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MJFF: Welcome to a recap of our latest Third Thursday Webinar here directly from expert panelists, as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time, by registering for an upcoming webinar at michaeljfox.org.

Karen Jaffe: Good morning, everyone. I'm Dr. Karen Jaffe. I am a member of The Michael J. Fox Foundation Patient Council and I will be your moderator for today's webinar. I am a retired OB-GYN, and I was diagnosed with young onset Parkinson's disease 15 years ago, and I'm aged 46. Currently I'm a proud co-founder of InMotion, an amazing wellness center in Cleveland for people with Parkinson's disease and their families.

Karen Jaffe: Today, our panelists will assess the many sleep issues that can come along with aging, as well as with Parkinson's disease, including acting out dreams while asleep. We'll share tips for managing sleep problems and cover research into the latest treatments for sleep problems. We've got lots to discuss, so let's get started. But let me first introduce our panel.

Karen Jaffe: Dr. Kirstie Anderson is a consultant neurologist, specializing in sleep disorders in Newcastle, in the United Kingdom. She also is a clinical researcher, studying sleep and how it impacts mental health and aging.

Karen Jaffe: We also have Otis Peeples, who is a retired police sergeant based in Chicago. He's now a behavioral health therapist. He was diagnosed with REM sleep behavior disorder many years ago. And we'll be talking about that directly, in a few more minutes.

Karen Jaffe: Last and not least, we have Linda Peeples, Otis' wife. She's a payroll administrator at the City of Chicago Department of Finance.

Karen Jaffe: So Dr. Anderson, before we dive into this specific topic listed here, can you help us all understand why getting a good night's sleep, which is something that we all want and need, can be so elusive for so many people, regardless of whether or not they even have Parkinson's disease?

Dr. Kirstie Anderson: That's a really good question. I mean, sleep problems of any type are just common. We think about the sleep we had when we were 18, or 19, or 20 and it set up pretty well then. We get a solid chunk of hours. We don't wake very much and we really have a rock-solid body clock as well, a circadian rhythm. We are hard wired to light. We have been designed to be awake when it's light and to be asleep when it's dark as night. So if you think about modern life, there's a huge amount of things that are out there to disrupt sleep. The commonest cause of feeling sleepy is really simple, not enough hours was in bed at night.

There's lots of things around work patterns and shifts. But also, we don't go out much now. Most of our work, most of our jobs take us inside for lots of people. So it's not just that the environment tends to be difficult for sleep. It's also the fact that there's lots and lots of different things that can disrupt the sleep. You've got a nice list there.

Dr. Kirstie Anderson: You've got people not getting through the day, without napping. That's actually really different to being agitated about not being able to sleep at night. That's insomnia. You've got people who and jiggle and can't keep their legs still and that kicks into the night. And then, you've got the fact that a lot of us, as we get a little older, weigh a little more than we'd like to. And the combination of getting a bit older and putting a little bit of weight around the neck can often make that snoring get louder and louder, until actually the warning sign is, the airway just collapses under the pressure and there's no noise at all. You stop breathing. Your brain jolts you awake and that's sleep apnea. And that's just really common. We have great treatments, but lots of people don't know they have it. There's all sorts of things out there that can really stop you getting a restful night.

Karen Jaffe: So in terms of Parkinson's disease, does having Parkinson's disease make it harder for people to respond to treatments that might otherwise get them back to a normal sleep pattern?

Dr. Kirstie Anderson: I wouldn't say so, actually. One of the big risk factors we know for Parkinson's disease and lots of neurodegenerative conditions, is age. We know that you're a little more likely to get this with every decade that passes and so we really have to think hard about what's normal aging change for sleep. And then you just have to look at the person in front of you and work out what's wrong with their sleep. There's certainly some sleep disorders that are very strongly associated with Parkinson's disease. In fact, some of them can be much more of a problem for the person you sleep with, than for you. But I would say that we've got really good treatments for sleep disorders. You just have to back, move away from the daytime disease and tune into the night and pick out what the individual problems are.

Karen Jaffe: Is there a situation where, as people get older, they need less sleep and that they just think they have a sleep problem, because they're not sleeping eight hours a day? But maybe they need less sleep than that?

Dr. Kirstie Anderson: That's a great question. I always say the same thing to my medical students. Sleep? You think about ages and stages. If you say how much sleep do you need? Well, that's like "What's your shoe size?" It's whatever's comfortable for you. So when you are 19 or 20, if you leave people to sleep and that's a good idea, teenagers are grumpy in the mornings, they will sleep eight, nine, ten hours. It's normal.

Dr. Kirstie Anderson: If you look at someone fit and well, without many medical problems they see their doctor with, at the age of 60 or 65, and we've studied big populations,

you're looking at about six, six and a half hours sleep. You may be in the bed longer, but in terms of what we measure, we'd expect the total amount of sleep, time to decrease over time. Certainly from the mid-thirties, onwards. Also, your body clock changes. You tend to be a bit more comfortable waking up earlier, when you're older and unbalanced. You are bit more comfortable going to bed later and getting up later when you're younger, certainly below the age of 25. So you have to think about the hours and the clocks, depending on how old you're.

