Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about the Michael J. Fox Foundation's work and how you can help speed a cure at michaeljfox.org.

Speaker 1: Navigating Parkinson's disease can be challenging, but we are here to help. Welcome to the Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the foundation's mission to speed a cure. Free resources like this podcast are always available at michaeljfox.org.

Larry Gifford: Hi, I'm Larry Gifford, a member of the Michael J. Fox Foundation Patient Council and co-founder of PD Avengers. Welcome to the Michael J. Fox Parkinson's podcast.

Sleep is essential to humans, just like air, water and food. When necessary, people can cope without sleep for periods of time, but the longer we are awake, the stronger that urge to sleep. Parkinson's disease and sleep are closely connected. Most people with Parkinson's have sleep problems at times. The disease itself may cause some issues like REM sleep disorder. You might also have insomnia or feel overly tired during the day. Two of every three people with Parkinson's have sleep issues, so it's important we're talking about it today.

Parkinson's and sleep are connected in complex ways that even scientists can't really figure out. Sometimes, Parkinson's disease directly causes sleep problems. According to one study, sleep related symptoms may be the earliest signs of Parkinson's disease. These signs may include things like thrashing while you're asleep. Other factors like Parkinson's disease treatments and emotional challenge can also play a role.

One thing's clear. For many people with Parkinson's disease, a restful night's sleep can be hard to find. I'm one of those people. Here's an excerpt from my personal sleep journal. "Tuesday. Woke up at 2:00 AM. Fell back asleep after 4:00. Wednesday. Woke up at 2:00 AM. Tossed and turned, couldn't sleep. Now up for the day at 4:15. Thursday. Asleep at midnight. Up at 4:45 AM. Tremors pronounced. Friday. Beck woke me up three times. I was yelling in my sleep and flailing about."

March is the National Sleep Foundation's Annual Sleep Awareness Month. This campaign celebrates the benefits of sleep. This is an opportunity to stop and think about your sleep habits, consider how much they're impacting your well-being, and take a step towards improving them. And we have a great lineup of panelists today. First, let me introduce Allen Dance from Richmond, Virginia, diagnosed with REM sleep behavior disorder in 2022 at the age of 59, and he is a participant in the groundbreaking PPMI study. Hello there, Allen. How are you doing?

Allen Dance: I'm doing good, Larry. Thank you.

And hello, Richie Rothenberg from Los Angeles, a fellow Patient Council emeritus member, diagnosed with young onset Parkinson's in 2004 at the age of 37. Hi, Richie.

Richie Rothenberg: Hello, Larry.

Larry Gifford: And you're there with your spouse and care partner, Julie Merson. Hi, Julie.

Julie Merson: Hello. Nice to be here.

Larry Gifford: And we've got Dr. Stephen Josa, neurologist completing the Edmond J. Safra Fellowship in Movement Disorder Training, graduates in 2023, congratulations, at the Research Institute of McGill University Health Center, Montreal, Canada. Co Canada Research focuses on the early prodromal stages of Parkinson's disease. Hello, Dr. Josa.

Dr. Stephen Josa: Hello. Nice to be here.

Larry Gifford: I'm going to start with you, Dr. Josa. Why is sleep so important?

Dr. Stephen Josa: Why is it important? I mean, the mere fact that it is something we do for eight hours a day, in general, that it's a third or a quarter of our entire lifespan, that implies it's incredibly important. But curiously, it's a topic that's been understudied for many, many, many years despite its obvious importance. It's so important that if you look at pretty much any animal, plant, fungus, even bacterium, each one of them displays some form of sleep in some measurable capacity. So clearly, sleep is important.

Why it's important? Well, clearly, it's important for restfulness. When we take away sleep from somebody, they wake up in the morning and they're unable to function as a result. Sleep has clear important implications on general well-being, health, but also cognition and ability to function during the daytime. So clearly, sleep, broadly speaking, is critical for life.

Larry Gifford: Critical for life, and it's so often hard to find. You can search for sleep. The harder you search for it, the less you find it. What are some of the sleep problems associated with Parkinson's?

Dr. Stephen Josa: Well, the clear ones that most people will probably identify are, well, the main big ones would be insomnia. And then the other one would be excessive daytime sleepiness, or just basically being sleepy during the daytime. To some degree, the two of them are quite well-linked, so if you have insomnia and you have terrible sleep, that may result in excessive daytime somnolence. But they can also be separate entities.

