evolve to be more intense and to be scarier. And again, to lose that insight into it.

Polly Dawkins:

So, it sounds like you're recommending that as a care partner, if you notice this or you're being told this, you should talk to your movement disorder neurologist.

Jori Fleisher:

Yeah, I would flip the cliché and say, if you think they're seeing something, say something. Right, because this can be, I mean this can be so frightening for the person with Parkinson's, but this can also be so frightening and confusing for care partners if your loved one can't tell you what they're seeing or what they're worried about, right? Or they're just acting erratically. Please, please, please bring this up. Right. It may be that medications need to be changed. It may be that there's something else going on. It may be that there's, you know, an infection underneath, or it may be that this is part of the course of the disease and in either of those scenarios there are things we can do. Right? So, I mentioned like that that class of medicines that we don't use as much anymore, the anticholinergics, those can certainly make hallucinations worse. Sometimes people can be on a medicine called amantadine, which can be helpful for dyskinesias in certain things. But as time goes on and as people age, it can increase the risk of hallucinations. And so, if someone comes to me and they're stable on amantadine for a while, but now they're hallucinating before I add something on to sort of try to keep the lid on the hallucinations, I'm going to take the amantadine away and see if just removing a medicine that could be making this worse, could be enough.

Polly Dawkins:

So even if what I'm hearing is even if the hallucinations are benign, they should-?

Jori Fleisher:

If the hallucinations are benign, it's worth saying something. If the hallucinations are benign, we don't necessarily need to change something. But I always want to know if the person is having them because then it's on my radar that they could be getting worse. And we need to keep an eye on this. Yeah.

Polly Dawkins:

If hallucinations happen for people with young onset Parkinson's and it happens early on, is that more likely medication related? And might have lost Dr. Fleischer here.

Melani Dizon:

Yeah, I think we lost her. It took a minute for us to lose.

Polly Dawkins:

We lost her video. Yeah. Right. Let's see if she- Yeah. Is able to join us back. In the meantime, folks, feel free to put questions in the chat. If Dr. Fleischer isn't able to come back, we'll grab

those questions and we will, we will answer them when we get her, and we'll write them up for you. I'm just going to send a quick text to her and see if she's able to hop back on. And I will do a little, anybody have questions you'd like to put in the chat?

Melani Dizon:

How many how about, how about we do a little poll? How many people how many people have had experience with this? How many of their, your people with Parkinson's or experiencing hallucinations or delusions of any kind?

Polly Dawkins:

Couple thumbs going in the air.

Melani Dizon:

Couple raised hands.

Polly Dawkins:

A couple raised hands as well.

Melani Dizon:

Yes.

Jori Fleisher:

Small children.

Melani Dizon:

Yeah.

Polly Dawkins:

Yeah. Lots more raised hands. Yeah. Somebody says they're on a medication. Yeah. See Dr. Fleischer is going to reboot her computer and try to join us again.

Jori Fleisher:

Oh look, can you hear me?

Polly Dawkins:

Yeah. We were just, yeah. Sorry about that. Internet. No,

Jori Fleisher:

I don't know what happened, but yeah,

Polly Dawkins:

We just asked the question and lots of hands got, got raised about whether people have experience with hallucinations and we're getting a lot of yes, raising hands and then people are talking about what they're experiencing. So, that's where we were when we, when we dropped off, we I think I had asked the question about young onset and early on experiencing hallucinations. Could that be medication related? And I'm not sure we heard the answer to that.

Jori Fleisher:

Sometimes it can be, but I think that can be really tricky. So, that I would definitely like talk with your treating neurologist to see what could be going on.

Polly Dawkins:

Super. Yeah. Do hallucinations happen while a person's sleeping? Or is that not related to hallucinations?