Karen Jaffe: That's good to know, because I think this eight hours is what we always think is the benchmark. And maybe some people are feeling like they're short on sleep when they feel fine during the day, they just don't get those eight hours. And so-

Dr. Kirstie Anderson: Absolutely.

Karen Jaffe: ... this is a good time for me to remind people that there's a Sleep and Parkinson's Disease publication that the Fox Foundation puts out. And this can answer a lot of your questions about the different topics that we talk about today and going into a little bit more detail about some of the specific sleep disorder issues that people with Parkinson's have.

Karen Jaffe: So Otis, you were diagnosed with REM sleep behavior disorders, I think, in 2011. But you have not been given a diagnosis of Parkinson's disease. Is that correct?

Otis Peeples: No. From what the doctor told me, I had characteristics of it, but it wasn't Parkinson's.

Karen Jaffe: Oh, it was not Parkinson's. So Linda, why don't you start us off with your experiences that relates to Otis exhibiting sleep issues and then how you got to the root of his condition, with the diagnosis of REM sleep behavior disorder.

Linda Peeples: Okay. How we got here?

Karen Jaffe: How it is you... Yeah, you told us the other day what you were noticing first.

Linda Peeples: Okay. What I was noticing first was his dreaming. He dreamed every night and they became violent at some point. I just say, he dreams a lot and he moves a lot. But it got to the point where it has started getting dangerous for me, because he likes to dream, so he says. But he has... Like he's at the show or something, at the movies, while he's dreaming and he's enacting whatever he's dreaming. And so, a lot of times he would be fighting. So as a result, I would get hit and also just tries things. Sometimes I would find him sitting up and he'd be driving a car. You know, "What is he doing?" Or either the sheets would be... The covers would be moving and he's running somewhere, while he's dreaming. But it got to the point where he was so violent that, like I said, for me and for

him... Because at one point he jumped out of the bed and hit the wall with his head. And I was like, "Let's see if he's okay, first."

Linda Peeples: And I knew it was getting dangerous then, when I saw something on a news program about REM sleep and it was a lady who was acting out as well. She had imagined herself as a tiger or something. And she jumped out of the bed and she injured herself so badly. And I was like, "That sounds like what Otis may have." So they gave a doctor's name and we called and made an appointment. And so, they did a sleep study on him. And then, because he, of course, just thought he was dreaming. But the doctor then told him that he did at everything that I said he was doing while he was asleep. But it became dangerous because he fell out the bed and broke his toe one time-

Karen Jaffe: Oh my word.

Linda Peeples: ... and it just got scary, because we would move the night stand out the way, things like that that might injure him. So that's how we're here so far.

Karen Jaffe: So was it years that he experienced these bad dreams, this dreaming acting out, before you realized it was a medical problem?

Linda Peeples: Yes, because a lot of people would tell me... Because I would tell people, "You know, if something happened to me, go testify for him because he'd be dreaming." But anyway, yeah, it got to the point where... It was years, like I said, before we took it very seriously. So he'd started really injuring himself and me as a result.

Karen Jaffe: Wow. But it didn't take them long to give him a diagnosis, now did it?

Linda Peeples: No. It was right away.

Otis Peeples: Mm-hmm (affirmative).

Karen Jaffe: But Dr. Anderson, I've heard it said that REM sleep behavior disorder is presumed to be Parkinson's disease until proven otherwise. Although we now know that Otis has not been given a Parkinson's diagnosis, please talk about RBD? Why it happens and how it relates to simply Parkinson's disease? And is it one of those non-motor symptoms that could concede, begin years before someone gets diagnosed with PD, like we see with the [inaudible 00:11:00] constipation?

Dr. Kirstie Anderson: That's a great question. So you first of all, said, "Is REM sleep behavior disorder, Parkinson's until proven otherwise? Well, no, of course not, because there's a good saying in medicine, "Never say never and never say always." So we've heard a lovely story and if I was sitting, as your sleep doctor, I'd be diving into the detail that goes right back to when, the very first time he just starts to shout out. And what almost everybody tells me is, this beautiful story that you tell me.

I say the same thing... Long marriages, they're great for sleep clinics. Then I get all the detail. So can I go right back? How far back do you think, when he first started to make a noise, shout or just [inaudible 00:11:46] the occasional, how many years back did that go?

Otis Peeples: One?

Linda Peeples: Well, really, we've been married for 41 years, so it goes back even to then when I think about it. I just thought, he's hollering, he's like he's in the cowboy, shoot them up with sound effects and everything.

Karen Jaffe: Yeah.

Dr. Kirstie Anderson: So what almost everybody says is, there's a creep on this. Maybe it's once a month, there's a big movement. Then maybe once a week. And then maybe two or three times a week. And then as you said, it gets bigger and more violent. And loads of people tell me that there's nice dreams as well, like driving the car.

Linda Peeples: Mm-hmm (affirmative).

Dr. Kirstie Anderson: But the big, fighting ones are the ones that are getting everyone in trouble. So the first thing to say is, "This is common." I tell people, "You are not alone." And there's no testifying on witness stands, because it's not your fault, Otis. That's really important to say.