So beyond just insomnia and excessive daytime somnolence, there are also primary sleep disorders that are common in Parkinson's disease. Some of them can include, of course, REM behavior disturbance, which you alluded to in your introduction. But other things that we might less commonly think about like obstructive sleep apnea, sleep disordered breathing abnormalities that might be seen in some forms of Parkinsonism such as stridor. As well restless leg syndrome, there is an association as well and can be commonly encountered in Parkinson's disease, as well as some other esoteric movement disorder abnormalities like periodic limb movements of sleep.

And many of these sleep problems kind of work together to produce either insomnia or sleepiness during the daytime. I'll also say that, as a consequence of having Parkinson's disease, many people with Parkinson's, most, will be on some sort of medication. And although those medications are clearly important for allowing you to function and to move as naturally as possible, they can also have deleterious effects upon quality of sleep or wakefulness during the day.

Larry Gifford: Well, so, Allen, you have recently been diagnosed with a REM sleep behavior disorder. Can you tell us about what your sleep issues were and how you got diagnosed?

Allen Dance: I sure can. A couple of years ago, I started to, I guess, have more restless dreams or movements in my sleep. My partner really is the one who noticed it, because I would sometimes awaken her with that, and she decided to do a little research on it because I was getting pretty active. There are times where she could tell my dream, "Oh yeah. You were playing volleyball last night," or "You're running. You had a cross country meet last night." Or she'll wake me in the middle of the night and ask me what am I dreaming because of my movements. So that kind of led us to do a little research and we kind of self-diagnosed RBD before ever going to a doctor and getting that confirmed.

Larry Gifford: Yeah. I developed RBD after a PD diagnosis, and for me, it was slow, unsteady, but more and more, I began to thrash around and jump out of bed and throw my fists in the air, or have my elbow just hovering over my wife's face at some point. It was very dangerous situation. So we now have to sleep in separate beds just for safety reasons.

Dr. Josa, is that common that it gets that where it's just so unpredictable, it's not worth the risk?

Dr. Stephen Josa: You face the situation that many people with REM behavior disturbance face, that it becomes safer to sleep in separate rooms even. It is a common scenario, unfortunately.

Larry Gifford: So in that case, it also impacts the intimacy of the relationship of the person with Parkinson's and their partner, which can really... There's so much already weighing on the relationship. Julie and Richie, maybe you guys can come in here now, talk about how sleep maybe has impacted your relationship.

Julie Merson: I mean, we're very lucky in that, Richie doesn't have that kind of physical acting out at night. And we got together after his diagnosis, so he was already kind of well into his medication regime and he had had the deep brain stimulator. And so what I came into at that stage was that, because of, like you were saying, doctor, the incredible amount of medication he takes during the day to keep him functioning and keep him having this amazing kind of second chance at life to lead a, ostensibly to the outside, symptom-free life much of the time, he would be completely unable to sleep at night without taking an enormous amount of sleep medication.

And that medication has changed a number of times. He's gone off the benzos, so it's different. Every six months to a year, he has to kind of adjust the sleep medication to see if it helps or what really helps him both get to sleep, stay asleep, and have a rested sleeping experience, which are three different things.

And how it's kind of affected our life the most, I think, is, because he's on these heavy medications, we have never left him alone with our kids overnight, not because he's not a wonderful parent and wouldn't do everything in his power if there was some kind of emergency, but because he's so heavily medicated. We just worry that if he were stumbling or something and couldn't... Just whatever, the worst case scenario, we would never want to put our children at risk in that way. So we have just kind of adjusted our lives in a way that maybe we wouldn't. We have an au pair. We have someone live in the house with us to kind of help for that, just to make us all feel better and safe. Because if he's worried about it, he won't get a good night's sleep anyway.

Larry Gifford: Richie, were you worried about that? I mean, is that something that weighs on you?

Richie Rothenberg: Yeah. I mean, I have to take enough medication to sleep, to counter effect. It did mean that I take levodopa and

The levels of ampules that going through my deep brain simulator and just life in general stresses. But it's reassuring to have someone here overnight. Then I can stay there, I can be sort of, it is basically when I go to sleep at night, I take my sleep meds. I'm relatively unconscious from whenever it kicks in till the morning, even though I get up to go to the bathroom.

