

Sleep and Parkinson's with Dr. Ronald Postuma
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Dr. Soania Mathur (03:00):

My name is Dr. Sonja Mathur. I am a family physician and I've also been living with the challenges that you've been living with for well over 22 years now. I do have the privilege of serving on the board of directors for the foundation and I also have very great pleasure of being your moderator today. Today at the top of our webinar is sleep and living well with Parkinson's disease. Sleep is definitely part of living well with this disease. It's part of our daily routine and opportunity for us to rest our bodies to find some relief from the motor symptoms of this disease. One of the few times that we can eat actually feel our muscles relax or stop tremoring yet sleep disorders unfortunately are fairly common non-motor symptom that can really affect your quality of life. So, joining us today to explore this topic further is Dr. Ron Postuma. Dr. Postuma is a professor at the department of neurology, neurosurgery faculty and medicine at McGill university in Montreal, Canada. Fellow Canadian. He is a clinical researcher and movement disorder specialists with an interest in a variety of aspects of Parkinson's, including early detection and prevention of Parkinson's and testing new treatments for non-motor symptoms such as sleep disorder. He also holds a master's in epidemiology. Thank you for joining us today.

Dr. Soania Mathur (04:15):

So, to start off the discussion perhaps we can define how much of a problem sleep disorders are in Parkinson's disease. How, how common is it?

Dr. Ron Postuma (04:25):

Very common. So not every sleep disorder is the same, right? And in fact, they're often opposite of each other. But if you sort of look at the whole course of Parkinson's disease over your life the chances that you'll develop one of the sleep issues related to Parkinson's are on the order of 90%. If you look cross-sectionally, so everyone say with Parkinson's right now maybe about half to two thirds of people are experiencing some issue with their sleep. So, it's really quite a common problem.

Dr. Soania Mathur (04:56):

And why exactly is sleep disrupted in Parkinson's disease? What's, what's happening in our brains that would cause that?

Dr. Ron Postuma (05:03):

Right? So, there's a, there's a lot of things. The most, sometimes when I give a talk, I actually show a map of where Parkinson's is, and one half and I show a map of all the areas that control sleep and the other half. And what you can see is that, you know, whereas we often think of Parkinson's disease, Oh, it says don't mean disease. In fact, it is not a doping disease at all. It just happens to be the way that we identify it. In fact, it has a lot of areas of the brain that are down in what we call the brainstem area that control things like sleep and mood and all these sorts of, of aspects in addition to the motor aspects, those are affected in Parkinson's disease as well. And so, if you look at the map of things that control sleep, when you look at the map of things that, that have Parkinson's, they, they overlap a lot.

Dr. Ron Postuma (05:51):

And in fact, so most of the sleep problems that we're having are really related to directly related to the Parkinson's disease. That's one. Number two, the dopamine state can make things a little bit worse as well. And so that's one of the commonest things we do for insomnia. We'll get into that later. I think number three, the medications can affect sleep, particularly be a sleepiness most of the time. Really the biggest one is the number one. It's, it's just a disease that affects the sleep centers, but the other things can play a role as well.

Dr. Soania Mathur (06:22):

Now is that why we find that the dopamine state kind of affects sleep? Like one of our listeners says that when they get into bed at the first, their hand tremor persists and annoys them and then they put it in the novel position or hang it off the edge of the bed and they're able to relax enough to fall asleep. And they're just wondering is, is the natural ebb and flow of dopamine and what it does play a part in sleep cycle.

Dr. Ron Postuma (06:47):

Yeah, definitely. So, it's not hard to imagine that if you were having bad Parkinson's symptoms, you won't be able to sleep. So, tremor is one, you know, it's something against your chest. How can you sleep with it, bumping against your chest like that? The other one is discomfort or pain or restlessness, which can often be symptoms that when the dopamine levels are a little bit low, you have it. An interesting thing about sleep is that and Parkinson's is that from the motor stent, while you are asleep, you basically don't really have Parkinson's and your motor state is, is, is non non-functional. And the reason for that is Parkinson's is essentially in terms of the motor problems, it's like there's a whole loop that we have that tells us whether to move or not. And when you have park and since disease you've got a problem with that loop.

Dr. Ron Postuma (07:34):

And in fact, it's just telling your whole brain and body, not, don't move, don't move. This is, you know, you, you're supposed to be standing still. Okay. Now it's not on a conscious level. It's on a very subconscious cycle sort of level. But when you're asleep, that whole system is asleep as

well in fact. And so basically during Parkinson's, during sleep you kind of don't have motor Parkinson's. The difficulty of course, is that all of us wake up all the time 10 times an hour people will wake up just for a few seconds, 10 seconds here, 20 seconds there, and then you wake yourself up and here comes a tremor, thump, thump, thump against your chest, woke you up fully instead of just having you drift back to sleep. So that's one of the ways that that dopamine can really affect department's asleep.

Dr. Soania Mathur (08:16):

So, you've sort of gotten into the next sort of topic I was going to ask you to explain in that sleep disorder sort of refers to a broad term, it's, it kind of encompasses different sleep issues of Parkinson's patients happen. So, what are the different types of sleep disorders that we see in Parkinson's? In terms of categories?

Dr. Ron Postuma (08:33):

Right. So really, I guess for the first one is insomnia. Okay. And insomnia, almost always, if it's related to the Parkinson's, of course everyone has insomnia now and again, but Parkinson's related in the song is always, excuse me, a difficulty in staying asleep rather than falling asleep. Some people have difficulty falling asleep, of course, like everybody. But if it's Parkinson's, it's usually staying asleep. The other one is sleepiness. So excessive sleepiness during the day. Okay. And usually in fact you think, Oh, that's because I have insomnia. No, in fact, no. It's, it's using it, in fact a separate problem. The other one is called REM sleep behavior disorder. So, we act out our dreams at night. We're supposed to be paralyzed when we're dream. That's normal. But you lose the promises, you act out your dreams. And then the last one, which is kind of related to insomnia, would be restless legs, which can sometimes happen usually later in in Parkinson's disease.