Otis Peeples: Mm-hmm (affirmative).

Dr. Kirstie Anderson: This is not associated with being violent during the day. This a common problem. This is out there in half the percent or one percent of men or women, but you know what? Guys are stronger, so when men hit, there's more bruising. So we certainly see more men in the clinic. This is a slowly progressive problem, as people describe it, but months and years. So I can just about beat your records with 40-year marriage. So my longest story is 56 years for somebody very slowly getting worse. But if you take it the other way, you can't get past the fact there is a risk that it will be your early warning symptom for Parkinson's, and people know that and they Google it. So I say the same thing to everyone. I say, "Look, first, I'm going to treat you. And I'm really interested to hear what you started to fix this. I would think that there's often good treatment, but then I'm going to keep in touch because, even if you've got no problems, if this is an early warning symptom, I want to be on it."

Dr. Kirstie Anderson: But the big research shows that about maybe 7 percent a year of people, if we follow them up every year, start to develop [inaudible 00:13:53] trouble. But it's not everybody. The longest studies out there would say that maybe 12 years down the line, more people than not have developed another neurological problem. But there's people with a long history, and I've been in practice 20

years and we're still meeting and they're still fine. So you don't say never or always, if that answers your question, Karen.

Karen Jaffe: It sure does. There's a couple questions from the audience who are asking, "How can I help prevent my mother from acting out dreams and how can I help myself understand I'm dreaming when I act out dreams?" Because they live alone or they live on a floor by themselves.

Dr. Kirstie Anderson: So how can you help someone? We've already heard from the guys here. You can go about as far as you can throw yourself. So really simple things, you move the sharp stuff and the nice stuff out of the way. You look at how far a hand can go, and there's some very simple safety measures where you make sure things around you are soft. That's a small but it's an important practical point, isn't it? And if you go away on holiday or to a hotel, I bet you both look around and think where the sharp edges are. Yeah. Both nodding. Okay. There's medication that can definitely help once the diagnosis has been confirmed. So we've heard about that sleep study. That's necessary. And so that's going to be something you're going to discuss with your sleep specialist. I think it's a really good question of how do you know if you live and sleep alone. I'd probably ask you, Otis. Did you remember some of these dreams? When you were woken, could you tell that the dream was coming with the ouch moment?

Otis Peeples: You could see it at times. As it progressed, as you said, it was more frequent after a while. When I was younger, as I looked back at my history, it would happen periodically. But as I got older, it was more vivid, more frequent. And you can tell, I woke up from a dream and laid back down and go right back into the same dream.

Dr. Kirstie Anderson: Yeah, exactly. So the point is, if I'd seen you on your own, you still would've told me about a dream that was memorable as well as the injury. So what you're really asking me is could it be any other type of nighttime event if there's an injury or fall or someone lands in a heap? Well, I think if we're thinking about the other problems that cause trouble at night that I see is seizures. They often come with very different symptoms. So most people, if you talk to them, although their wife or their bed partner may remember more, they will still be able to tell you about the dream narrative. And that's often what makes you realize it's REM sleep behavior disorder.

Karen Jaffe: Somebody's asked me in the audience whether it's wise to wake up a person when they're acting out the dream.

Dr. Kirstie Anderson: As long as you keep out of their way if they're swinging a fist. Okay. So there's two things there. There's an old... Yeah. Okay. So we got some wise bed partner answer that one. But two things. There's a myth. It is dangerous to wake a sleepwalker, so sleepwalking is different. That comes out of non-dream sleep. Now, the point about sleepwalking is actually you are quite a long way from wake. It can take several minutes to come around. We've already heard from the guys here that actually you can pop out of the dream and go straight back to

sleep. It's really characteristic for RBD, for REM sleep behavior disorder, that you're quite easy to wake. And again, I'd really like your perspective on, I think you've both been managing this for some time, haven't you? You would move out of his way and you'd turn him out of the way. Or do you think he was easy to negotiate with, to talk to at night if you had one of these things?

Linda Peeples: Well, it depends. When he's in it, I can kind of tell when he's escalating and it seems like it's getting dangerous. So I've learned not to touch him as much, but my voice, I'll just try to wake him like that and try to... Because he'll be rolling towards the edge of the bed where he's about to fall out. And I'm like, "I got to try to stop him at some point." So usually, if I'm speaking loudly, he'll wake up.

Dr. Kirstie Anderson: Exactly. So you've worked out the solution yourself and you've given us the answer. That's exactly right. Bed partners get really good at the buildup, going, "Trouble's coming. This is the point I wake him, I move him." Or to be honest, you jump out of the bed and you go and sleep in the spare bedroom.

Linda Peeples: Yeah. True.

Dr. Kirstie Anderson: Some people are braver than others, so it's perfectly safe to wake someone. It's a pretty good idea to wake someone if you can tell the buildup. I would always believe a very sensible bed partner in a long marriage about that. There's no danger to that.

Karen Jaffe: It really does highlight how this can be a two-person problem. You have two people not sleeping well.