PART 1 OF 4 ENDS [00:11:04]

Larry Gifford: Is it a restful sleep?

Richie Rothenberg: I think so. I mean I sleep pretty well. I fall back asleep pretty well. I think it's restful. I've been looking at my eyes, I don't know. I don't know if it's rapid eye movement or not. I think there is.

Larry Gifford: Okay.

Richie Rothenberg: Do some dreaming, but I'm definitely, it makes me more confident and able to be home with the girls if someone else is there.

Larry Gifford: That's good. That's good. Dr. Josa in some people RBD can begin early symptom of Parkinson's appearing years, even decades before the Parkinson's diagnosis. What have you learned through your research about this connection?

Dr. Stephen Josa: You're absolutely right. That R.E.M. behavior disturbances does, in almost all cases, about at least 80% of cases will present ultimately a diagnosis of a synucleinopathy. These synucleinopathy's include Parkinson's disease as well as dementia with lewy bodies and multiple system atrophy, which are all sort of related forms of Parkinsonism. You're quite correct in saying that it can precede it by decades. The average sort of annual rate we estimate in somebody who has RBD is that between six to eight percent per year every year will ultimately develop one of these synucleinopathy's including Parkinson's disease. The discovery of RBD is actually quite recent. It was described clinically in humans in only the eighties and the connection between RBD, and Parkinson's disease was only in 1996. So it's actually a relatively new illness. Very, very exciting part of this though is that we now have the very powerful predictor of people who will develop Parkinson's disease. It is to say that again, in the majority of people with RBD, most of them will at some point develop Parkinson's disease. But they don't yet have it. This population of people are now a very critical population in which we can study not only the progression into Parkinson's disease and other parkinsonisms, but in fact have clinical trials in which we try to stop or perhaps reverse the process completely. So it's actually an extremely exciting time to be studying RBD

Larry Gifford: So it's not that everybody with RBD ends up with Parkinson's, but most of them

Dr. Stephen Josa: Quite correct. As I said, our best estimates is that over a fifteen to twenty year period, probably about eighty percent or more will get it. Now you might ask, well what is that other twenty percent? Now to some degree, some of that twenty percent are perhaps from secondary causes. Secondary causes are things that may trigger RBD A well-known example are certain antidepressants. Now that said, although sometimes these antidepressants may trigger RBD, you take them away, the RBD goes away. Nonetheless, in those people where it happens, there might ultimately be a predisposition to ultimately getting primary RBD in the first place. That is to say that they will at some point develop RBD regardless of antidepressant use, and as a consequence may later develop Parkinsonism or Parkinson's disease. There - I should also say that there are many things that look like R B D but that are not RBD

So things that may resemble RBD are, for example, in obstructive sleep apnea, if somebody has an apneic event, that's when they're asleep, but they're not able to breathe for a short period of time, they might struggle for air and beat around with their hands and as a consequence they may resemble RBD, but it's not. It's our OSA's. Obstructive Sleep Apnea is not associated with Parkinson's disease, or at least not in any way near as strongest connection as RBD Other things that can resemble it are other forms of parasomnias. Things like sleepwalking, otherwise known as somnambulism, in addition to other clinical entities may resemble RBD But are not actually RBD

Larry Gifford: Thank you. Clarifies it even more, which is great. So, you know, we don't want to scare anybody unduly, but it is one of those things that is a precursor for many to the next level of Parkinsonism.

Dr. Stephen Josa: I should also very much stress that the only way to clinically diagnose RBD is with a validated sleep study or polysomnography. So even though sometimes we're fairly certain it's RBD, we can't actually make that diagnosis with formally without a sleep study.

Larry Gifford: So you had mentioned how important this subcategory this group of folks with RBD are that the P.D. hasn't onset yet. That's where Allen Dance is right now. Allen, how did you find the PPMI study?

Allen Dance: I'm trying to recall now. I was connected to it with the urologist that I reached out to. I couldn't get an appointment for a long time, but he mentioned that as a possible source. My partner also is a researcher and she found the PPMI site and I recommended as well. So I've been a participant in that study almost as soon as I found out or got confirmation that I had RBD

Larry Gifford: Yeah, the Parkinson's Progression Markers Initiative, or PPMI, is sponsored by the Michael J. Fox Foundation. It's a study in volunteers with RBD, both with and without Parkinson's to see how PD comes on and changes over time to develop better treatments and ultimately prevent the disease. So you found that the study, how have you found it? Why are you personally doing it?