Dr. Soania Mathur (09:31):

So, if we go back to the first one, you mentioned insomnia. I know you said, I mean there's lots of people that have trouble falling asleep in sort of the general population, but you mentioned in Parkinson's it's a bit different. Do people with Parkinson's disease have trouble falling asleep or is it afterwards that they wake up

Dr. Ron Postuma (09:47):

And but really if you look at falling asleep, trouble just, it's the same as everybody else. Okay. The classic Parkinson patient. Now, if you're, if you're a 30-year-old with Parkinson's, things are totally different. But if you're, you know, the average sort of, you're in your fifties, sixties, this sort of age, it's, oh goodness, I can barely stay awake. It's, it's nine o'clock, I'm falling asleep in front of the TV and then I'm awake at one in the morning, two in the morning, I can't get back to sleep. And often people will notice that they have this pattern. It's nine o'clock at night, and then

they sleep for like four hours and then they can't sleep again. They get out of bed and two hours later they can sleep again. So that's a common pattern that we also see in Parkinson's disease.

Dr. Soania Mathur (10:27):

We here I guess for the initial insomnia, we hear about something called sleep hygiene as a method to help regulate our such sleep wake cycle. And could you explain what that means?

Dr. Ron Postuma (10:37):

Yeah. So, sleep hygiene is, is basically the series of things. It's often part of what we call cognitive behavioral therapy. It's just one part of it. So, this is the number one treatment for insomnia. And people who don't have Parkinson's, it's way better than medications. Okay? And the idea is to train yourself how to sleep. And there's a lot in it, but the basically summarize briefly, it's first of all, do a whole bunch of sleep hygiene things, which means don't do all the things that tend to keep you awake. And I must say most of my Parkinson's patients is pretty instinctive. They all kind of know this, so it's not there. Most of our Parkinson's aren't going clubbing at four in the morning, you know we're not, you know, we're not drinking coffee to two hours before bedtime. Some of it is so obvious that's almost never the problem.

Dr. Ron Postuma (11:26):

But one sleep hygiene thing I do notice Parkinson's patients tend to make a mistake is the rule of insomnia is if he can't stay in, if you can't sleep, don't stay in bed. What happens if you stay in bed is you start to associate the bed with this horrible torture chamber where I lie awake for hours and hours unable to sleep, and then you develop an association and one that association goes comes. Then you basically can't sleep all. And one of the paradoxes of insomnia which drives every insomnia crazies. You have to not think about falling asleep in order to fall asleep. And so, if you're lying in bed thinking about it, it's just not going to work. And so, if, if you have reasonable motor state that you can get out of bed, if you're not too bedbound, for example, usually what I say is, okay, it's one in the morning.

Dr. Ron Postuma (12:14):

You're up now go up, go read a book for an hour or two a sit in front of a TV, hopefully not too bright. And then when you feel sleepy, go back again. And many people I find have that pattern that I just told you about the four hours and the two hours and the two hours of extra. If that's who you are and it doesn't impair your life, just go with it. Rather than fighting it with medications and pills. So that's the big part of sleep hygiene that we need, really need to be aware of.

Dr. Soania Mathur (12:39):

What are the other things that people should be looking for? And with sleep hygiene, you mentioned some of them are fairly common that we don't tend to violate, I guess. But what are they

Dr. Ron Postuma (12:52):

Keeping a relatively regular schedule? Okay. So, this is a big problem with adolescents of course, or people who work shifts or weekends this sort of thing. So, you try to go to bed at around whatever it is, 11 o'clock every night within an hour or two as much as possible. Okay. Make sure that you get adequate exercise, particularly if you have trouble falling asleep, you need to avoid exercise in the late afternoon. If you have no trouble, then that's no problem. I get good light exposure throughout the day. Actually, that's the biggest treatment for somnolence that probably you can just do on a daytime basis, but also probably helps insomnia is that don't sit inside all day around midafternoon. At least get outside sun on your face and it helps reset your cycle. Obviously if the room is too noisy or too quiet or the bed is too hot or too cold or you know, all these sorts of things, you know, be aware of the things that make you unable to sleep. Just be aware of those and watch out for those. I mean there's a list of the, under these, you can get them off the internet very easily, actually. Just sleep hygiene, insomnia and they'll, you'll see a list of like 50 things.

Dr. Soania Mathur (13:58):

Perfect. Is there anything that your Parkinson's physician can do if, say you've tried all these sleep hygiene methods and you're still having difficulty with your sleep, are there changes in your medication, for instance, that might be an issue or what other factors do you have to look at?

Dr. Ron Postuma (14:12):

Yeah. So, if the sleep hygiene is not a big problem and the sleep is a problem, you can't just go with it, then we have to think about what we're going to do. Medication-Wise usually. Okay. And so, I, I have an order that I personally follow. I see lots of people with Parkinson's. The first thing I do is I make sure the dopamine system is okay. So, if just like you talked about your stiff, you're sore, you can't turn, or even you don't always feel it. If you're a person who fluctuates and your medications lasts for four hours and then you take your last pill at 10:00 PM and now you're awake at two in the morning and you can't sleep again, maybe all you need is another dose of your levodopa, for example, at two in the morning, that's one of the commonest things I will do.

Dr. Ron Postuma (14:51):

Or I'll, I, you know, many standard Parkinson regimens are three times a day before breakfast, before lunch, before dinner. And so maybe I'll say, okay, let's spread it out. Let's add before bedtime as well because you're having trouble sleeping. So that's the first thing I always do. If that's not a problem then we have to think about other medications and here is where it gets,

excuse me a little bit difficult because most people who don't have Parkinson's have trouble falling asleep. Okay? And so, all the pharmaceutical companies have tried to design medications that whose whole job is to get into your system really, really fast, knock you asleep, keep you that way for a couple of hours, and then the natural rhythm takes over and everything's fine. But if you have a problem staying asleep, you've got the opposite problem. And there's not a lot of medications that are designed to do that.

Dr. Ron Postuma (15:39):

If I want to give you a medication to kind of knock you out, but the knock you out six hours from now, then it's going to also knock you out 16 hours from now when you're supposed to be up during the day. And so, there's a series of a few medications that, that I will use. The one I use most commonly is the old antidepressant medications. That's just what they're called, that what we call the sedating antidepressants. And there's two of these. One of them is doxepin and we've done a little trial on this. And another one is trazadone, which has not had a trial in Parkinson's disease, but it's been done. The Alzheimer's divisions use it all the time. And the idea here is we're not treating depression at all, but it turns out that when you get at low doses of these medications, they're kind of like, you know how Benadryl puts you to sleep.