Jori Fleisher:

That's a great question. So, there are some funky neurologic terms for hallucinations that happen around sleep. So, technically you're not hallucinating while you're sleeping. That's kind of, that's dreaming, right? Dreaming is sleeping hallucinating. You're seeing stuff that's not there, but it's only existing in your brain. But what can happen is almost that like sleep gets leaky in Parkinson's, by which I mean that people can start to doze off and they might start to have a dream and then open their eyes. They might know roughly where they are. I'm in the bedroom, but the person who is chasing me in my dream down that alley is also in the room with me. And they're seeing something while awake. Their brain is awake, their eyes are open. They think that the thing that was happening while they were sleeping is still at least partially going on either coming up out of sleep or just going into sleep that they kind of start to go to sleep and they're sort of having hallucinations. So, those can sometimes happen first before a person is having hallucinations, you know, full on during the daytime without being around sleep. And I think we'd said, you know, do all hallucinations. They don't necessarily need to be treated if they're not, you know, harmful and they're not scaring the person, but let your treating physician know that they're happening so that they can sort of be keeping an eye on it, making sure to ask you at every visit.

Polly Dawkins:

Let's talk about some strategies that you've seen people use. And maybe some of you in the chat could also tell us strategies you use when specifically, around hallucinations. And maybe let's talk about delusions because that might be a little harder for a care partner. Care partners use with hallucinations.

Jori Fleisher:

So, the number one thing is you cannot argue with them. You cannot, you will not win. You are never going to win because their brain is producing this phenomenon. So, a couple of awesome things that I've seen. So, for some people they will carry around a flashlight or the care partner will have a flashlight, you know, either on a belt loop or something like that that they can use. And I've had a couple of folks where if they're having a hallucination, their sort of reality check is they'll pull out their flashlight and they'll shine it on whatever they're seeing and that makes it go away. So, for some people that works. I've suggested that for other people it hasn't worked. But it's benign enough that it's easy to try. But it's something that's very, like the person themselves, you know, can sort of do it.

And you just remind them like, oh, did you use your flashlight? If they say they're seeing something, not, you know, it's not there. Did you use your flashlight to try your flashlight? So, that I think can be helpful. But the others are distracting redirect. So, you're not going to win by saying that the thing is not there. Their brain is telling them that. So, if they're seeing a bear on the front porch, oh, you know what? I just tossed some food out front. They're going to go have a snack and then they're leaving. Let's go in the other room, let's go turn on the tv. Let's, you know, I've seen people, it doesn't matter what you say about the hallucination, right? It's just kind of, it's their okay. Right? If it's their people in the house, oh, you know what, they have to leave in two minutes. They told me they're leaving in two minutes. Okay, bye. Go on to something else. Right? It's, I mean, literally a change of the channel.

Polly Dawkins:

So even don't you as the care partner interacting with us, if it were real, is it's an okay strategy.

Jori Fleisher:

Absolutely. So, I was thinking about this right before we joined the webinar. I was talking to an amazing care partner yesterday, and her loved one has a really hard time describing what he's seeing. He has very, very advanced dementia, but she can tell when he is getting upset and she could tell, you know, she sorts of recognized this look on his face and her kind of looks like he's looking at a bunch of different people. And I saw her lean down to him and go, are they there? And he goes, yeah. She said, are you worried? Yeah.

You think that they want to hurt you? Yeah. She goes, well, tell them they need to go through me. And she just, you know, she was just like, they're going to have to mess with this. And she had some choice words for them. I mean, she leaned into it while making him feel safe, right? So, it wasn't, there's no one here. And if someone were here, I would kick their butt. They're

going to have to, you know, they're going to have to mess with me. So, just you know, I told them they have to leave. They need to get outate here. This is not their spot. Go. Okay, you want some popcorn, right? Whatever it is, but like, address it and then move on.

Polly Dawkins:

You said distract redirect.

Jori Fleisher:

Yeah.

Polly Dawkins:

And was that,

Jori Fleisher:

And if it's benign, so if it's something that is not scary, if they're seeing little kids playing out in the front yard, if they're seeing animals that are not scary, if they're, you're seeing something like that, you can join them in that reality. Not pretending that you see it but tell me about that. So, I have people where, you know, they'll see their pet from childhood and how old were you when you got bingo? What did he look like? What was he like as a puppy? What was she like as a kitten? What is he like to play with? Did they come to school with you? What did they do? Right? Like, tell me what was a silly story. You know what, remember that time when you told me that? So-And-So got into this thing. What was that like? Right? What was your favorite thing to do with them? So, you're not only not trying to prove them wrong, but their brain is also almost giving them this like gift of a memory that they have sort of more salient feel to, you're letting them enjoy that memory. You're giving them sort of joy and connection to share that with you. It is not doing them harm; you are not making it more likely that they will hallucinate more.

