



YOPD Council

Sleep, Light, Nature, and Parkinson's

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Davis Phinney Foundation

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

Everyone's hopping on, I'm gonna give you all a second to get on. If you want to say hello and where you're calling in from, we would love that, you can just click the little chat icon at the bottom of your screen and say hello and let us know that you can see and hear us. Who's gonna be first? Who's it gonna be? Ahh Julie from Colorado. Warwick, New York.

Great so good to see you all. It's great to see you guys. My name is Melani Dizon and I'm the director of education and research at the Davis Phinney Foundation and today we are here for our YOPD Council monthly webinar. We're going to be talking about Sleep, Light, Nature, and Parkinson's. A super important topic. I don't know anybody who lives with Parkinson's where sleep is not some sort of, they have some sort of relationship with it, maybe they sleep too much or sleep too little or never sleep at all, so we're going to talk a little bit about those things, and some of the things that we can all do to improve our sleep. I'm gonna enable the transcription.

So, if you see the closed caption on your screen. Then it's working. If you don't want to see it because you don't like the words on your screen you just click the little arrow on the bottom dashboard where it says like transcript or CC for you. And then you can say hide subtitle, and they will no longer be on your screen. If you want to chat, feel free to do so. You just click the little chat icon at the bottom of the screen. Tell us hello, leave comments, ask questions, anything that you want to do in the chat is great.

Leigh and Jackie are in the background from Davis Phinney Foundation, and they will be providing any links and comments throughout the session today. When it's over I will provide recordings, audio, video, also the transcript and whatever show notes we have.

If we talk about some things in the chat box that are a link and you don't want to write it down or you miss something don't worry, we will provide all of those in the show notes afterwards, so you don't have to worry about missing anything, we'll make sure you get it.

And I have, oh wait, I do have a little poll I wanted to share that I completely forgot about. But I'm going to share that at some point, and I just want you to take it so that it's not really a poll, it's a feedback. So, if you have ideas and topic ideas you'd like us to discuss, feel free to fill that out, any comments you want to share with us. It's all anonymous.



Feel free to share it, and we will discuss it with the group and see what we can come up with. It's really nice to have people share what's on the top of their mind and what issues are their biggest challenge.

Okay, so before we get started, I'm just going to have each of you for those people who are new to our monthly council, we might all be unfamiliar faces. So, if you could just say hello, who you are, how long you've been living with Parkinson's, and why you like being part of this council, that is great, I'm going to start and then I'm going to end with Gaynor who's going to be sort of leading this session today. So, Amy, can you introduce yourself?

Amy Montemarano (YOPD Council Leader, Davis Phinney Foundation Ambassador):
Hi, I'm Amy, I'm in Philadelphia, Pennsylvania, I'm 54. I was diagnosed six years ago at age 48. And I've been on the council I guess for a year and these guys are kind of like my cyber besties at this point it's really fun.

Melani Dizon:
Great. Thanks. Heather?

Heather Kennedy (YOPD Council Leader and YOPD Women's Council Leader):
I'm trying not to get emotional because I just came from the WPC and getting to see you all here today, all at once in one day is a lot of good stuff. So, thank you very much. And I love to see everybody's faces pop up and thank you again for my necklace, Amy is very creative with her necklaces. I've had Parkinson's for approximately a decade, I think I probably had for 15 years probably looking back you know you start to remember all the symptoms over 10 years. I'm Heather Kennedy. I live in the Bay Area. And I love to pop off about the non-motor symptoms of Parkinson's. That's my favorite thing to do.

Melani Dizon:
Thanks, Heather. Steve? You're muted sorry.

Steve Hovey (YOPD Council Leader, Davis Phinney Foundation Ambassador):
Hi, Steve Hovey. I live in Saratoga Springs New York. I am 64 and I was diagnosed with Parkinson's at 50 so about 14 years ago. I think the reason that I love being on this council is I think the only way we learn is, I think we learn best by sharing experiences and I think that's what we all get as colleagues, you know, with this council and what we're hearing back from the people that join in.

Melani Dizon:
Great, thanks. Kevin?