They're kind of antihistamines and they're very good for keeping sleep maintenance so you have more efficient sleep, especially in the later part of the night. So that's usually my first line. If a person is depressed, then I might use actual antidepressants. But again, not the new ones, the old ones the old ones, which appear to be more sedating than the other ones. That's always what I do first.

Dr. Soania Mathur:

What about the medications? And a lot of people hear about the sort of Pam, the lorazepam, the clonazepam, that sometimes they will hear other people taking for their sleep. What about the those medications for sleep?

Dr. Ron Postuma:

So, the PAMs you have to be a bit careful about because they're habit forming. Okay. So, lorazepam for example, it's not, your system gets kind of used to it. It's like a thermostat you know, and now your temperature is set to a certain amount of those pan benzodiazepine medications every night.

Dr. Ron Postuma (17:19):

And so, you just get used to it. Now you need it. And so, it's, and then you end up chasing it. So, we try not to do that once in a while probably. Okay. You see a lot of people using clonazepam, which is a medication also prescribed for anxiety. I stay away from that as much as possible

because it has a 48-hour half-life. In other words, it's around in your system for days and days after you take taken. So, it'll make you sleepy during the day. There's another class of agents that are kind of like that. They're called the benzodiazepine agonist, and these are all the Zed medications. So, Eszopiclone you know, they have brand names like Lunesta, I, they're all different in different countries. These probably are a little less habit forming. Again, they do probably work for Parkinson's, so I will sometimes use them. But they're not you know, again, it's exactly the problem where they're, they've been designed to put you to sleep and so they help a little bit less at keeping you asleep.

Dr. Soania Mathur (18:17):

Are there any other dangers besides addiction to these sleeping medications that

Dr. Ron Postuma (18:22):

Well, essentially, they can make it a little bit too sleepy. So, if you're up at too high of a dose, you can get sleepwalking behaviors. So, this is a common classic on an airline. Someone really, really wants to sleep, so they took a whole bunch of the Zed medications and then what happens is you get hit some turbulence or if you're in a bed, you hear a dog barking and you partially wake up, you're half asleep awake and then you act all confused and do crazy things. So that's a common side effect of these medications in general then not really very dangerous. I don't want to oversell them as being a problem. We use them all the time. Most of the time it's perfectly fine.

Dr. Soania Mathur (18:57):

And discussing medications, Parkinson's medications themselves, are there any that are more prone to aggravate a sleep disorder?

Dr. Ron Postuma (19:06):

Right. You can get, you can get funny things with the Parkinson's medications that are different in some people than the other. So, most of the time, most of the Parkinson meds tend to make you fall asleep, but there are some people for whom it will keep them awake. And so, you might just want to keep an eye on that and so you could just find out yourself. So, you know, I really can't sleep at night. Let me just hold my, you know, assuming I'm not very, very sick for Parkinson's, let's hold that bedtime pill and see what happens. Oh, my sleep is much worse. Okay. No, I need to. Okay. Or if I see it gets better, then maybe that's a signal. So, you, you know, an experiment for a night or two if your doctor's okay with it is perfectly fine. One medication to be aware of is selegiline, which is a medication I like, and I use a lot. It has some amphetamines in it. That can be a really good thing if you too sleepy, but usually a, that's the reason why I tend to prescribe it in morning and at lunchtime. So, it's all washed out by the evening.

Dr. Soania Mathur (20:04):

Right. And are there any natural supplements that you know of that may work? The patients can try as well.

Dr. Ron Postuma (20:11):

So, the classic one is melatonin. You can get that from all sorts of sources. You can buy it over the counter. There have been some studies on melatonin and the jury's out really on whether it works or not. I think it probably you, if you push the doses pretty high, it does put some people to sleep for sure. It's mentally, it also might work on the REM sleep behavior disorder, this other problem. But when you look at the studies, they, it doesn't look like it does very much. Maybe part of the problem is, is that when you have Parkinson's disease, this system, your circadian system that melatonin is supposed to be targeting is in fact degenerating. That's one of the reasons that you're insomniac. And so maybe you just don't have the target for that medication. So, it's okay to try. I know some people find it's useful. It's not very dangerous. It just makes you sleepy the next day if you take too much. So, no problem with using it if you're otherwise, well, most of the time is not a big difference.

Dr. Soania Mathur (21:07):

I, I've seen there's a real variability in terms of dosage for melatonin that you get over the counter. Is there any particular dose that you suggest patients start at?

Dr. Ron Postuma (21:16):

I typically go with three milligrams is my usual starting dose. Five maybe six if two, three milligram pills 10 don't go pass there. There's been cited with 50. It's probably okay, but that's a lot. If you have jet lag and I use melatonin all the time for jet lag, it's a great treatment for jet lag. So, I fly to Europe and I take them out with tone and I, you only need about half a milligram to get the full effect on your circadian cycle. And so, when you're using these really high doses, you're basically forcing the system to kind of put you to sleep a little bit. Generally, it doesn't help very much to go on a higher dose.

Dr. Soania Mathur (21:51):

And when you get sleep from any of these medications that you've talked about, is it as good quality sleep as you could normally achieve if you, if you didn't have Parkinson's? I guess.

Dr. Ron Postuma (21:59):

Yeah. So that's the thing that I don't really know. I mean every, everywhere I travel internationally a lot. And so sometimes I'll use the, the these awful clone kind of this ed medications and I must say the next day I, I feel just as tired. I, it doesn't really seem to help me

very much. Like I, I sleep, but I'm not sure. We don't bring good evidence on the restorative value of that sleep. And it's hard to measure because actually you can do a lot better without sleeping. You think you know, people can go without sleep and they think they're horrible, but in fact they perform relatively well. The, the sedating antidepressant medications that I mentioned earlier. So, the trazedone, the doxepin, they probably do improve the quality of your sleep. We've done some studies, w and they're very small. I don't want to oversell them, but you know, for example you would think that maybe they make your cognition worse. But in this one little study that we did, the cognitive testing was actually better on those who were using it. So, it was only six people, but don't take too much into it. So, but there's a sense that that is a more restorative kind of sleep.