Polly Dawkins:

Good to know.

Jori Fleisher:

So, I've heard, you know, someone say like, well, if I, you know, if I play along with it's going to keep happening. It's the disease, it's going to keep happening because the disease is going to keep happening, right? The more someone is stressed out and agitated, that's going to make it worse. So, if you're fighting and prime, you know, proving it wrong, you may actually make it worse. But calming them and being with them in that moment, absolutely not. I had a couple where, I can't remember if we talked about this, but every morning he hallucinated a circus, like a three-ring circus out in their back patio. And his wife thought that this was fascinating and just

delightful. And their morning routine was literally they'd make coffee, they'd sit down, they'd look out the back window, and he would describe what was going on in the circus that day.

And here's what the fire eater is doing today. And the trapeze person is doing this. And it was a whole like thing that was their ritual. And, you know, she found it fascinating, and he found it comforting and gave him a space to tell stories. It got him talking. They were connecting, right? And so, they were able to find kind of joy in that together. I think, you know, that's kind of a unique case, but if there's something that's reminiscent of that, right? Can you be with them in that moment? And I Mel, put in there, remind the person that they're safe and move on. Absolutely. If there's nothing else, you're safe, you're okay, I'm here. That makes sense.

Polly Dawkins:

What if it's a situation where it's more violent. We've heard about people running through the house with knives trying to get at the intruder. Any suggestions there?

Jori Fleisher:

So, I think the, you know, the best strategy is prevention, right? So, I'm going to take a step back from that and say, if, you know, if your loved one has hallucinations, if they have a tendency to have more violent or like persecutory hallucination, someone's coming to get me. They're threatening me. Put the knives away, put them up. I see Becky says she put them up. I had, you know, a care partner who kind of joked about this, and they were like, well, because of the visuals, spatial stuff, my loved one kind of doesn't look up anymore as much. So, I don't really have to put things like in boxes away. I just put them on a higher shelf. You know, if I need something, I step on step stool and I grab it, but put the knives away. I will, you know, very, very seriously say regardless of your feelings on gun ownership, gun control, I think we can all agree that a person who has dementia or who has hallucinations should not have easy access to an unloaded, to a loaded and unlocked firearm.

I am constantly shocked and horrified. And how many of my people that I care for have loaded and unlocked firearms in their home while also telling me that kids and grandkids are also visiting, and that the person has hallucinations. I have folks who have PD dementia, who are retired law enforcement. And the thing about Parkinson's is, you know, again, different from an Alzheimer's dementia. If you have someone who had a gun in the home and has Alzheimer's and you put it in a safe, they're not going to remember the combination. They're not going to remember the lock, right? They may not remember where the gun is. They, someone with Parkinson's will remember where it's memory is not usually the thing that's impacted. They will remember where it's, and if they're fueled enough by fear or the hallucinations or whatever's going on, they will go get it.

And they will not have lost the motor memory of how to use it. But what they will have lost is that connection with reality where they may think that they're, you know, shooting at an intruder on the front porch, but it's kids trick or treating or it's family coming in, or it's, you

know, a cleaning person, a male delivery work, yeah, whoever, right? Or it's the care partner. So, I know someone mentioned the delusional jealousy, this imposter, you know, imposter syndrome, some of these other things. This gets very dangerous and very scary very quickly when we have those symptoms that aren't, you know, well controlled. And we have weapons in the house. So, if you think to yourself, my loved one doesn't have those symptoms. We have, you know, weapons in the house, but it's fine. I'll know when the time comes that I need to get rid of them. Sometimes this can sneak up on us. So, I would have those conversations early, kind of like driving conversations is, you know, people retire from certain things. So, instead of talking, you know, we're not taking things away. We are retiring from work. We are retiring from going down the stairs and carrying the laundry at the same time. We are retiring from driving at night. We are retiring from keeping the gun under the pillow on.