Allen Dance: Right now there's not a lot I can do to fight the RBD. But, I can make a contribution, or if I can make a contribution, that'll help an understanding of RBD and how it progresses in Parkinson's. I'd like to do it. It's not a very difficult thing to participate in. It takes a little bit of time, but, if I can make a difference and hopefully help figure out the disease and ways to slow it down or ways to make it go away, I want to do my part.

Larry Gifford: Thank you. Thank you for doing that. Research is so important. Without people volunteering for research, there is no research. So thank you.

Julie and Richie, how have the sleep issues in your life evolved over the course of your relationship? Have you seen it change?

Julie Merson: Well, that's a great question. I mean, as Richie's evolved and everything he's had to take has changed. All different kinds of his medications every year or so have to be slightly adjusted and including -

it was interesting you said to me because Richie, like a lot of other people, take antidepressants as part of his Parkinson's regime. So it's interesting to me that there's a connection between that and RBD, Or there could be a connection. Again, that's not Richie's sleep issue. I think one of the things when he decided to go off the Benzodiazepine, in my experience, he doesn't quite get as deep asleep anymore. So he's very lucky. He'll get up several times a night to go to the bathroom and he falls right back asleep. But he's up a bunch of times. I am not so lucky as to be able to get back to sleep so quickly.

I don't know if it's my mom ears that's always listening for some child in distress. They're ten now, so they're pretty good at sleeping. But I kind of wake up every time he does, and it's also just making sure, did he bump, did he fall? When he's sort of very medicated in the night and he hasn't had, you know, his Parkinson's medication, it's easier for him to fall or hurt himself. So I kind of get very alert and wake up and sometimes I can fall back asleep. But often, like last night, he woke up at 3:15 and I just kind of read from 3:15 to 5:00. So I mean for me, I think he's getting good solid sleep. It doesn't seem to me that it's as deep as it used to be. And then I know that can have an impact on my sleep. And also when he doesn't get as good a night's sleep, it has an impact on his Parkinson's symptoms. If he doesn't sleep as well, he's more likely to stumble the next day. So there's kind of this cascading world of effects, but I was not around the beginning of the Parkinson's or sleep journey, so Richie may have more of a take on that.

Richie Rothenberg: I do know that if I get RBD, I'm definitely [inaudible 00:20:27] Parkinson's [inaudible 00:20:29]. That's one good thing.

But yeah, the transmission's been pretty startling. It was really a trial and error to get to the point where my doctor is writing combination of enough cocktails to put me down. Cocktails meaning just a cocktail of meds, no cocktails, but the meds to the point where it can effectively get me to sleep. It's more of an impact on Jules really, because I mean she'd probably be better off if I had a Benzodiazepine or was in a different bed or different room. That's another story.

So I'm able to do, it's sort of part of it's a cruel comedy of having Parkinsons. It's Like getting old. You get old. It's hard for you to walk. You have to pee a lot. And with Parkinsons, [inaudible 00:21:17] having to pee a lot. That happens because of Parkinson. It's a cruel joke. It's like, and you don't take any medication overnight, so at least I don't, So I'm off my meds until six in the morning. The way Parkinsons works, the Levodopa goes through your system really fast.

Larry Gifford: Yeah.

Richie Rothenberg: It's harder to walk at that time. So it's just like, you know, it's a cruel key comedy of affairs with [inaudible 00:21:50] even about things like PE and falling down. It's all just part of the game.

Larry Gifford: Well Richie, you bring up a good point. Not only are sleep issues associated with Parkinson's, but also they happen when people get older.

Dr. Josa, can you talk about how do you know if it's because of the Parkinson's, or just because I'm getting gray hairs?

PART 2 OF 4 ENDS [00:22:04]

Dr. Stephen Josa: There is a huge overlap. You're quite right. And, yes, some things are worse in Parkinson's, but yes, there's an overlap. I will say that if you pull older adults that don't have Parkinson's and are otherwise generally healthy, about a third of them will complain of insomnia. Of course, at least two-thirds of people with Parkinson's disease, so about double, have insomnia. So it clearly seems to be more of a problem in Parkinson's disease specifically. So some of this has to do with normal aging. When we are born and as we grow, we have a circadian system. This is a clock within our brain, which over the course of 24 hours or so, tells us when we should be alert and when we're awake and when we should sleep.