Dr. Soania Mathur (23:08):

That brings up the question how much sleep is enough really? I mean, is it, is it, you go, you hear guidelines, eight hours of sleep is a necessity or, you know, but as you're saying, if you don't feel unwell from getting less sleep, is that the guideline that you use usually, or is there a certain amount that you,

Dr. Ron Postuma (23:26):

Yeah. Yeah. Don't worry about it if you're not sleeping very much. In fact, one of the big things of sleep hygiene training is to teach you not to worry about it so much. You know, your body will ultimately get the sleep it needs. Now, it may not be at the time you want. You might find that your now need those early afternoon naps whereas he didn't need them before. But you know, if it fits with the lifestyle, just get it count very carefully the hours that you're asleep, but you think you're having trouble with insomnia. So, I have many patients who say, oh doctor, I can barely sleep. Well what time do you go to bed? I fall asleep front of the TV at eight o'clock and then I wake up at two 30 and I can't sleep. Well that's six and a half hours. That's the normal duration of sleep for a 65-year-old person. You've just gotten your full night. So, you know, when you get older you definitely, most people sleep less. If you're anywhere above five hours and you feel fine, don't worry about it.

Dr. Soania Mathur (24:19):

Perfect. That's good to know. Let's move on to maybe sleepiness, kind of the opposite, but connected obviously to sleep disorders that they, they talk about excessive daytime sleepiness. What exactly is that?

Dr. Ron Postuma (24:33):

So basically, what that means is you fall asleep when you don't want to be and it's during the day. Okay. And so, there's a couple of, there's many, many patterns that people will get. So, one of the commonest is, is a medication induced sleepiness. So especially if you take you really big doses of Levodopa say three times a day, I have many, many of my patients to say I take the pill and

half an hour later I just have to sleep. I have a 20 minutes sleep and then I'm okay. That's very common pattern. There are also the circadian rhythm shifts, like, you know, the early to bed early to rise. So, the people falling asleep in front of the TV at eight o'clock. Okay. That's a different type of sleepiness as well. And then there's people there, a lot of people who have general sleepiness are just generally sleeping period. So, we think like I mentioned earlier, I think, Oh, it's because I had a bad sleep last night. That's why I'm sleeping today. But if you are in fact look at people who were sleeping, they're sleeping 10, 12, 14 hours a day, it's an overall change in their sleep drive and they, they sleep like a rock, but they just need tons of it.

Dr. Soania Mathur (25:34):

And is that due to the Parkinson's disease specifically? The way it's affecting the brain.

Dr. Ron Postuma (25:39):

It can be. And that usually when it's, when it's due to the Parkinson's itself, it's usually a little later in the disease. So, after you've had it for a few years for example those who are memory troubles, for example cognitive memory troubles associated with Parkinson's, which tend to happen when you're old. They're all sleeping almost you know, so it has to do with sort of a general brain issue when you're sleeping 14 hours a day. Okay. If you're, if you've had Parkinson's for three hours and you're really, really sleepy all the time and you're cognitively perfect and you're relatively young, usually that's medications.

Dr. Soania Mathur (26:16):

And what other things could cause daytime sleeping as other than medications? Like I'm thinking along the lines of breathing problems and that sort of thing.

Dr. Ron Postuma (26:26):

Yeah. So, there's always a question. So, the sleep apnea comes up very often when, when we talk about a sleepiness and to what degree is it a problem in Parkinson's disease. And so, sleep apnea means you basically your, your airway gets blocked, you stop breathing. So, your brain you up. And this can happen a hundred times, 200, 300 times a night. And in the general population, sort of people that don't have Parkinson's, that's a very common cause of sleepiness. What's weird about Parkinson's is that it doesn't appear to be a common cause of sleepiness at all in Parkinson's disease. And so, in fact, we, we've tried to look as many times as people look again and again, they look at people who have apnea people who don't. And the apnea people are no more sleepy than the people who are not. So, it was really something strange about that.

Dr. Ron Postuma (27:12):

Now you could spin a whole bunch of things. Right, of course if you are, you know, somewhat overweight, particularly if you have a lot of weight on your neck, if you're a lot of abdominal

weight, which is most, which is not most Parkinson's patients, but there are definitely Parkinson's patients who are like that and you've had out for maybe 40 years and now you're sleepy and you got Parkinson's. Well has nothing to do with the Parkinson's. You've had apnea, fixed the apnea and you might get better. Okay. But if you are, you know, relatively thin and you've got Parkinson's and you're getting sleepy now and you were never a snore and you never stopped breathing, I don't think it's likely that apnea is playing a role.

Dr. Soania Mathur (27:52):

And what about what we hear sleep attacks, what are these exactly and how common are they for,

Dr. Ron Postuma (27:58):

Right? So, sleep attacks essentially mean that people are falling asleep almost instantly. And this came up a lot in the report very long time ago, particularly with the dopamine agonist medications. So that's like the private packs on the red ticket teen. The ropinirole is when people particularly are starting those medications. The sleep system is very sensitive, and they can fall asleep just like that in one second. And this has obvious major implications if you're driving. In reality, it's relatively uncommon to that, that it happens just like that when you talk to people, most of the time they're saying, I felt a little sleepy, I was fighting it and then I fell asleep. Okay. And so, what I often did, this has big implications for when you're driving. So, if you are sleepy and you are driving and you have Parkinson's, your brain is not like another person's brain in terms of ability to fight sleep.

Dr. Ron Postuma (28:53):

You have to stop, you have to stop instantly. And even if that means pulling over the side of a freeway, I would probably rather do that than fight sleepiness while driving. Because if you're fighting the sleepiness, particularly if you're on medications, you do not have the power to resist it. You will fall asleep without realizing it and you'll kill yourself or somebody else. So, pullover cat nap it for two minutes. Usually that works. And then just get out, run around and try again. If you feel sleepy, pull over again. And a lot of my patients who have this will say, okay, I'm not sleeping. I'm not driving. And the first hour say after I take this pill, because I know I always get sleep. Schedule your day around times when you know you'll be well

Dr. Soania Mathur (29:34):

That's great cautionary advice for sure. Cause you're right, it could really impact you in a very negative way if you were to continue driving like that. One of the questions we got is how can you tell the difference between excess of sleepy but daytime sleepiness and just the regular fatigue that we get with Parkinson's? Is there a word?