And if it helps, you know, can we, can we revisit this in the future? I have someone who every single visit wants to talk about, can I get back to driving? This person is absolutely unsafe and will never get back to driving. Can we talk next time about getting back to driving? Sure, we can talk about it, right? And so, can we talk about, you know, bringing things back into the house in the future? Absolutely. We can talk about it. That is, that's not a lie, but the outcome is probably not what the person is hoping for, right? So, if we can prevent that scary situation, that is ideal. The other prevention strategy I would say is you can call the non-emergency line for your local police station. If your loved one is having hallucinations, if they're having delusions, you can call the police and say, I want you to put an alert on the house.

The person who lives here has hallucinations. The person who lives here has dementia. If a call comes in from this house, at least when the police are coming in, they know that this is not someone who is, you know, aiming to attack them necessarily. They may be able to approach in a different way, right? And so, that means that if you ever feel unsafe, if you ever feel threatened, just like any other situation, you should call 9 1 1. Right? You. But if there's a chance to make that interaction safer and say, my loved one has dementia, please handle with caution, right? Handle with care. That can go a long way.

Polly Dawkins:

That's a heavy topic.

Jori Fleisher:

It's a very heavy topic and it is not something that comes up in most cases most of the time. But I bring it up only because we'd want it to be a never event. So, you know, if you're somebody you're like, we don't even have Nerf guns in my house, great, amazing. But if that applies to you, if there are knives, if there are crossbows, I have parkinsonian crossbow hunters, right? Lots of different things can be weapons. If a person is scared and activated enough and really thinks, and usually the hallucinations that are scary, the person with Parkinson's is convinced that someone is harming the people they love. And so, I think that's the terribly ironic thing is, you know, they are trying to defend you, but you actually may be the person who gets hurt. So,

recognizing there's nothing about your behavior as the care partner, you are not causing these hallucinations.

And I think that's also, you know, that's the transition to the delusions too. Someone brought up sort of this imposter syndrome and the cheating, right? So, can I call out those two things? People can have delusions about all kinds of different stuff in Parkinson's. They can, you know, be convinced that the government is tapping into things. And there can be a lot of things about technology and wires and stuff like that. But the most common ones that we hear about are delusional jealousy or Othello syndrome. If you're feeling Shakespearean, which is this fixed belief that their, you know, partner, their significant other, their spouse is cheating on them, despite all evidence to the contrary and absolutely no evidence in favor of it, there is nothing that you are doing if this is going on. You are not acting, dressing, or speaking in a way that is causing this.

You are not, this is the disease. If it's going on, tell their neurologist, tell their psychiatrist if they're seeing someone. I feel like I hear this from care partners who've been sitting with us sometimes from months, sometimes for years and going, there must be something I'm doing that's making her think this about me. It's not you, it's not you, it's not them. It's the disease. So, that's number one. And this can often be, you know, they may not come out and say it, but though your loved one may get agitated when there's, you know, a person of the opposite sex in the house, oh, that's the boyfriend, or they're just looking at them suspiciously, right? I've seen this within my own family with my loved ones who have this diagnosis and watched the delusional jealousy happen towards another family member convinced that that very known, recognized person was someone trying to, you know, steal someone else away and tried to say, it's not you, but I think you need to leave the room right now.

You need to exit the scene right now because this is not making things better, right? So, if there's a repair person coming to the house, especially frequently, right? If you can try and schedule that maybe for when a loved one is going to therapy or something else, if this is an issue that can help trying to minimize any of those folks, if you see that it's clearly one person that comes in and your loved one gets really worked up. You find a way for it to be someone else that can be helpful. So, that's the delusional jealousy. The other is this imposter syndrome delusion, or what's called Capgras phenomenon. So, it is this fixed idea and fixed in the way that it will, it will keep coming back, even if the person from one moment to the next might go, oh, never mind, I know who you are.

But this idea that they're looking at the person that they know very well, and they're convinced that that person is an imposter. So, you're not Judy, you're the other Judy who's the real Judy coming back, right? And you're like, I'm Judy, eh, how many other Judy's do you know? Like I'm it, right? I had people during lockdown did not leave the house or with their loved one 24/7, right? Weeks and weeks on end. And the person with Parkinson's was just like, there are five of you. Where, which one's the real one, right? This is not, there's nothing you are doing, this is part of the disease. So, it's something in the back of the brain that is having like a disconnect their brain is telling them. And whether this is because of those visual spatial changes that their

brain is picking up on something and going like it, something feels not quite right that looks like them.