Dr. Kirstie Anderson: Yeah, there's two for the price of one in a sleep clinic.

Karen Jaffe: Yes, I'm sure. So while most folks on this webinar are probably familiar with this message, join the study that can change everything, let me take a minute to update anybody in our audience who are not familiar with this. The Parkinson's Progression Markers Initiative, or what we call PPMI for short, is the Foundation's landmark study that is trying to identify a biomarker for the progression of Parkinson's disease. And this study has the real potential to change the way PD is diagnosed, managed, and even prevented. But in order to do this, thousands of recruits are needed. And this important study needs all of us to contribute, to help out. And believe it or not, there is a place for everyone on this webinar to help because the PPMI needs people with Parkinson's and people without Parkinson's.

Karen Jaffe: And for those who are even unable to travel to a research center or don't have a research center nearby, there is now an online component for anyone who's over 18 and living in the United States. They are hoping to soon be able to recruit people from other countries as well. And of course, they're recruiting folks with specific symptoms, including those with sleep disorder issues. So we can get to the finish line if each of us steps up to run a leg in this race. And so

my call to action is to click that get started button that's on your screen today, and to be a part of something bigger than yourself by helping out and joining the PPMI. Otis, you are a part of the PPMI or are you not?

Otis Peeples: Yes. I joined the PPMI initiation. It was about 10 years ago is when I first-

Karen Jaffe: Oh, you've been in the study for 10 years already.

Otis Peeples: Yes.

Karen Jaffe: Great. And how has your experience been?

Otis Peeples: I was curious when I was first diagnosed with the REM sleep disorder, and I was told that I had characteristics of it may turn into Parkinson's. That was one of the reasons that I looked at it. And then if I could help find a solution or be part of helping to find a solution, it would make me feel good. And so I joined the study. We did go to the doctor, taking different tests, but basically just checking to see if my symptoms have changed or if they had grown more. And it is a long-term thing, but I see them twice a year now. So it's kind of boiled down to stuff like that, but it's been an experience of me feeling better about myself but also knowing that it's helping to try to find a solution to Parkinson's.

Karen Jaffe: That's true. And as a person with Parkinson's, I thank you for your participation. It is a very important clinical trial, so I encourage everybody to go ahead and press that get started button and get some more information and to join us in our quest for the answers to this problematic neurodegenerative disease. So Otis, as you look over this list, is there anything that you had to deal with that is not mentioned here? Things that you think are exacerbating your problem? And you've talked about the things that you've changed to make a difference in your sleep, but I'm just wondering whether there's things that you noticed that if you did differently, you would have a better night's sleep?

Otis Peeples: Now, basically everything on this list is what you go through. You kind of set up your own formula of what works well for you. I do take melatonin that helps me go to sleep, but it doesn't say that I stay asleep. I try not to eat after a certain hour. I try to stay away from the stress. And yes, everything on the list works. Those are the things that I use to keep me halfway, right, because I still dream. I still go through it. And I've noticed that when I break my routine is the times that I escalate or the dreams get real vivid. Or if Linda's trying to wake me up, I'll pull her into the dream and talk back to her. Yeah.

Karen Jaffe: Well, Dr. Anderson, I'm interested that there's this slide. It does identify many of the common culprits, but can you talk a bit more about the effect of DBS that may have on sleep?

Dr. Kirstie Anderson: Well, of course that's a small number of people, isn't it? You think about DBS. So two things, the very positive effect of deep brain stimulation is that you're going

to get better motor control. It's a really small thing, but it's very uncomfortable to not be able to move normally at night during sleep. We don't think about the fact you're designed to move and roll over and turn every 15 minutes or so. And one of the things that people with Parkinson's say is they're just sore. They're sore because they're stiff because sometimes the medication's wearing off. So you'd be hoping that people are getting better motor control. Of course, DBS, we know for some people, if we look over time, can have an impact on mood. And mood and sleep are absolutely intertwined. But overall, you're going to select people carefully and hope that the improved motor control is going to, long term, give a beneficial effect on sleep, sometimes set against evolving worsening sleep, sometimes coming with worsening mood for some people.

Karen Jaffe: And what about the side effects of medications, especially the dopamine agonists? I mean, I have plenty of friends, people with Parkinson's, who are on dopamine agonists that keep them up late at night, wee hours, being able to not say good night to their phone, their tablet, their laptop, behavior that wants to take on one more brain game or the next episode of their favorite Netflix show. What's going on there that's-

Dr. Kirstie Anderson: Yeah, so dopamine agonists are really interesting because, of course, they use less now. Dopamine agonists, obviously a licensed therapy for Parkinson's disease. But as people may well know, they're also a licensed therapy for restless leg syndrome. In fact, they would be considered a gold standard treatment, very good research trials. But one of the big problems we increasingly recognize is that the dopamine agonist as a drug can make you impulsive and you even have somewhat obsessive, repetitive behaviors. That can be minor, but it can feed into those checking behaviors close at night. One more thing, one more thing, back on phone. So that's a small thing. Having said that, certainly some people, when they first start dopamine agonists, say that they feel quite sleepy.