Dr. Ron Postuma (29:53):

It's not. They can be mixed up with each other. Okay. But probably the simplest way to tell they're not the same thing at all. Okay. First of all, fatigue, the physical fatigue of Parkinson's disease and the sleepiness of Parkinson's. Since these should not be considered. So, you can have both, but they're not the same thing. Okay. And what I usually just ask is if you sit quietly in a chair, do you instantly fall asleep? If you do, then you have sleep, then you have somnolence. Okay. If you're not actually falling asleep, then you're feeling sort of mental fatigue, physical fatigue, totally different phenomenon.

Dr. Soania Mathur (30:24):

Right? Oh, that makes sense. So, what can we do, what can we do as patients when we have this excessive daytime sleepiness? Is there anything that,

Dr. Ron Postuma (30:33):

So, I must say this is one of the harder ones to fix. So, what you can do is what I mentioned earlier, the, the bright light is probably, there's now a pretty good trial demonstrating that it can be useful. And this is particular. If you're a bed-bound or at home all the time people in, in long-term care facilities, they can often be very dark and very gloomy places. What I would do then is I go by one of those light boxes. You know, those are really, really bright 10,000 Lux light boxes. You get it for a hundred bucks, something like that. And you just have that around and you, you don't look into it directly. You just have it in the room many, many times. You, you just put that light box, say next to your book when you're reading and it's, it's shining.

Dr. Ron Postuma (31:17):

Like if you're sitting, you know, at this sort of distance or in front of you, this, this, this just shining on the side of your face. And that helped quite a bit. Get good exercise. We didn't mention this with insomnia, but there's actually now just published a really terrific study demonstrating that vigorous exercise is so good for sleep. So, it, it, it, what exercise does is it gives you the restorative, really good quality sleep that you're not getting in Parkinson's disease as well. And so I, I tell my patients exercise every day hard enough so that you're sweating your sleep quality will, that is probably the most effective thing we have for sleep quality and that it's, so obviously it'll affect his insomnia as well, but it also should affect someone's.

Dr. Soania Mathur (32:09):

And is there a time of exercise? I've heard timing. Exercise is important when you're trying to,

Dr. Ron Postuma (32:15):

Yeah. So, if you have trouble falling asleep, you don't exercise a PM. Okay. Because when you exercise for somewhere between two hours and say up to six or seven hours, you may have difficulty falling asleep and everybody's different. I mean, I can't exercise at eight. I'll be up till

three other people can go to exercise at 10 fall straight asleep. So, don't worry about it too much. If you're falling asleep, no problem. This is not an issue. Generally, we try to do the exercise during the day if possible. What about coffee? Caffeine in general. So, it's very obvious that coffee keeps everybody awake at some level. And so we've actually done studies on coffee to see whether it helps. It's, it's not that obvious. So, what I think probably what coffee does is it's a nice, good short-term boost if you're, so I'll often tell my patients, okay, you know, you're always falling asleep at nine.

Dr. Ron Postuma (33:08):

You have to go for dinner, you want to stay awake, just have a coffee, you know, at 6:00 PM. Okay. So, you can stay awake for that dinner, that time. But you don't need to make a habit of having coffee every day at 6:00 PM to keep you awake after. If you do it every day, it's not harmful to you. It's not harmful. It just stops working. As a weak agent now, you can certainly drink coffee. I drink coffee every day. I like it. It keeps me alert, blah, blah, blah. It's no problem. But if you want to keep, make it, keep you awake it's, it's the change. It's an extra coffee or, or a coffee when you otherwise wouldn't have, but that'll probably help during those few hours afterwards. And what about your doctor? Does your doctor have anything in his armamentarium that he can help you out with when it comes to, right.

Dr. Ron Postuma (33:55):

So, there's a few medications. There are some that are coming into clinical trials, which I think are quite interesting and they're not available yet. There's, there's Ritalin, you know, like the kids use for attention deficit disorder. That probably helps. There's a medication called Modafinil, which we don't really know why it works, but it does help keep people awake. Okay. There are some medications that will that we take at night to really drive people asleep. The, the guy, the Xyrem is one of them. It, it's so expensive and so difficult to use that practically speaking, I've, I've used it once in my entire career. But it works. It's very difficult cause it's the date rape drug. It's so people, so it has lots of legal medic ramifications. Right. I hope, I'm thinking of all of them.

Dr. Ron Postuma (34:50):

I've, I may have forgotten some, I must say that most of the time medications for somnolence I don't find particularly effective. And so what I'll often just tell people is, you know, maybe just schedule a couple of naps throughout the day rather than me adding another pill. Yeah. How do you feel about an app? That's a good question. In terms of anyone with a sleep disorder, sleep disruption, right? So, if you have trouble falling asleep, then that's when you need to worry about your naps. Okay. If you're not having trouble falling asleep generally, then you can worry a little bit less. If you are the sort of person who sleeps 14 hours a day, all right. And you're sleeping well at night, then by all means have your naps. It's fine. Try and schedule and make, keep them short. So do like other people do, like, you know, the executives, do you know, the classic business executive who sits at, closes his door five minutes out and then up again you do get, no,

you don't get you lose your sleep drive, you release your sleep drive without getting sleep momentum, without getting sleepy throughout the day.

Dr. Ron Postuma (35:51):

So little catnaps throughout the day, if you're really sleepy, especially when they're planned, it's fine. Go ahead. It's okay.

Dr. Soania Mathur (35:58):

It's okay. Okay. That's good to know. Let's move on to REM sleep disorder. Cause that's something that people have been asking about the acting out of dreams. Can you explain to everyone what REM sleep behavior disorder is? Exactly.

Dr. Ron Postuma (36:13):

So, if you don't have Parkinson's and many of you don't have Parkinson's as well. We have a normal system whose job it is, is when we dream to keep us paralyzed. So, when you're dreaming, you're kind of in an almost wake state. It's sort of this, if you look on a sleep study, it almost looks like the person's awake, but you're having all these vivid and active dreams and it's an important stage of your, of your sleep, probably for consolidation of memory and motor training, et cetera. But the system that is supposed to keep you paralyzed is affected in Parkinson's disease. And so now you're capable of acting out your dreams. And so classically, this'll be during the REM periods, which are usually later in the night. So, you know, four in the morning, five in the morning, that sort of time whatever your dream is, what you do now, it's not walking. You can't walk during these episodes. But it's usually thrashing around talking, having a conversation everything, you know, everything that you're dreaming. So, you know, people smoking a cigarette or singing a song, giving a lecture, and you're unaware of it if you're the patient yourself, unless you happen to wake yourself up. But if you sleep with someone, they'll tell you all about it. And so, it's, it's, it's quite a funny sort of interesting kind of problem.