Kevin Kwok (YOPD Council Leader, Davis Phinney Foundation Board of Directors Member):



Hi everyone, I'm Kevin, I'm the refugee that lives between Boulder Colorado and Ann Arbor, Michigan, where I'm dialing in from right now. I've had Parkinson's now for almost 12 years, I was diagnosed at age 48.

And for me, one of the biggest things which I like about this particular Council is the unscripted, unfiltered, unadulterated sort of kitchen confidential version of how we talk about our disease. I think I've learned so much from all of you. And I also frankly feel like just the candid conversation allows us to go into places that oftentimes, when we attend sort of sanitized seminars, we don't go as deep, so you guys mean a lot to me in terms of, I like Amy's term cyber bestie.

Melani Dizon:

Great, thanks. Ok Gaynor?

Gaynor Edwards (YOPD Council Leader, YOPD Women's Council Leader):

I'm Gaynor, I was diagnosed eight years ago, and I love the whole idea of being cyber besties, that's the T shirt phrase of the day, surely, and unscripted oh god yes. And so, and that's definitely going to be a case in point I think with this one.

And I'm quite sleepy myself at the moment, I'm a bit, you know when you get a little bit jittery, because you are properly sleep deprived, I think I'm going through that at the moment, so it could be an observational lesson for us all as well. Let's see how it goes. And if I drop off, I have not actually fallen asleep in a webinar before, that we have on screen.

Melani Dizon:

That'd be amazing.

Gaynor Edwards:

Whereas the audience of course you know we make allowances for that. And so, what should we do first? I think might one of my presenting symptoms, and I think it's very common as a presenting symptom is insomnia, should we start with that, maybe?

I think probably five years prior to diagnosis, I was suffering with insomnia, and as you do, you put it down to stress. And it's not until you get diagnosed and you read other symptoms and you go, aha, that's what that was then. Anyone else like to chip in on the first time they became aware, was it a reason to get into the doctor in the first place? Kevin?

Kevin Kwok:

Yeah, I could tell you that my dealings with sleep problems have evolved over a period of time, even pre diagnosed Parkinson's. You know I was one of those individuals that actually didn't need much sleep when I was younger. I was one of those really annoying night owls that could stay up and watch David Letterman and be up at five six in the morning and going to classes.

And that was the story of pretty much by early days just functioning on three to four hours of sleep and no problem. But I found that there was something has changed over time. I know that and we'll probably talk about medications later on because I think some of the medications that we take can actually complicate our sleep issues. But I have gone from not needing sleep to always needing sleep, always feeling tired and there's a real spectrum of change that happened during that period of time.

I'd love to hear from the panel how they've changed, but for me, if I had to rank the number one symptom that comes about it's sleep, fatigue, and excessive daytime sleepiness. And I think that triad all sometimes tend to get merged. They're not exactly the same and they are different things but they're very interrelated.

So, with that, that's sort of my story.

Gaynor Edwards:

Do you find that the sleep, can I ask the panel, do you find that the sleep issue is that you wake up, maybe four hours into a sleep pattern, or is it a struggle to get to sleep in the first place, or is it a mix of both or has it changed?

Kevin Kwok:

It changes.

Steve Hovey:

I started off with heart having a really hard time falling asleep and that that goes back to pre-diagnosis. And, you know, I just would be dead tired, I would go to bed, and just lay there until like, you know, two, three in the morning and then have to wake up for work at six. Now I fall asleep, but I wake up after, I mean it's almost like on the dot, like four hours after. If I go to bed at nine, I wake up at one, I go to bed at 10, I wake up at two. And it's only been within the last month that I've kind of found a solution that's been working really well for me, I'll be happy to share it at the appropriate time and I mean that works for me, so I don't know if it would work for anybody else but it's, but yeah, definitely changes over time. The other thing that I think is really weird is that I went from waking up at five to four to three.

So, I was getting six hours, then five hours then four hours and I'm hoping it doesn't get any worse than that, I'm kind of in this holding pattern right now.

Gaynor Edwards:

Over what period of time are you kind of losing an hour?

Steve Hovey:

That's been over the last five years. And so, now I just don't fight it, I get up, I go downstairs, I walk around, I go outside on the porch, get some fresh air. And I'm pretty OFF at that time too. But I'm finding that getting up, walking around, taking some medicine, and again, I can talk about that at the appropriate time, but I then go back to bed, I read for a little while, so I'll be awake sometimes for an hour and a half to two hours.