Dr. Kirstie Anderson: And for a while, people thought that sleep attacks were a big problem with these drugs. I'm not sure I have seen that or we've seen that in our research. I think it's probably more often that we recognize the higher doses of the drugs can lead to behavioral change and the behavioral change is what's stopping sleep onset. And I don't know what feedback you've had from your friends using them about which of those things. If, on the other hand, you have quite nasty restless legs, they might be quite good medications. You need to stand back and look at the person and look at their tablets, thinking about the day, but also thinking about the night and what their sleep problems might be before you prescribe them.

Karen Jaffe: Dr. Anderson, can you start us off with what constitutes good sleep hygiene?

Dr. Kirstie Anderson: Yeah, sleep hygiene's a rotten word, isn't it? It makes it sound like you've got to wash your [crosstalk 00:26:20] before you go to bed, it's a terrible word. But what it actually really means is just understanding a bit about how sleep works and about how the day works. So it's the behaviors, the things you do during the

day, the things you do at night, that are going to make you sleep well. Being out every day and being active every day sounds that it's something that's nothing to do with sleep, but it's an enormous part of sleeping well at night. We're designed to be out, we're designed to move. One of the things that the lockdown told us is that most people had a little bit of trouble settling when they were really restricted and couldn't go out and couldn't move as much. If you think about sleep itself, very, very simple, small rules, the bedroom should be cool, dark and quiet. And that's it.

Dr. Kirstie Anderson: Actually, I don't over-complicate life. If you bring your daytime world into your bedroom, make it the place that you do all of your work and sit on your phone and take those really stressful late-night emails, then really your brain doesn't quite know what's the day and what's the night. So really simple: cool, dark, quiet, take everything else out of the bedroom. There's not much more to it. There really isn't. Sometimes there's very, very long checklists of stuff, but I tend to go, "Go to bed when you're sleepy."

Dr. Kirstie Anderson: That sounds like a really stupid instruction, but some people go to bed two hours earlier than they're sleepy because the other person they're with goes to bed at a different time. And pretty much get up at the same time every day-ish. I mean, it's not a hard and fast line, but setting that sort of an anchor point that you kind of get up when you wake up is good advice. And long marriages or short marriages, if you're laying in bed really cross about something, it's not a good idea to keep it in the bedroom. Go and take that somewhere else as well, okay?

Karen Jaffe: And is exercise something helpful that people could do? And if they do, should they do it before bed or stay away from that time period?

Dr. Kirstie Anderson: Okay. So I love exercise. I like exercising, but I love exercise for my Parkinson's patients because it's really important to have something that you can do, which you really feel is rock solid science and is good for everything. We know that there is good data to show that out of breath exercise is good for Parkinson's disease, but it's pretty good for everything. So if you do out of breath exercise, anything that you enjoy, I'd probably say activity, do something that you like that gets you out of breath every day, as long as you do that not just before bed, probably not in the one or two hours before bed, otherwise stick it where you want, really. It's much better to do it than to worry too much about the timing. So no, I wouldn't be hitting the gym really late at night and then getting into bed all or full of adrenaline, but exercise is fantastic for sleep. And it's good for Parkinson's. So you've got two for the price of one there.

Karen Jaffe: I love this exercise that gets you out of breath. And people always want to know about how much should they exercise. And boy, that little caveat kind of sort of sums it up.

Dr. Kirstie Anderson: 20, 15 minutes of something you enjoy that gets you out of breath. Don't over-complicate it. Don't do something you hate. If you like walking, pick up the pace.

If you're someone who likes crazy gym things, do that. I don't care and I don't mind. And the research shows it makes very little difference. I suppose if we are thinking about Parkinson's and about good control of walking, there's maybe a little more evidence for treadmill than other things, but it's really small. If you're talking about sleep, it doesn't matter. Get out of puffing something you enjoy, it's good for sleep.

Karen Jaffe: Great. And can you speak about the use of medications for sleep disorders like Clonazepam and melatonin?

Dr. Kirstie Anderson: Yeah, I'm a big fan of melatonin. So [inaudible 00:30:20] notices on that. That would've been my first go to drug. So melatonin is really interesting, so naturally occurring hormone. Your pineal gland within your brain produces this. So melatonin has two, three jobs, really, I suppose, in the Parkinson's clinic. I heard it just gets you off to sleep a little and it might be that you also act out the dreams a bit less. Certainly some people will say things... yeah, good. We've got a nod. And I would actually push the melatonin up in someone with REM sleep behavior disorder, I would use quite high doses because it's just so safe. This is a drug-

Karen Jaffe: Can you give us what that would be? The dose you're speaking of?

Dr. Kirstie Anderson: Yeah, 10 to 12 milligrams. Yeah, very good question. So I would go up to at least 10 or 12 milligrams, very comfortably, and I would really strongly reassure the patient, this is a safe drug. People want to know they're not taking things they're going to get hooked on, or it's going to wear off. If it works, it works. And it usually stays working.