Dr. Soania Mathur (37:30):

What's the danger of it though, if you're

Dr. Ron Postuma (37:33):

Right. So, the only danger of it, it doesn't really affect your sleep very much. Obviously, you didn't wake yourself up. If you're screaming in the middle of the night from a nightmare, you can actually wake yourself up from your own screaming or you can punch the wall and that'll wake you up. But most of it's really, safety is the only issue. And so, you know, if especially if you're having intense agitated dreams, like you're fighting someone and you're sleeping next to someone and you're punching that person, you're really going to punch that person or falling out of bed. So, one thing, you know, if you tried to get up and go to the bathroom cause you had to

pee and you lost your balance and you fell, that's okay. That's it. But if you fell out of bed, you don't know why that's probably a REM sleep behavior disorder.

Dr. Ron Postuma (38:17):

Maybe once, maybe not. But if that's a repeated pattern of you, you're probably having a dream that you're running and then you're like start moving and you throw yourself out of bed for example. Right. So that's the danger. So, if you're doing it and it's, and you tend to have nightmares and you have to be pretty careful about what you do and so many sleep apart. So, they don't hurt their spouse keeps sharp objects away from the bed. Don't have a bed that's four feet high off the ground cause that's a long fall. I often have patients who are concerned about what to do and I, and, and they're concerned about its effective sleep and I say, well, if you want to cure it, and then I put here in quotation marks, it's not fixing the problem at all, but really you can manage the consequences of REM behavior sort of perfectly well if you have a mattress on the floor with no sharp objects cause they only consequence of behavior behaviors is injured.

Dr. Soania Mathur (39:06):

Right? Just certain medications aggravated. Is it seen more as with the influences?

Dr. Ron Postuma (39:12):

Yeah. Yeah. So, the classic group of medications is aggravated or the antidepressants and basically almost every antidepressant can do it. Antidepressants have this side effect. It's not a bad thing actually. They're kind of motor activators. They activate your motor system directly and so they're a very common trigger of more movement in the middle of the night. And so, if you're on an antidepressant, you didn't really need it and now you're acting out your dreams, then maybe you can get rid of it.

Dr. Soania Mathur (39:38):

Other than the safety precautions, is there a treatment for RBD?

Dr. Ron Postuma (39:43):

So, the melatonin, I mentioned it earlier, that's what we usually do first because it's so safe. It's so easy to use. And we'll, I'll only do it if it's bothering a person or maybe the person has Ramses behavior disorder and they're having a lot of insomnia and they're kind of sleepy during the day. Maybe I'll say, well, let's try and get two or three birds with one stone, so we'll use melatonin. In that case, the one that really works is the one I mentioned earlier, clonazepam. But I really try not to use that because it makes you sleepy during the day and therefore, you're a little less cognitively alert and actually also can increase risk of falls because you're sleepy as well. So, I will definitely use it if, if the situation is dangerous and if it's not dangerous, I try, try not to treat RBD, the rescue behavior sort of in general actually if I can get away without it.

Dr. Soania Mathur (40:27):

Okay. But there and I think this is an area of interest for you. There's been studies that have shown that RBD can be a prodromal marker for Parkinson's disease. Can you explain what that means? What the studies have shown?

Dr. Ron Postuma (40:40):

Yeah, so, so it turns out that, so we think of Parkinson's diseases as motor disease. But if you look at the way Parkinson's develops, it doesn't develop in the motor system at all. And so most of the, we think that in most people that starting either in the olfactory areas or down in your, in your gut area, and then it kind of walks up your brain and it goes into the areas of the brain STEM that are involved in relation of your sleep and some of the mood issues as well. And then only really at, at, at these later stages, does it get the motor system? Now this is variable. Everyone has a different, okay, some people go straight to the motor system first, I think. But the idea is that therefore it's targeting the sleep areas before it even targets the motor areas and especially this RMC behavior disorder.

Dr. Ron Postuma (41:26):

So, we now know that people who have REM sleep behavior disorder now not just walk, sleep, walking, not just sleep talking. But if you don't have Parkinson's yet but you have a REM sleep behavior disorder, you have Parkinson's and so 80 to 90% of people will end up getting either Parkinson's disease or the what's called dementia with Lewy bodies, which is kind of a Parkinson's, Alzheimer's combination. And almost everybody gets this, and it can be 10, 15, 20 years before. So many of you are on the chat now or your spouses in particular goes, oh my goodness, he was doing that five years before the Parkinson's ever started. And we hear that all the time.

Dr. Soania Mathur (42:09):

Is there any marker that's as strong as that?

Dr. Ron Postuma (42:14):

Yeah, no, it's, it's by far the strongest. And so there, there's some suggestions that the other sleep disorders might be slight risk factors. So restless leg syndrome, not when you're 20 years old and restless legs, but if you start getting restless legs syndrome and you're 65 and you've never had it before, that might be a slight risk factor, but it's kind of doubling your risk. Excessive daytime somnolence. So, people are falling asleep all of a sudden at the age of 50 and they never used to that's a risk factor for Parkinson's maybe, but kind of one and a half fold. And insomnia might be a, we don't really know, but it probably wouldn't be on the order of one and a half or two-fold. REM sleep behavior disorder is 50 or a hundred-fold. So, it's really quite different. Yeah.

Dr. Soania Mathur (42:58):

And how has, knowing that about REM sleep behavior disorder, how's that going to affect our research when it comes to looking for better treatments or,

Dr. Ron Postuma (43:05):

Right. So, this is a big area of research because you know, realizing what I just told you about how the Parkinson's spreads around the brain, that kind of means that you had Parkinson's in your brain maybe 10 or 15 years. Okay. Before you ever actually presented with the disease, particularly those who are older. I think it's really like that and we have all these great symptomatic treatments for Parkinson's, but you have nothing to slow down the underlying degenerative process of Parkinson's disease. And we've been working very hard on getting that. Maybe one of the reasons is, is because, well, maybe it's too late. It's already been 15 years. If we could go back 15 years in time and catch you, then maybe some of these agents that have failed in the past would be would work if we would actually prevent Parkinson's from ever happening. So, there's a lot of research on this trying to find, you know, trying to get the, trying to get ways to diagnose Parkinson's early as early as possible, and then maybe try some of these, these drugs that are being developed in the early stages.