But then I sleep like a baby for another three hours and when it's all said and done, I get my sleep, so that's working now. I'll talk to you about it in a year, we'll see how it goes.

Gaynor Edwards:

There is a theory that people sleep in a sort of naturally four-hour cycle. And then you'll wake up for an hour and then have another, maybe for us like one cycle if you're lucky, I mean sometimes we just have the first one.

Heather Kennedy:

A second sleep you mean? That's a nice, delicious treat the second sleep. When I was young, I was staying at someone's house I was maybe like five and I didn't know what Parkinson's was, but I remember I was asleep in my bed so just picture a little kid's version of this ready? And all the sudden I see by my bed, and I see the person kind of doing this and being really confusing and I'm like, oh, they've turned into a zombie. Mom, Mrs. Smith is a zombie. You're not gonna believe this, I went to bed, and she was fine. She's in my room. She can't move Mom, what are we going to do? And I realized that's me every night now, so I'm Mrs. Smith, every night, I can't move. I wake up stiff.

After four hours, yes, like clockwork and same thing with you, Steve, I wake up a little bit earlier each night, or the second component of this, prior to Parkinson's, and I can always fall asleep anywhere, by the way. The second component before Parkinson's when I couldn't fall asleep, you think about everything you ever did, and said wrong. Remember that dumb thing I did in fourth grade or how I dumped milk on Joey Kaposey, oh my gosh, you know, you're still thinking about that lying there in bed, trying to go to sleep. So, it's twofold and Parkinson's come with anxiety, so we probably get it with all of it.

Gaynor Edwards:

And the panel would now like to extend its apologies to Joey.

Heather Kennedy:

Yeah, sorry Joey.

Gaynor Edwards:

So, what about if you struggle to get to sleep at the start of the night, do you try with kind of you know just going to sleep later cuz I went through a period of just not bothering to go to bed till 2am.

Heather Kennedy:

Yeah, you stay up and you watch the Jeffrey Dommer documentary, it's great, or Jack the Ripper. It's really relaxing.

Melani Dizon:

I just wanted to ask, since all of you have mentioned a little bit about sleep, did any of you have REM sleep behavior disorder? What was your experience with that? Kevin?

Kevin Kwok:

You know it's not been officially diagnosed, even though I've been to sleep labs and have done the official sleep studies, but I've noticing more and more frequent bouts with REM sleep behavior and vivid dreams.

And those have seemed to happen for me not deep in the early part of sleep but when I wake up and fall asleep again my partner tells me that I lash out, and that's usually at 4am, 5am, you know, during that period of time. But I still think that they're trying to figure out what REM sleep disorder really is.

Gaynor Edwards:

I think I chase rabbits. It's like the dog, you know when they chase rabbits, I do that in my sleep, which I think is part of the REM thing.

I think you're right Kevin it's that second cycle of sleep that it tends to kick in. And the dreams, really vivid and, yeah, but if you share a room, if you, you know, go to the WPC or whatever and share a room with a fellow Parkie. You do have to keep an eye on each other, I think.

Melani Dizon:

What about you Amy?

Amy Montemarano:

Yeah, I'm trying to stay awake. I have always been a light sleeper, but a good sleeper. In the sense that I felt refreshed, but I would wake up very easily.

But I have a really hard time sleeping these days, and it's kind of a mix of what all of you have said, and I think what Steve said when he said you're just exhausted, but you can't go to sleep. That's the worst feeling.

And that's how pretty much I am every night around bedtime and then again when I wake up at one and then when I wake up at two then when I wake up at four and then when I get up at 430 but I'm starting...

Melani Dizon:

Oh, sorry, Amy you're cutting out a teeny bit.

Amy Montemarano:

Oh, can you hear me now? I would say that I get a really good night's sleep about every fourth or fifth night and I'm really grateful for that.

And when it comes to vivid dreams I have a very unusual experience, and that is that I am dreaming more vivid and they are always a full-length movie that features Robert De Niro, like in my head. I wish I could remember them because they're really great screenplays. And that's just weird. But it's been fun kind of.