And with natural aging, the circadian system breaks down a little bit and becomes less efficient even as we age normally. In Parkinson's disease though, it becomes even more complicated. Parkinson's is what we call a neurodegenerative disease. And so although clearly, it affects motor function by targeting specific parts of the brain, we are only now understanding and learning that it also affects things as complex as the circadian system. So it is to say that your sleep-wake cycle by virtue of having Parkinson's disease is disrupted and that leads to poor sleep.

I will also say although I said that insomnia is fairly common in otherwise healthy adults and it's more common in Parkinson's disease, the complaints are actually a little bit different. Although about equal numbers of people who don't have Parkinson's disease and do have Parkinson's disease, although both will complain about the same rate about difficulties of falling asleep. Duly, what you identify is quite clear, most people with Parkinson's disease complain a lot more about frequent awakening and being unable to go back to sleep. And as a consequence, that also carries over to the bed partner as well.

Interestingly enough, RBD, although it can be dramatic, acting out your dreams, jumping off your bed, and such, actually, in most cases RBD is not the problem. It's as simple, unfortunately as things like having to get up frequently to pee. In fact, frequent urination during the night or nocturia like we call it, is probably the number one complaint that people have. Not only does it wake you up because, "Oh, I got to go to pee." But, you, "Uh-oh, I have to get up to pee, that means I got to get out of bed, somehow get myself over to the bathroom. Maybe I have to wake up my bed partner to do so." It becomes a whole process and it's so difficult. So what you have described, you hit the nail on the head in so many different ways.

Larry Gifford: Well, and Allen, I know your partner first noticed that you were acting out your dreams. How has RBD changed you and your partner's nighttime routine?

Allen Dance: Well, first of all, we kind of joke around that my having RBD means she has RBD because she's the one that usually wakes up when I'm making movements in the middle of the night. If she wasn't in bed with me, I usually sleep through the night fine, so I guess I'm still early on and I'm getting a glimpse of what's coming down the road. But really she's the one who is the one who deserves a little combat duty because she gets in bed and she knows that there's a chance that I may start getting very active with my arms and my legs. It's not, to the best of our knowledge an every night thing, but the only way we know is if I wake her up.

So if I don't have it happen one night, I don't know if I really didn't do it or if I didn't wake her up. And we as a couple have always kind of quite frankly, snuggled up and slept kind of spooned at night. And this has really totally changed that because if we start to sleep that way, it's a little anxious for her. It's relaxing intimately. It means a lot to us to snuggle like that. But she also knows that once I'm asleep, there's a chance that she could get hit and it's happened before. It's a low probability, but if there's only a 5% chance of you getting hit at night, you may not feel like 5%'s a very low number.

And it's a scary thing as well that she can be asleep and with no notice, right out of the blue, my hand could come out and I could hit her in the face. So it's changed a lot of dynamics for us. We call the middle of the bed the neutral zone, and I sleep on my side of the neutral zone. So we may meet at the middle to begin of the night, but I stay to my side so she can have a safe area of the bed. And unfortunately, sometimes that's still not enough because I wake her up and then she can't get back to sleep. So I wake up in the morning and one of the first things I do is I look over to see, okay, does she survive the night? I'm the one with RBD, but she's the one who half the time wakes up in the morning in a different bed because she needed to do it to get to sleep.

Larry Gifford: Yeah. That was happening in our relationship too, so that I just ended up going to a different bed and we've had to find new ways to find intimate moments and to take those moments of conversation through the day or just sit in bed and be with each other and then go into separate beds for sleep or you just have to keep evolving. And communication's really the key, right? If you don't want your partner to fear sleeping because they might get hit in the middle of the night.

Allen Dance: It's one of those where I apologize every time and she's always great about it, "You know, you don't need to apologize. There's nothing you can do about it." But you do feel bad. It's like I'm making her lose sleep and I feel like going to another bed. But she's like, "Well, you are sleeping and it doesn't happen every night." So rather than me being in a separate bed or the two of us being in separate beds every night, we begin each night giving it a shot and it's not like it's an all night thing. She describes it as it's maybe three or four minutes in a night, once or twice a night when she's noticed it happening.

And so we usually roll the dice, well, we always roll the dice by staying in bed to begin the night. It's just a question of will she make it? And I usually make one nature break during the night, and usually I get up out of bed, I go to the bathroom and I come back and I'll look. Sometimes she's there, sometimes she's not. You expect that she's there, but she may have already had to bail out because of a dream I had.