Dr. Soania Mathur (44:09):

So, they're kind of being looked at in parallel first finding the patients that would need the treatment that's trying to be developed I guess in that way.

Dr. Ron Postuma (44:17):

Yes, exactly. Yeah. So, it's, yeah, there are treatments that are being developed and they're being tested and there's always a few going on. There's some that are quite interesting. The, this nucleon based therapies are by far the most interesting, I think for everyone who's in the field. In other words, fixing the underlying protein and there may be ways of getting that fixed now. And so these are our in trials right now on Parkinson's and now it's just trying to get the companies about these products to try and get them to use them earlier. And these people who don't have Parkinson's yet. And it's just, it's trying to get them as hard cause these are, you know, these are multimillion dollar. That's that they have to make every time you worry about, you know, whether it's going to work or no,

Dr. Soania Mathur (44:59):

You have. So, and the last category you mentioned earlier was the periodic leg movements or the re I guess most people's blanks. Yeah. Yeah.

Dr. Ron Postuma (45:11):

Syndrome basically is as you're trying to fall asleep, generally you feel that there's this hard to articulate discomfort in your, usually in your calf, sometimes elsewhere, and you kind of have to move as soon as you're moving, it goes away. But as soon as you stop moving, there it is again, this creepy crawly, achy, unpleasant sort of symptom that you get. This is not seen very often in early Parkinson's disease, but we see it relatively often in later Parkinson's disease. It has a very strong ethnic predominance. So, Caucasians get this by far more than just about any other ethnic group. And it happens later on Parkinson's disease because you treat, so let's ignore Parkinson's and completely, okay. So, I, I have restless legs. I'm 30 years old. I treat it with the same dopamine agents that are used for Parkinson's disease, even though it has nothing to do with Parkinson's at all.

Dr. Ron Postuma (46:03):

But it happens to work. And if you, in fact, if you treat these people with dopamine agents around the clock, they start getting restless legs worse. And so, what happens is this phenomenon called augmentation, that's the name. So, what happened if you might have had the tendency towards restless, but you never had it, and now you've got Parkinson's and we started treating your Parkinson's appropriately as we should. But this, this is around the clock. Dopamine therapy. And so now your restless sites that you barely noticed starts to become noticeable because we augmented your restless legs into existence. And so many people notice later on that this becomes a problem. So, what do you do? It's hard to do much about it, to be honest. There are a few medications, so you know, you can treat with dopamine, but right. You need that for your Parkinson's.

Dr. Ron Postuma (46:52):

So, you don't want to mess too much with your Parkinson's treatment. Trying to get the restless legs under control. But clearly if there's a hole at night you know, the same thing that I talked about, insomnia and maybe a plug the hole with dopamine therapy or a few other medications that one can use the Gabapentin, the GABAA medication. So, there's pregabalin and Gabapentin that can help a little bit. But it's a tough one to deal with. A lot of people notice this worse than the summer. And so, if they can keep their calves cool, just stick their legs out from under the covers that often help going for a bit of a walk and help, but also can make you tired. So, it's a tough one to, to do anything about to be honest. So, if you or your care partner suspect that you've got something going on with your sleep what should be their next step?

Dr. Ron Postuma (47:38):

What do you recommend people do other than the hygiene stuff we talked about? Right. So, I mean, you, you, you, so it's, it's difficult right? Cause there, they're totally different problems. And so, if you have insomnia, you should make sure you're getting a whole lot of exercise. Don't stay in bed if you can't sleep. If you need medications, ask for them. Okay. If you have somnolence, watch out for those peaks in the doses. Is that the problem? Are you are, are you snoring a whole lot? In other words, you had happened all your life and it's a coincidence. Are

you getting enough exercise? Are you getting enough light? If you have REM sleep behavior disorder, can you ignore it or can you just live with it and you have restless leg syndrome, you know, get, get your exercise sleep as much as possible.

Dr. Ron Postuma (48:21):

Definitely talk with your physician about this. Moving to sort of, specialists are generally getting pretty comfortable with these issues. You know, it's not just, we call us those movement disorders, but most people are really know how to treat Parkinson's, are getting pretty good at treating all of the non-water aspects. And like, not just this, but the constipation and the, and the bladder dysfunction. They, everything else has massive list and so most good Parkinson's specialists will have a couple of tricks up their sleeve as well. And what about sleep studies? Did they study aunts? Yes. When you go for a sleep study, if your physician refers you for a sleep study. Okay. So, what can, if it's not really clear what's going on with your sleep, sometimes they'll, they'll your physician might order an overnight sleep study. In other words, measuring the way that you sleep.

Dr. Ron Postuma (49:06):

It's generally useful for REM sleep behavior disorder if you're uncertain. Although to be honest, I almost never ordered, cause if you give me a good sense of a REM sleep behavior disorder, you have Parkinson's, we're almost never wrong. Cause it's so common in Parkinson's. It can be good if you think you might've had apnea all along. Most of the time an overnight sleep study is not really required. Most of the time we just see, oh yeah, you got Parkinson's, your sleep looks like a total mess. Which it does. Unfortunately. It's very, like I said, the sleep systems are deregulated and so often there's a lot of wakefulness, a lot of, you know, stages aren't, are, are, are unstable, et cetera. But there's not much actionable on that. So, most of the time I don't order the sleep studies, honestly especially I do sleep and it's very rare that I actually order one.

Dr. Ron Postuma (49:54):

I've often wondered how it even make sense when you're in such an artificial environment that you can't do it for insomnia. So, the classic of insomniac patients is, you know, as soon as they get a sleep lab, oh my goodness, they have a 10-hour beautiful night. Right. Cause they've taken away the associate, they're no longer in that horrible torture chamber bed. They're in a different bit and they sleep fantastically. So yeah, it's useless for insomnia as sleep study. But there's a few questions that have been coming through the chat and a couple of

Dr. Soania Mathur (50:27):

Them are about THC and CBD for sleep and feeling on that

Dr. Ron Postuma (50:33):

Have good studies. It's so difficult to study. CBD. We've been trying for years and, and paradoxically, the legalization that we have in Canada has made it worse because now wherever we can just go get it. And, but getting, you know, a stable supplier is almost impossible. We really don't have good science on what CBD does. Firstly anecdotally, okay. And only I know from talking to my patients, like I said, it's legal in Canada, so everyone just go and get it. People do find often that it, it does, it, it, it can help insomnia and particularly the, the little bit more CBD rather than the THC can cause hallucinations. Right. And that's a big problem in Parkinson's disease. But the CBD predominant preparations are probably relatively safe. I have no real science to back that up, but they're probably relatively safe. They have my patients do notice that insomnia is a big issue. It can help that some people around see behaviors that are graded a bit better. It's not going to help somnolence. Right. Cause that's in fact, that's what it's doing. And it's a CBD at night. It's, you know, for anxiety, discomfort, sleep. I think it probably helps, but again, don't quote me on that because it's not been studied.