It sounds like them, but something is not quite right. Right? We've all had the experience for, if you've seen like bad generic knockoffs of something, right? I was just in a Mexican restaurant, and they had a sign for Dr. Prepper, and it was almost the right logo, but not quite. And there was an extra R in there. And I looked at it for a second. I was like, Dr. Dr. Prepper, right? It like for a second, we were there. And then I was like, nah, that's not quite, that's not quite it. I almost imagine that that's what's going on is that the person is like, you're the Doctor Pepper equivalent of their Dr. Pepper loved one something and it's not something you're doing. You didn't put on a new dress. It's not the different lipstick, it's not the different shoes. It's something about the diagnosis that's causing this.

So, I've seen people do a couple of different things, and they will say, "oh, you know, you're right. She asked me to just sit in for a few minutes. I'll, you know, she should be back in in two minutes. I'll let you know when I'm leaving and then leave the room. Say bye. Use their name. Bye Bob. Good to see you today. Judy should be back in a few minutes and then when you come back in the room as you're entering, honey, I'm back. It's Judy, right? And walk in the room and sometimes that can work. I've had some people where they seem to find like a thing that the person accepted as only the real so and so, would know. And they would sort of use that as their like secret password. But for other people, that doesn't always work, right? They'll say like, how would we know that? You know, on our first date we went to such and such, or Dad, of course I'm your daughter. Like, do you remember that time that I dropped the bubble to ice cream on my toe and you know, whatever. That's just what they would tell you to say, right? So, if that's happening, it's not that you didn't come up with a good enough password, it's that that strategy is not going to work.

Polly Dawkins:

Are there treatments for hallucinations?

Jori Fleisher:

Yes.

Polly Dawkins:

Yes.

Jori Fleisher:

So, number one, we make sure that there aren't medications that are making this worse. Not just the Parkinson's medicines, but there is kind of a hierarchy of if we're having hallucinations, delusions, some meds are better than others. And I think this surprises people a lot to hear, but always our safest and our most effective is going to be levodopa to this day. Why is that?

Because it is what the person is missing. It is the closest thing to what their brain needs. So, a man may go dopamine, agonists, make go and open content, all those things. Those may go leniency; those may go levodopa typically stays and it can still be making hallucinations worse or delusions worse. In some people it's not causing it, the disease is causing it, but it's sort of like pouring a little bit of gas on the fire.

Levodopa is the least likely, it's the least gassy of this right? To be doing that. And it can still be doing it. So, there are folks for whom, you know, one strategy may be pulling back on the levodopa and recognizing that the tradeoff may be, we may lose a little bit of mobility, but if that means that we're having less delusions and hallucinations, sometimes that's an okay trade off, right? But we also want to look and make sure, are there any other medicines that are making this worse? So, I just talked with someone about this last night, which was there are loved one developed an infection. They were prescribed an antibiotic, and then the very next night they got wild, crazy hallucinating out of control. And the loved one called and said, could it be the antibiotic? It's a very common antibiotic. And I was like, it doesn't usually do this. There's no reason it should do this. They had read online and if you read, you know, the box that comes with anything, anything can do anything. And that's true. But I was like, it's not something we usually see and lots of people are on this, and I should have fought my nurse, you know, and I've trained her again to say, are you taking anything over the counter?

Because there are lots of additives in cough and cold medicines, lots of things in allergy medicines that can absolutely exacerbate hallucinations and delusion and confusion. So, really the safe thing for people with Parkinson's who have a cough, or a cold is plain going That's the chemical name of the medicine. So, that is plain Rubitecan, Plain Mucinex and the store brand versions.

However, drug companies, the drug stores love to package them together so they can say it's, you know, Robitussin severe Robitussin Plus. Because if you could get Robitussin plus, why wouldn't you get that one? Right? That's better. It's not because all the things that they're adding to make it plus and max and severe and you know, whatever are these extra additive medicines and those are the problem. So, I just got a follow up today. Person's still taking the antibiotic, they still have the infection. They didn't take the over-the-counter thing. Lo and behold, so much better, right? And so, I was going like, oh my gosh, is this a case report? Could this come an antibiotic actually cause a problem? No. Think about what else people are taking. So, it's the same stuff in Tylenol PM in Advil, pm anything pm It's not the ail, it's not the Tylenol, that's a problem.