Heather Kennedy:

Robert De Niro's waiting, talking Italian, remember that song?

Melani Dizon:

Heather, I love that song.

Gaynor Edwards:

How fantastic, it's like if you go to the cinema and see a Robert De Niro film and you say guys, I've seen this one!

Heather Kennedy:

You didn't pick one where he's in Brazil right with the ducks... "are your ducks in need of replacing?" where he comes in a man in, in and out man alone...

Amy Montemarano:

No no these are original screenplays in my head. He's usually in the middle, not Taxi Driver young, but not too old. Kind of in the middle.

Steve Hovey:

One of our guests wants to know if it's a young Robert De Niro or an old Robert?

Amy Montemarano:

Did you hear me? I think I'm cutting out again. Middle aged, in the middle. Not Taxi Driver.

Melani Dizon:

Oh sorry, Steve were you gonna say something?

Steve Hovey:

Oh yeah when Amy cut out, I was just gonna say that it's the unfortunate thing is like it's, we're kind of like making light of it, but, it drives your day, you know, with Parkinson's if you have a bad sleep, your day is shot, you know, on the really bad days, and you kind of go through stages and I'm on a roll lately but a month ago I wouldn't have said the same thing.

I mean like you want to work out, but you have no energy, you know, you want to like, I tell Nancy, oh yeah, don't worry about I'm going to fix that burned out bulb, I gotta get the ladder from the basement and it never happens you know, but with sleep it's like, all right, give me the to do list, it drives everything.

I don't know how people, I mean I'm fortunate now that I don't have to work, but I don't know how people like Amy I know you're still working correct? I don't know how you do it.

Amy Montemarano:

Yeah. Just do what you do, do you have to do. Just do it. Yeah. It's hard though when you have to be somewhere on someone else's time for sure.

Heather Kennedy:

Yes, specifically on someone else's time, that's so important to note, because there's a regular clock and then there's the Parkie clock. My friends are always like oh I didn't know you're going by Parkie time this time Heather and I'm like, it's always Parkie time.

Gaynor Edwards:

Yeah, it's always Parkie time.

Kevin Kwok:

I'd like to pick up on what Steve said about it drives everything. You know for me for Parkinson's symptoms, it's not just you know the dystonias that I feel come with a bad night's sleep. It's the non-motor symptoms that are really get affected.

I mean my ability to think straight, to communicate, just everything is tied. The non-motor symptoms are all related to sleep. And I think Heather, you said earlier that you've been very outspoken about non motor symptoms. My belief is that it sleep can be improved, you can actually deal with a lot more of your symptoms.

Heather Kennedy:



Do you remember when Shell Bell gave her on talk about how sleep was the biggest bubble of all, she's like sleep, exercise, medication, you know, friendship was his biggest. That's important. Yeah.

Kevin Kwok:

I think for young onsets, we're still trying to function in the regular world. And the sleep becomes destroyed, so all the interactions, work, friendships, relationships, all get affected because of lack of sleep, and daytime fatigue it's just, they're all so intertwined.

Gaynor Edwards:

And it becomes more stressful doesn't it the whole time because I'm thinking I can't sleep it's going to ruin my day tomorrow, I've got to do this, this, and this, I've got an early start yada yada yada.

Kevin Kwok:

And then of course you don't sleep as well.

Gaynor Edwards:

Exactly, exactly. Then you're on that that downward spiral aren't you. Although I started to use it or try to use it the other way and I just came to the theory after so many years of insomnia that I was going for a meeting, and I am too tired physically too tired to be stressed. And once I've kind of put that mindset, I think it helped.

Amy Montemarano:

Yeah, I do that too Gaynor. You get to that point, after which, you're kind of just buoyed by your fatigue.

Gaynor Edwards:

Yeah, exactly. You don't have the energy to worry about it anymore. It's just go with the flow really.

Amy Montemarano:

I also find that even just little micro naps really help a lot. And I have two couches at my office at work. I can choose which one, one's little, one's long, but just you know 5/10 minutes on that thing, and the day gets immediately better.

Heather Kennedy:

Our presidents used to do that.

Gaynor Edwards:

Yeah, and Mrs. Thatcher used to do apparently. I'm not sure if that was good or bad, I'm not entirely sure.