Dr. Soania Mathur (51:54):

What if someone's on duodopa?

Dr. Ron Postuma (52:00):

So duodopa is so those of you don't know, it's, it's a pump that provides a Levodopa into the small intestine directly and it keeps the people, it keeps the levels of the doper safe. Sorry, a safe, stable throughout the day. Most of the time people unhook their Duodopa at night. And so you may find that your sleep gets worse because of all the things I just talked about. Right. so maybe in many cases when that happens, we're using the, if not the Duopa that may be a cinema CR controlled release or just regular cinema throughout the night to help you sleep. So, if you're taking off the Duopa and then you can't sleep, you may need send it out throughout the day. Sorry, throughout the night,

Dr. Soania Mathur (52:42):

Throughout the night. And cognitive behavioral therapy, you mentioned it when you were talking about sleep hygiene, but is there a role for formal cognitive behavioral therapy for patients?

Dr. Ron Postuma (52:52):

Well we did a little study of it, but again, it was a very small number of people. It, it did appear to be useful when, when he did it, there haven't been pretty good studies. It is the primary therapy for insomnia and the general public, if you can't fall asleep, I think is probably something to use. If you can't stay asleep, I can't tell you what's going to work. But you certainly can try it. You can get online CBT now. There are a few companies that run these things. It's like \$200 or something like, so it's not that expensive really. If you compare that to all the medications that you'd be take in all this time and, and it's certainly worth the shot. But yeah, again, the studies on CBT in in in Parkinson's are relatively limited.

Dr. Soania Mathur (53:43):

Okay. So, we're getting sort of towards the end of our time, but I really want to ask you are there any clinical trials underway that we should be looking for that are showing promise for a drug or treatment that will help with sleep disorder? Anything coming down the pipe?

Dr. Ron Postuma (53:58):

Yeah, there's a few there. So, there's one thing that's got me kind of interesting is this class of medications that deal with orexin or hypo cretin. This is the this is the famous abnormal neurotransmitter of, of narcolepsy. And people with narcolepsy have this thing where they fall asleep all the time during the day, and they have unstable sleep at night. And so, they're flipping in and out of their sleep stages at night and they're falling asleep all the time during the day. And I spent some time reading sleep studies and I would read some Parkinson's sleep studies tend to go before that shirt looks like a narcoleptic sort of a sleep pattern. And people have and thought that there's just a bit of a narcoleptic type of sleep pattern in Parkinson's disease. Again, maybe related to degeneration of these sleep regions. And so, these are being studied right now. I'm finding that quite interesting. I think there's ongoing studies of, there's some CBT studies that are ongoing. There are some exercise studies that are still ongoing. There are a few other drugs. I can't, I can't list them off the top of my head, but you know, it isn't an area that pharmaceutical companies are interested in dealing with. So, you know, you'll, you'll see them come up, keep your eyes.

Dr. Soania Mathur (55:08):

There's hope. That's good. And your own research. Dr. Postuma, do you want to mention anything that you are working on right now that is interesting? Yeah.

Dr. Ron Postuma (55:19):

Yeah. Right now I'm working. So what I really pivoted to doing most of my time spending is, is working with these REM sleep behavior disorder patients trying now to really figure out who's going to get Parkinson's, who isn't going to get Parkinson's or when they're going to get Parkinson's and try to get the, these, these agents in clinical trials. That's really what I want to be spending my time on as much as possible.

Dr. Soania Mathur (55:43):

Yeah. And one last question from the audience that they really would like address. That's DBS and sleep. Is there a problem?

Dr. Ron Postuma (55:52):

Yeah. And so, DBS probably helps sleep most of the time. Okay. Now it depends a little bit on where exactly those leads are. But it's exactly, analysis is just like you want to fix the domain therapy at night because that's what's causing insomnia. DVS is, it's just electric Sinemet. It's, it's not really doing anything very different than the Levodopa does. It's just doing it with a battery. Right. And so, most of the time there is improvement in the sleep when you use DBS or continuous dopaminergic or a treatment during the night should help. But on average now, one of the complications is that sometimes the DBS electrodes aren't quite in the right place and people get a little impulsive, for example, or can have judgment difficulties if, if it's, if, if, if the lead is, is what we call two ventral. And then of course there's people could be completely screwed up because you're eating all night or things like this. But most of the time if it's a good DBS procedure, your sleep should improve a little bit.

Dr. Soania Mathur (56:51):

Well that's good to know. Any, anything else you want to say about how important sleep is for patients? Self-care routine? Any other parting words of advice?

Dr. Ron Postuma (57:00):

Yeah, so if you have to do one thing, get exercise. If you're having trouble sleeping, you should be tired from exercise out of breath and sweaty once a day, whatever it is. There's no magic exercise. But try and find it. Your, your quality of sleep will improve. You should be less sleepy as well during the day. That's the one thing I would tell you that you can do yourself right now.

Dr. Soania Mathur (57:23):

It seems, it's so interesting. All problems seem to lead down to that one thing that we all seem to hate to do it, but you're absolutely right. So, thank you so much, Dr. [inaudible] for costumer for everything, your expertise and your advice. It's so greatly appreciated. We can't thank you enough for that and thank you everyone for joining us today and I hope you found your time with us. Helpful and educational. We'll, I'll be sending you a link. I know there's some questions about this talk being available afterwards and we will send you a link so you can share the webinar with other people. And always remember I say this sort of at every end of every webinar, but we don't have control over our diagnosis. But how we face the challenges that this disease brings into our lives really is our to ours to determines a focus on optimizing your quality of life, educate yourself, empower yourself, and also celebrate your daily victories. Thank you very much. Sure.