People with Parkinson's can take pain medicines. It's the PM component. So, if your loved one has forever been taking Tylenol PM to go to sleep, I want that gone before I even consider adding in an anti-psychotic. Because why would we pile a medicine on top of a medicine when instead if the medicine could be fueling the problem, we just get rid of it, right? And it doesn't mean they can't take Tylenol. They could take Tylenol and melatonin if we need something for sleep, right? Or other safe sleep medicines there. We don't have time today, but there are safe sleep medicines for people with Parkinson's. Not typically the ones that are over the counter

other than melatonin. And there are a host of medicines that we can use both for cognitive impairment and for delusions and hallucinations. So, there's a lot online. If you ask uncle Google, Uncle Google will tell you don't give your loved one with Parkinson's antipsychotics. They can cause problems and make it worse, not all of them. So, there are a lot of different medicines in that class of antipsychotics. It sounds very scary. Antipsychotics. Some of them for people with Parkinson's are and should be very scared. So, medicines like Haldol or Haloperidol, very common old medicine often used in emergency rooms. If someone comes in agitated, they get Haldol. But for someone with Parkinson's, it can irreversibly worsen their symptoms.

So, it is a, some of these medicines there are dopamine blocking, right? So, a person with Parkinson's isn't making enough dopamine and these medicines can basically go to the brain cells that need to see the dopamine that you've got left and like put up a fence around that nerve that like, nope, no dopamine's getting in.

Polly Dawkins:

Nope.

Jori Fleisher:

This means that Parkinson's gets hugely worse, but it's not all antipsychotics; and they come in different doses, and they're different strengths. So, the milligrams of one are not equivalent to the milligrams of another. So, there are safe, safer antipsychotics that we can use and that we use frequently in people with Parkinson's and can really help quality of life. Melatonin does not interfere with dopamine. That's a great question that Michelle just asked.

Polly Dawkins:

Asks about sudden appearance of religious mania. Have you heard of that as a type of,

Jori Fleisher:

I have, it's not super common in my experience, but it's not uncommon. I have folks where, you know, maybe they were religious before, but it takes on a whole new level. So, you know, I would definitely talk with the neurologist, talk with the treating team about this. And it's hard, right? Because just like politics, we don't want to, you know, step on things and it's like, well we're not trying to like, you know, medicalize religion out of people. That's the last thing that we want to do. It's, if it's a problem though and it's leading people to, you know, make poor decisions, and do things that they wouldn't otherwise do, you know, then absolutely that can be part of, that can be part of a mania that can be part of the delusions or hallucinations. So, please bring it up to your loved one's physician.

Polly Dawkins:

As we begin to close our long session here today. Joy, are there topics that you were hoping you could touch on the delusions that we didn't get to or hallucinations?

Jori Fleisher:

I think I saw someone said something about hearing constant music.

Polly Dawkins:

Oh yeah. So

Jori Fleisher:

Auditory hallucinations, hearing things is less common but is increasingly recognized. And it seems like auditory hallucinations may be slightly more common in women for reasons that we don't understand. And it's the hearing, the constant music can be one of those things, so can be part of it for sure. And again, if it's not bothersome, lean into it. Do you want to dance to the music? Right? Show me, you know, and I've had people where they're like, I hear the music, it goes like this and let me show you. And it's often music from childhood teenage years, twenties, it's kind of, you know, stuff that was salient, you know, and stuck. So, he doesn't need to be medicated away unless it's bothersome, right? And then yes, we should think about it. I'm trying to think of other common delusions or things that, you know-

Polly Dawkins:

Yeah-

Jori Fleisher:

Really worked up about. But, but yes, I think Jeannie wrote in, did you say there are meds to help MCI, mild cognitive impairment? Often, we will use the medications that have an indication for dementia. We may start them in someone who's got signs of mild cognitive impairment. So, we certainly have people where there, you know, they're worried about it, they're getting nervous. So, you know, we may start those medicines. And the challenge is, so what I tell people about medications that we have for dementia and cognitive impairment is we are not there yet.