Melani Dizon:

Steve, I wanted to talk a little bit when you said that you know you don't want to exercise, and it's obviously it's like a catch 22, you exercise, you actually sleep better or potentially right? Depending on when you exercise, some people are very sensitive to the exercise at night there's no way they can sleep. And some people it's too hard for them to get up in the morning, so it's very variable, but Steve is there anything that you've been doing or trying that will like, you're tired, yes, but you still go out there and exercise?

Steve Hovey:

Yeah. You know, really, I was having a really bad time sleeping. Pretty much this winter and into the spring. And I was letting myself, make, like, well, you know, I've got to get this done, you know I had some you know obligations that I needed to get done. So, I'm too tired, it's either that or work out.

The other thing that's a reality is when I can't sleep, and I'm sure the rest of you guys can relate to this, you can't sleep, your symptoms are worse.

So, it's sometimes like you know, you go to the gym and there's like a bunch of people around, you know, and normally they see you okay, and you're like walking around like a mummy. It's embarrassing. So, I've got to admit that that comes into play too. A) I don't think I've got the energy to work out but it's really kind of embarrassing when you're so OFF, you know, but even before I got on this better sleep pattern, you know, which is great for me, you know, it's still, you know, certainly not what my wife is able to pull off.

I just made myself go back to the gym, so that's become a priority it's like okay, I am going to make, you know, 8:30 - 10 o'clock or whatever it may be today, that's going to be when I go to the gym ride my bike or whatever, no matter how, how I feel.

And it does make you feel better and the other thing, too, that is just, I found extremely important, is just getting outside and now that the weather is nicer, you know, I'll just jump in my car and just go for a hike for an hour, just find some trail in the woods and oh my gosh, it just clears your head and makes you feel so much better just getting outside, you know, being part of nature and sunlight. So those are really important.

Kevin Kwok:

You know why that works, don't you, biologically?

Steve Hovey:

Tell me.

Kevin Kwok:

Well, what happens is you have a gland in the brain, the pineal gland and exposure to sunlight actually produces melatonin which some of us take supplementally, and that helps to normalize the time of days when you should be sleeping or not. So that's what they tell you when you travel internationally for jetlag is to get outside and take a walk and reset your clock.

Melani Dizon:

Yeah, so there's been a ton of work done with light therapy and we're going to talk a little bit about that and see if people are using it, or you know how they're benefiting from it but essentially, you can gain tremendous benefits from exposing your eyes to the sun to the light in the first beginning part of the day as the sun is rising and the same as at the end and anywhere from two to 10 minutes can have a really big impact.

We're going to share some resources that talk all about it and talk about light therapy and would love to know if any of you are using light therapy or if any of our audience members have used light therapy, and we're going to we're going to give everybody a challenge today at the end of this session for a month, that's around this to kind of see what we can do with it, because it not only helps, can help with sleep, but it also helps with blood pressure and many other diseases and issues biologically, so I hope we can get to some of that.

Gaynor Edwards:

This is the vitamin sun, they call it, don't they Mel? The vitamin sun, the morning and evening sun which is your vitamin D release that turns it into serotonin. So, walking the dog is going to help you sleep, a healthier mood, get your vitamin D going, get your melatonin going, kick it all into gear, hopefully. Then you just have to worry about the dog snoring.

Heather Kennedy:

Yeah. I was just listening to a talk by Steve Earle the former pro climber, he climbed El Capitan you may have heard of him. I'm sorry Mason Earle, Steve Earle's a singer. Mason Earle got encephalitis, and is primarily bedridden and he talks now, he has his eyes covered, I don't know if you know this about this particular disease, but you get over stimulated fast, and his whole joy was going outside, taking in nature, lots of sounds and light and movement and he can no longer do that.

But he said for the rest of his lifetime, that is where he goes, that is the sweet spot, that's what calmed him down. And he can prove this vitamin D is true and that getting outside actually raises your health level if you do it consistently because he was, aside from getting this, I mean he was really so healthy so happy. And so, he can return to that place in his mind with those images, and that's really what's been getting him through.