Dr. Kirstie Anderson: We've got to be very straightforward about drugs that don't have a really big, randomized control trial. You'd find most sleep specialists would put people on melatonin first line, but we know that there aren't really big, good quality randomized control trials to guide that. These are just big case control studies. Clonazepam I would use second line because it can make you feel a bit groggy in the morning. And if you are a bit older, if someone's in their seventies or eighties, it will increase the risk of falls at night. But it's certainly effective to decrease REM sleep behavior disorder. If I was thinking about insomnia without acting out dreams, I'd much prefer a behavioral strategy. I would not want to use drugs first line if possible. I'd try and get them doing things right during the day and the night first.

Karen Jaffe: So what do you recommend when a person with Parkinson's has tried all of these management options, but still is in a sleep deprivation mode? They're on melatonin, they're on Clonazepam, they just can't find the right combination of things that will get them a good night's sleep?

Dr. Kirstie Anderson: So I'm going to stand back and I'm going to say, is it one problem or more than one problem? So we've had a lovely, straightforward story of acting out dreams.

We knew what it was. We've got a tablet; it's helped a bit. Not perfect, but it's better than it was. Yeah. Good. So, but what you really describing, I think is different, aren't you? You're describing someone I think agitated about the night. So I'm going to step back and say, what have I missed? Is there some sleep apnea there? Do I need to do a sleep study to look at the breathing? Is there some kicking, restless legs? Have I got the nighttime drugs right? If all of that's been done and people aren't getting up five or six times at night to pee, getting up once at night to pee is normal over the age of 45 or 50.

Dr. Kirstie Anderson: Well, goodness, I hope it is, because I do it. But getting up six or seven times, it's really disruptive. So you're going to treat all of that stuff. If someone is just got a racing mind, they're just furious, they're chasing sleep in there, then I'm going to do sleep diaries and a behavioral strategy. So we step back and we say "Write it down. Give me two weeks of sleep diaries, then I'll look." And the diaries we use, which I'll share happily, they're day night diaries. They really actually look at the 24 hours. They go back to "Okay, let's actually look at the cup of coffee, the exercise, when you do it, when you're peeing, when you're eating, what time you're getting into bed, how much sleep it feels like you're getting, what time are you getting up, and whether you're falling asleep." So we look at two weeks of data, because when sleep's a mess, it's really hard. You're just frustrated and agitated and you forget what good sleep's like. So we write it down.

Karen Jaffe: Wow. That might make them so tired that they fall asleep!

Dr. Kirstie Anderson: Perfect. Win win! Okay, and this is what... a couple of small things. What you don't do is use your Fitbit or any other proprietary gadget. Yeah. So what you don't do is use your watch. We have some people come and say, "I thought I was sleeping fine, and then my fancy watch told me my sleep was terrible." And I say "Well, take your watch off." Okay? That's fine. Okay, that's the treatment. So your watch should be used for your daytime step count. We love it for that.

Dr. Kirstie Anderson: It's quite good at picking up, your big handset, window for sleep. So I like the time it's off. Okay, it's off at one in the morning, because you're doing too much streaming TV and you're up at six. Okay, you're not sleeping enough. But you take your watch off at night. You only fill the diaries in once a day. People worry about filling in diaries, but it's your recollection and you don't fill it in the middle of the night, because that's a really good point. You're saying that people might be too intimidated or not want to do the diaries. They're pretty effective. There's a good evidence base for doing this.

Karen Jaffe: That's great.

Larry Gifford: A landmark study that could change the way Parkinson's diseases is diagnosed, managed, and treated, is recruiting participants now. PPMI, or the Parkinson's Progression Markers Initiative, needs people with and without Parkinson's, especially people age 60 up who have close relatives living with the disease. Take a short survey today at michaeljfox.org/ppmi to see if you're eligible. That's michealjfox.org/ppmi.

Karen Jaffe: One of our audience members is asking if they have a sleep difficulty, is that indicate a need to increase their carbidopa levodopa?

Dr. Kirstie Anderson: It depends what the problem is. I mean, if I was talking to someone like Otis and he was saying he was acting out dreams more, I wouldn't be increasing the Parkinson's meds, I'd be increasing the melatonin, maybe even considering a second line drug. I'd be really looking at again, going back to what the problem is. Is it pain? Is it stiffness? Is that what's keeping them awake? Then you might want slow-release levodopa at night, but is it something else? Just go back to take a history, go back and just listen to... we've heard this beautiful story. All I had to do was sit and listen, I go "Okay, I know what this is." People will tell you and get the bed partner in as well. Really important for the bits that the person wouldn't know. Do you snore? How do I know unless I sleep next to someone? So you go back and you take the history, and you work out what the problem is.

Karen Jaffe: What I think for those people dealing with sleep disorders really want to hear the most about, and that is, what is the future of sleep care? What should we be looking for down the line here that might be coming down the pipeline for improvement in sleep disorder problems?

Dr. Kirstie Anderson: Really good questions. I suppose the things that have come out of COVID that have been good, and again, I might ask Otis, did your appointment switch to telephone or remote during the pandemic? Did your specialist do things not face-to-face, out of interest?