We wish we had something where you took the medicine and the person is restored back to who they were at some point before, right? And most of the time that's not what we see with these medications. Well, so then why would you even prescribe something? So, here's why these meds were approved basically. So, we're talking about medicines like donepezil, Aricept, or Rivastigmine, called Exelon. So, these are acetylcholinesterase inhibitors. These were tested first in people with Alzheimer's disease and what they did was they randomized people with the disease to either get the real drug or the placebo and they follow them over time, and they checked their cognition over time. And what they found was that people getting the placebo

were declining and people getting the real deal were declining, but they were declining at a different pace. And so, when they compare big groups of people and how long did it take for someone to worsen by this many points on this cognitive test, there's a difference, right? But on an individual person level, what does that look like? That often looks like, doc, we started this medicine six months ago and mom seems the same and as hard as it is seeming the same cognitively may actually be a win. I would hope for a bigger win too. If you're like, what kind of win is that? Nah, right?

I would hope for a bigger one than that. But in the course of a disease that if we leave it untreated, it's going to keep declining. If we can get some stability, that's progress, right? So, I often hear they're like, I don't see a difference. Sometimes I think about these, these cognitive medicines. I will frame these to people as like, I want you to think of it as a vitamin. Like when you take your Centrum silver, are you waking up and going, aha,

Look, you know, this is so much better. No, you're taking it because you believe it's doing something underneath, right? Which they are, right? Think about these. Think about the cognitive medicines more in line like that. It's doing something underneath to slow down what the progression otherwise could look like. We may not see a big improvement, but I mentioned that those tests, those studies were done in big groups of people with Alzheimer's. It looks like from smaller studies with people with Parkinson's, these drugs may be a little bit more effective in people with Parkinson's than they are in people with Alzheimer's. So, I do have folks, I would say it's maybe 20% of people who come back and go, I notice a difference. Like there is a clear improvement. And the other thing that's been interesting is since we've been using these cognitive meds more in people with Parkinson's in the last 10 plus years, there have been studies that have shown that in people who have freezing of gait where their feet get stuck, either when they're first standing up and trying to go or they get stuck crossing a threshold, there may be some benefit of these acetylcholinesterase inhibitor medicines, these, these cognitive medicines in people with freezing of gait.

Why would that be? Well, the chemical circuit, so acetylcholinesterase is working on acetylcholine, acetylcholine like dopamine does a lot of different things in the brain. One thing it does is help with memory and thinking, but another thing it does is there's an area deep in the brainstem that's related to walking. And walking is controlled by all kinds of different things. Some of those are dopamine related, but some of those are not dopamine related, some are acetylcholine related. And so, if we can fix some of the acetylcholine chemistry, some people walk a little bit better and some people who have not violent, terrible hallucinations, but more manageable hallucinations, some these cognitive meds can help with that too.

Polly Dawkins:

Thank you for that.

Jori Fleisher:

Yeah,

Polly Dawkins:

We are coming to the close here. We've got a couple of a couples of homework ideas, that we've come up with for all of you in the in the chat. If your person has hallucinations or delusions, can you think about a new strategy that you might employ for coping this week? You already talked about distracting, redirecting, or even joining the person. Could you try one of those strategies and see what works best for you? Any other homework ideas, joy, that you'd like somebody to try?

Jori Fleisher:

I think, you know, think about sleep. Think about your sleep; think about your loved ones. Sleep, right? I'm not making big changes, but can you make the bedroom sleep-friendly? Turn down the thermostat by a degree, right? Room darkening shades can go a long way. Can you listen to a meditation together before getting into bed? Or can you pull the beds apart a little bit? Or place a body pillow or like a bolster pillow in between, you know, if you're getting kind of whacked during sleep, how can you help your sleep, and how could you help your loved ones sleep?

Polly Dawkins:

Those are some great ideas. Thank you, Dr. Fleisher. Thank you for joining us and sharing your wisdom. Thank you, everybody, for being here, and we'll see you on Monday and see you during it next Friday.

Jori Fleisher:

Thanks for sticking out with a hard topic, everyone. I wish you a great week.

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