Larry Gifford: Dr. Josa, oftentimes my events are accompanied by very vivid dreams. What does that tell you?

Dr. Stephen Josa: Well, you're quite correct that the textbook examples that we see of RBD are often quite dramatic. They're often events where people are struggling and fighting against somebody or some unnamed thing. And there's one school of thought that perhaps, well RBD episodes occur because you're having a dream where all the adrenaline's pumping and then you need to move in order to jump out of the way of the car that's getting after you or the tigers that's chasing you. Quite curiously though, there's been perhaps a shift in how we view RBD. It's possible that a lot of RBD is actually quite subtle, that RBD dreams can be as simple and as any other sort of dream.

There's some very interesting research coming out of France. Dr. Arnulf is the lead author that has actually examined dream content in RBD. And they've documented many, many, many examples of, yes, there are occasions of fleeing from alligators, but there are also many instances of what seem to be very pleasurable dreams. People smiling during their sleep as they experience a pleasant sort of dream. So although the ones that are often brought to our attention, the violent sort of dreams that make people jump out of bed, probably the majority of dreaming in RBD is actually quite simple and quite as natural as any other regular dreaming.

Larry Gifford: Well that's good to know. Before we wrap this up, I want to go around the room and get a piece of advice from each of you, if we're either people with RBD or Parkinson's or care partners, on maybe some tips you've acquired over the years in regards to how to make it work. I'll start with Allen because he had his hand raised there. I think he wants to add on to Dr. Josa.

Allen Dance: Oh, we've got a little bit of a different question. I'm not quite sure what advice to give at this point. I guess be prepared to say I'm sorry, because early on you're disrupting someone else's sleep and I guess sometimes have a little fun with it. Dr. Josa was saying they're not all violent dreams. Sometimes she wakes up and I'm in the middle of a business presentation or something funny is going on, I'm literally laughing in my sleep. And she will sometimes wake me on one extreme to calm me if I'm getting really active. But on another extreme, she's just really curious and she'll ask me, what am I dreaming about? And the irony is that I always know. I always know in an exceptional level of detail and I'll tell her the dream and then I fall right back to sleep.

So I don't mind her doing that. And sometimes she's just curious, "What are you laughing so much about? Or what are you presenting about?" I guess have a little fun with it. It's not all fun, but where there's a window, enjoy some of the uniqueness that your life is bringing you.

Larry Gifford: Allen And maybe keep a sleep journal, a dream journal. That would be interesting to look back on over the years.

Dance: I haven't tried that yet, but that's a good recommendation. I made a note of that. Thank you.

Larry Gifford: Richie, what advice do you give people?

Richie Rothenberg: Well, I give other more holistic advice like sleep, meditate, eat well, exercise, try to get to sleep again if you can. And try to have a sense of humor of in your life through it. Having the ability to laugh at yourself is very important to [inaudible 00:32:35]. And we all pull different levers and knobs to accommodate for our Parkinson's, to deal with our situations. Because they're very, very distinct. I mean, there's a commonality. Everybody thinks of levodopa for sure, or dopamine. And it's just a matter of what different concoctions you need for your specific situation.

And it's the end as was told to me by a friend of mine when I got Parkinson's. It's the best chronic disease around, everybody disease. That's the best one.

PART 3 OF 4 ENDS [00:33:04]

Larry Gifford: Julie.

Julie Merson: Well, I second everything out and Richie said, but I would also say that for me, the communication has been, just being able to... Because especially when you're both tired, it's very easy to react and not communicate clearly. And I think when we've been able to say, "I'm exhausted, I know it's not your fault, but can you help me out today?" The communication has been very important and very... Because we want to still sleep in the same bed and we want to be able to have that as part of our life. But I will say the most important thing is the humor. And Richie brings an incredible amount of humor into both Parkinson's as a whole, but even if he does wake me up in the night, he's able to joke about it and be funny. And while he sometimes could even have to crawl on the floor to get back to the bed, we have a way to be able to laugh about it and that makes it feel like we're on the same team and we can get through anything together.