So, nature is invaluable, it's free to everyone, we can always go find a walk, a height, just like Steve says, you know, Amy, Gaynor, Gaynor I know you walk on the beach sometimes. I've seen you send pictures of your dog and Mel you're outside a lot I can tell I know that you're an athlete, like you're amazing. I can tell you you're thin and trim and fit and Kevin I know your lifestyle. So, we're all getting outside as much as we can and that vitamin D's everything.

Melani Dizon:

I want to talk a little bit Kevin because you did, actually, I wrote something a long time ago about nature within the book, *The Nature Fix*, and we talked about, Kevin, your experience in Breckenridge, but I just want to share this really, this great quote from the author Tim Beatley is a professor at the University of Virginia, and the other, the writer of the *Nature Fix*, which is a great book, I highly recommend it.

It's not for just for people with Parkinson's it's everybody, but he says we are hard wired from evolution to need and want contact with nature, to have a healthy life emotionally and physically requires this contact, the empirical evidence of this is overwhelming. Exposure to nature lowers our blood pressure, lowers stress and alters mood in positive ways, enhances cognitive functioning, and in many ways, makes us happy. Exposure to nature is one of the key foundations of a meaningful life.

So, when you're able to do that in combination with the sun. And yes, people with Parkinson's are more prone to melanoma, but you can certainly spend some time a little bit of time outside without sunscreen to let that absorb for 15 minutes or so and then put on the sunscreen, but you can do that and really impact so if you can be outside and in the beginning of the day for a few minutes standing next to a tree all the better.

So, Kevin, why don't you talk a little bit about your experience with that and actually the other piece to look at is in the *nature fix* there's a, like we have a pyramid for food, there's also a nature pyramid. And you can see like what's on the bottom and what is the whole thing that you need on an everyday, weekly, monthly, yearly basis.

Kevin Kwok:

Sure, so for me, you know, I took part in a Parkinson's program, which involved a great deal of being outdoors, this particular Breckenridge experience involves skiing, but just being up there, feeling the sunlight and a blue sky was tremendous. I mean, it just all of a sudden, the world got good right. With all that. So, I'm a high proponent of being outdoors, as much as you can.

And for me, my favorite thing to do is actually combining that with mindfulness. So, if you can find a place where you can actually meditate outdoors and feel the sunlight. To me it just calms everything down, your anxieties, your depressions, your blood pressure, everything becomes normalized.

Heather Kennedy:

Just showing that nature is always right there for us it's always outside the window, there's always a tree that you can talk to. They'll be your friend. No, I'm just kidding. Seriously, it is like the standing people that's what the Native Americans used to say so there's a lot of energy there like a fungus among us, you know.

Gaynor Edwards:

And you can't see too many sunsets, can you?

Amy Montemarano:

I have one of those sun lights that you plug in for the mostly over the winter but it's phenomenal. Turn that thing on in the morning.

Melani Dizon:

There's a company that you guys can check out for those online that don't know about it it's called Joov, they have a bunch of those lights that you can check out lots of people do Amazon has it but Joov has a really interesting light therapy tool. How often do you use it, Amy?

Amy Montemarano:

I don't have a particular brand, but I use it every morning to wake myself up and give myself some energy and it really really works for me. That's the most productive time of my day so it helps. At this time of year, I just walk outside, but over the winter, it's really great. Yeah.

Gaynor Edwards:

Has anyone tried the red lights, the, what is it called, is it near infrared, anyone had to go with those?

Amy Montemarano:

That's when I see my Robert De Niro movies, when I wear my, I have like one of those little vie-lights that you put in your nose.

Melani Dizon:

Wait, what is it?

Amy Montemarano:

The one I bought is called a vie-light or Vie, it's I think it's from Australia, but it's a red light that goes up your nose, it's supposed to be the closest thing you can get to get into your brain, I'm not sure if it works, but I don't necessarily feel any different, but every once in a while, those movies are just really cool. So, and they're usually correlated for some reason so I know, something must be happening.

I don't want to either endorse or not endorse I mean I'm sure it has a lot of studies behind it, I mean I've read the studies but I think that the infrared light, really only works for people with Parkinson's if they can get it into the brain, right, because otherwise it's supposed to be really good for your metabolism, when you go into those Infrared Saunas it's like you're sort of all over, health and well-being, but there are some people who have rigged up some helmets and try to get the infrared light into the right place.