Otis Peeples: Yeah. I would go in face-to-face once, and then the second one would be telehealth, where we would do Zoom or on the phone and stuff, so.

Dr. Kirstie Anderson: And how did you find that? Was that okay?

Otis Peeples: It was okay for me because I use it myself. The hard part about is checking the neurological test of the hands and movement in the feet. I found that that was awkward sitting your laptop on the floor so he could see me walk down the hall and stuff like that. But basically though, we're at a stage in the study where those are the major things that they're looking at and stuff. So me coming in once a year for a face-to-face was good enough at this time in the study.

Dr. Kirstie Anderson: Yeah, so really interesting perspective. So the stuff that we brought out of COVID, is that not just sleep health and sleep monitoring, is that some stuff can be telehealth and some stuff, as you've just said, actually can't be. You're coming back to more personalized care. So some of things that I think was really interesting in terms of studying sleep changes and how we can help people, was how much we can do remotely. And I might go really simple with the commonest sleep disorder, which is sleep apnea and a CPAP machine. And the devices have just got better and better and better. And that was something that almost entirely went remote because, and I mean, Otis, you sound pretty switched on a lot of this testing, but someone like yourself, I would be giving

you the device and you the app on your phone. And you'd be telling me if there was any problem with your overnight breathing, because you'd be good enough to do that. So I think some of the computerized medicine is really good for some of the sleep disorders. I think studying sleep changes the big... The big block we have, is that we still consider this gold standard sleep study, coming into the sleep lab to make the diagnosis, like REM sleep behavior disorder. And, it's, can we do better? Can we do home monitoring, can we do things that are less gadgets, less wires? Most people don't love the sleep study, they do it because they have to, and it's a lot of wires and they don't sleep very well. It's quite artificial.

Karen Jaffe: I have a two-year-old granddaughter who they have a little baby monitor, a camera that can watch her sleep and right in their house. So I'm not sure why we can't do something similar for adults and to have just a small camera that just records a night of sleep in their own bed.

Dr. Kirstie Anderson: Yep, exactly. It's setting up standards to know it's as good as the way we diagnose things at the moment. So that's happening quickly and there's just lots of nice home gadgets that will just look at sleep. Lots of the research we do used some version of actigraphy, essentially a wristwatch with an accelerometer, detecting various things, including light to do population health studies. We know they're better than pen and paper sleep diaries, we know they're not quite as good as the sleep bag, but you can look at thousands of people and look at how sleep patterns change in time. You know, just like the PPMI study, we are picking out early warning markers of good or bad aging. You know, my whole point about RBD is that I want to see people who act out their dreams, so I can get them into really good shape. I can make sure they have good brain health as they get older.

Dr. Kirstie Anderson: So I think there's a lot of interest in how much you can use worsening sleep as a biomarker of trouble coming, in terms of another health problem. And for that you use population-based things, and that's going to be things like, whether it's an apple watch or something else. So these are amazing good population studies about, can you pick out a high risk population? So that's probably studying sleep changes. In terms of testing new treatments, probably some of the biggest advances are coming in the stimulant drugs and some of the drugs that are coming out for conditions I treat like narcolepsy. So there's been some really exciting advances in some of the sleep weight drugs. We have more drugs to give our patients better choice now than we did before.

Dr. Kirstie Anderson: And in terms of community and learning from the community, one of the really nice things, whether it's this web or anything else is, I listen to bedtime stories for a living. It's a great job. So the best thing about our joined up big world, is that we've got this chance to pick out pattern recognition because of all of the internet, because of all of the things that we sort of joined up, in terms of that repository of patients telling us, how can we learn from patients to pick out patterns. So I think the big population studies like PPMI are absolutely vital.

Karen Jaffe: Well, and that would include also the Fox Insight study, which is an online study that asks Parkinson's patients and controls questions about living with Parkinson's disease. And I think that those kind of large-scale studies can pull together enough information from enough people that they can make some clinical decisions based on what they should... What somebody might be able to do to get some relief from some of their symptoms. That's I think is really gets Fox Insight, which is not the same online study as the PPMI is, but for people who are interested in participating in online research, it's a good place to add your voice. Somebody's asking whether diet matters or alcohol, the impact of alcohol on sleep, sleep problems.

Dr. Kirstie Anderson: Alcohol, more than diet. So since Shakespeare wrote about it, we know what alcohol does, it makes you pee a little more, it makes you behave a little badly, and it makes you snore a little more. So it's an interesting drug. It's not great for REM sleep behavior disorder, because of the way it's metabolized, your liver is really good at getting rid of alcohol. So it's a drug that tends to be removed very quickly from the system, so you fall asleep a bit quicker, but a bit lighter, but as it comes out of you, get REM rebound essentially, about halfway through the night. So if you have quite a lot to drink, almost everybody recognizes that they'll have some slightly worse, vivid, sweaty dreams. If you already have a dream sleep disorder, then it will make it a bit worse. So alcohol, on the whole, not to be used... It's not a great sleeping tablet, and it's not good if you have nightmares, if you act out your dreams, or if you snore loudly, then I say, have a glass of wine in the middle of the day, but don't drink close to bedtime. I think sleep doctors care when you drink, not so much what you drink and not too much.