Larry Gifford: I love that sense of humor and also just the communication gets you through so much. If you just say it out loud and not assume that every people know what you need in the moment, I think that's... Because people with Parkinson's, our levels of observation decrease exponentially over time. So I don't notice the things that I should notice. So my wife's like, "Do I really have to ask you to do this?" I'm like, "Yeah, you really do." Dr. Josa-

Julie Merson: You and every other husband.

Larry Gifford: Dr. Josa, what advice would you give people if they find they're having some sleep difficulties?

Dr. Stephen Josa: I will say, first off, speak with your doctor. And I say that actually a bit with a bit of facetious nature to it. I say that because it's not necessarily easy to speak to your doctor about sleep. The reason for that is manyfold, but in part it's because many general doctors and certainly many neurologists that are general neurologists have actually very limited training in sleep. Many are sleep-deprived themselves as well. And so it becomes sometimes a hard thing to talk about. That's why it's actually quite important, as you sort of alluded to, perhaps to keep some sort of a sleep log. Just as in people who are chronic migrainers or people who have headaches keep a journal about what triggers their migraine, what makes it better. Exactly the same sort of sleep journal can be actually quite illuminating both to you as well as to your physician.

How often are you waking up and why are you waking up? Is it just to pee? Is it because you have pain or dystonia or it's hard to get out of bed? Make a note of, well, what were the stimulants I had that day earlier? Caffeine after 2:00 PM is probably not actually a great idea, but it'd be something you might identify by jotting these sorts of things down. And then having that discussion with your doctor specifically about sleep allows you to review your medications. We talked a little bit earlier about how certain medications, although they're what you need to get going to move, they can also have a deleterious effect upon sleep. And so often a review of medications or an adjustment of medications is also important at least to consider. I also want to very, very much stress the importance of non-pharmacological interventions that are things that are not medications you take, but things that you personally can do.

Exercise is exceedingly important. Not only do we know that people with Parkinson's disease who exercise ultimately do better than people who do not, people who stick to an exercise program actually tend to sleep better at night. Even people who have insomnia when they have studied these people and entered them into randomized control trials to test exercise in people with Parkinson's disease and sleep difficulties, their sleep is actually better over in the long run. And finally, I would say another key non-pharmacological therapy is actually light therapy. You can think of light as a drug. Light is a thing that stimulates you in the morning to get you up, to get your circadian clock going. But as a consequence, too much light towards the evening with our bright blue

LED screens are actually extremely stimulating. Sometimes simple things like having a filter on your computer that adjust the light level to more of a warmer orange kind of glow towards the evening.

Sometimes that's even enough to help promote sleep in people who have insomnia, and by the opposite end of it, people who are excessively tired or excessively sleepy during the daytime. There's actually some great evidence starting to come out that light therapy in the morning, so a very bright light lamp sort of in your face as you prepare for the morning, actually can give you quite a bit of benefit in terms of improving tiredness throughout the day. So very much yes, as a neurologist, yes, we like to give medications to try to solve problems, but actually you as a patient are actually quite empowered to do many of these non-pharmacological things yourself.

Larry Gifford: I want to thank all of you for being here and talking about this. You're able to be very vulnerable with us and we really appreciate the behind the scenes. I do want to remind everybody that participating in the research is one way to feel empowered and to make a difference. If you have RBD or act out your dreams, you could play a critical role in our landmark research study. The Parkinson's Progression Markers Initiative or PPMI is learning more about the connection between RBD and brain disease and to understand who gets Parkinson's, who doesn't and why. And those insights could lead to better treatments and cures. If you have RBD and don't have Parkinson's, call 866-525-PPMI. 866-525-PPMI to get started and speak with a study team. For more information on RBD visit michaeljfox.org/dreams. And once again, I want to thank our panelists, Julie Merson and Richie Rothenberg, Allen Dance, and Dr. Steve Josa.

Julie Merson: Thank you. It's great to be here.

Richie Rothenberg: Thank you, Larry. It was great to be with you as always.

Allen Dance: Thank you, Larry. I appreciate your being on the call.

Dr. Stephen Josa: Thanks for having me.

Larry Gifford: For everyone who is here until Parkinson's isn't at the Michael J. Fox Foundation, I'm Larry Gifford. Thanks for listening.

Speaker 1: Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about the Michael J. Fox Foundation at michaeljfox.org. Thanks for listening.

Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about the Michael J. Fox Foundation's work and how you can help speed a cure michaeljfox.org.

PART 4 OF 4 ENDS [00:40:41]