Karen Jaffe: And so speaking of drugs, there's been several questions about cannabis and its impact on sleep. Does it help?

Dr. Kirstie Anderson: I mean, cannabis is an incredibly... is not one drug. That's the first thing to say, isn't it, it's a whole mix of chemicals. So this is a compound, if you like, with uppers and downers in it and it depends exactly what people are taking. And there'll be people who feel that it's relaxing, and that they fall asleep easier if they have cannabis close to bedtime. As you might imagine, that's not something I'm going to endorse or recommend, but people tell me that.

Dr. Kirstie Anderson: And probably in the UK, we have a very large number of people who ask me about CBD, so I'll probably do that because it seems nothing I treat... I can't think of a patient who hasn't asked me about CBD, whether it's their sore knee or their sleep or anything else. In the UK, most of the CBD that comes out of a health food shop is such small quantities of active chemical, it's not going into the brain. So any benefit, it's a little more likely to be placebo. So I say what I say to everyone, if you want to spend your money on something, I'm not going to argue over it, I don't think it will do harm, but I don't know what's in it. There isn't at the moment research to say it helps. So I'll probably stick with what we know, if research emerges we'll update ourselves. But yeah, that's what I say if someone asks me about CBD.

Karen Jaffe: So I have here for Linda from the audience. She wants to know is if you're nervous when you go to bed and how do you relax and that go of the worry that your partner may have an active night?

Linda Peeples: Am I nervous? I'm not, I guess after all these years, I'm not nervous that I'm thinking I'm not, but I think my behavior maybe shows I am. Like they said, it affects both of us. And as I'm listening and watching in this webinar, I'm noticing how I have been affected by it. And some of the things that you're speaking of, I'm like, maybe I should look into that a little more for myself, because I'm on guard. I feel like I'm always watching out, I don't want to get hit, I don't want to be harmed, a little apprehensive and probably not resting as well as I need to, because I'm always on guard, looking out.

Linda Peeples: It's better over the years, it's gotten better, as he's gotten a little better taking a melatonin, I know he's not as violent as he used to be, but he still has episodes and they're not as bad as they used to be. But still, for me, I'm still kind of, sort of on guard. So I don't know if that answers your question. I'm okay, it's not like a big concern, but it is still something there that kind of lingers to let me know to be still a little... you know, not getting I don't think a hundred percent of what I need to get, as far as sleep.

Karen Jaffe: So trying to relax and not worry takes a bit of your day. I'm sure that anticipation over the years it's gotten better, but it just, it never goes away once you know that it's the possibility.

Linda Peeples: Yeah, I would say that. And like I said, it's better, but it is still, no... It's something I just do, I guess I've gotten used to it over the years.

Karen Jaffe: I can't imagine, Dr. Anderson, what happens when you have a couple who are both dealing with REM sleep behavior disorder.

Dr. Kirstie Anderson: I always think how impressive and how well people cope with it, because actually the majority of people are as calm and straightforward as we hear the two of you today. They work out perfectly well that it's not the person's fault, but the stuff that makes it better... but almost everybody tells me that it's bubbling under the surface like that. I think that's a really nice description, very typical. And there's people who, in all honesty, decide that they will sleep separately. There's a lot of people will say, well, no, it's really important to us for lots of other important reasons that we share about, there's very personal decisions. But you're absolutely right. A bit like a new mum with a young baby that's being on guard, you're listening in there- [crosstalk 00:48:50]

Karen Jaffe: Right, right, you always have one ear open.

Otis Peeples: Mm-hmm (affirmative).

Dr. Kirstie Anderson: Yeah, it is like that. Now people... we've talked about needing a little less sleep as you get older and everybody wakes, it's normal to wake, but I think that experience is really common. As I said, we are treating two people in the clinic for sure.

Karen Jaffe: And somebody's asking whether the restless leg syndrome is related to RBD.

Dr. Kirstie Anderson: No, it... Well, okay, so the reason I said a sleep study is really important is because there are mimics, when somebody says that they're twitching, particularly if there isn't a really good bed partner who can give you that lovely, clear story, I absolutely have patients who have both on their sleep study, they twitch and they kick. It's certainly true that someone with run sleep behavior disorder has a slightly more restless night, but I would think of them as, and treat them as, two separate conditions. They're both just common, and, again, restless legs get a bit more common as you get a little bit older. So, so no, I would think of them and treat them as separate really.

Karen Jaffe: Great. Well, it looks like we've used up all of our time here, I want to thank you again for being part of our community, and I'm thanking you for joining us today and thanks for our panelists for sharing your time and your expertise. We'll be sending a link to the webinar on demand to listen to again, or share if you'd like, we hope you find it helpful. If you're interested in supporting The Michael J. Fox Foundation, helping fund research toward a cure, there is an icon you can click on at the bottom toolbar of your screen that leads you to a page where you donate. This is Karen Jaffe, I'm signing off, thanking you and having a great day and, hopefully, a great night's sleep.

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