Heather Kennedy:

Right, like the lampshade guy?

Amy Montemarano:

Yeah the lampshade guy. And then the studies that they've done on that I think involved that kind of infrared but I'm not sure there's any commercial products that you can buy. The closest thing is this thing that goes up your nose, which is really attractive.

Kevin Kwok:

Should we talk about medications for sleep, Gaynor?

Gaynor Edwards:

Medications for sleep or how your Parkinson's meds affect your sleep if you change? Or both. So, well take the lead on this then, Kevin.

Kevin Kwok:

So, for me, you know, being the pharmacologist on this panel, medications can both initially help and actually complicate things for you down the road.

You know I used to travel with a little bit of Ambien when I was traveling internationally, and my neurologist told me make sure you take it because it's important to get your sleep. But then over time I found myself taking it almost every single night instead of periodically. And I went for a period of about two years when it wasn't addiction, but it was sort of a behavioral need. If I didn't take my Ambien, I couldn't fall asleep.

And then what I would find out is that I was not sleeping with high quality. And so, then I'd wake up tired and so that I would be taking Ritalin to boost yourself during the day, or I'm always with my caffeine, right.

Heather Kennedy:

You should always sleep with high quality Kevin.

Kevin Kwok:

What's that?

Heather Kennedy:

You should always sleep with high quality Kevin.

Kevin Kwok:

You should but it changes, you know with the introduction of pharmacology, right? And then as I was taking other medications like Mirapex, I would ruminate all night long. And so, this became, what was useful, became this vicious cycle. And I can actually honestly say that I was addicted to drugs in that point in time.

And the same neurologist who said, take them you need your sleep now wouldn't refill my prescriptions for them. And so, what was interesting for me is that I've gone to sort of more of a homeopathic version of using different things like melatonin, CBD, THC, hot showers, meditation, and other things. It's funny now I sleep seven eight hours a night. Now I still wake up tired, that's the issue for me now. But I'm curious if that's evolved for you all as well.

Heather Kennedy:

Is that partly because of DBS do you think Kevin? Because I'm noticing more sleep with me already.

Kevin Kwok:

DBS definitely improved my sleep. Have others tried medication for sleep?

Steve Hovey:

I've tried, well trazodone for a while. And then my movement disorder doc, said you know why are you taking that and I said well because my general practitioner told me it would help and he said I really don't think you need it, stop taking it.

I stopped taking it and it was, you know, I think you're right Kevin, I think you almost become like psychologically addicted to this stuff because first couple nights I was like oh my gosh I'm never going to fall asleep.

And then within a couple of days I just, you know, I didn't need it. Then, of course, I have some nephews out in Colorado where THC is legal, and you know, of course they supplied me with all kinds of miracle sleeping agents. And I tried that and again in the beginning I thought like, oh wow, this is great, and then it didn't work. I mean, so, but that's for me, I know other people swear by it.

So, I figured the CBD, the THC oils, you know the powders, I tried them, they didn't work so I'm not even going to continue with that. So really what I'm doing now is just more behavioral.

And again, it's healthier and that's worked better for me, but I will say this. I do and I don't know if this is like medically proven to be, but I actually did a little bit of research and they said that Sinemet really doesn't help promote sleep.

But what I find is when I wake up, and I need medicine, I'm like jumping out of my skin, right? I take the Sinemet and the Rytary, a lesser dose, and it calms me, and I'm able to fall back, and that's what I've been doing lately between that, the walking around, reading a little bit. So that has worked well for me.

Gaynor Edwards:

So sleep hygiene and then just kind of a low dose that works for you? it's knowing your own body and your own meds isn't it as well?

Melani Dizon:

Are you taking your medicine, your Sinemet, you Rytary when you like initially wake up in the middle of the night before you go downstairs and walk around and do all that kind of stuff?

Steve Hovey:

Right. So, I take my, take my evening dose, I don't take any extended release. I just, when I wake up, I take it.

But I just think, you know, my parting comment is just that it's so important, sleep, I've come to understand as now I'm into my 15th year diagnosed and my sleep problems started before that, that I've come to the realization that, like I said before, it drives your day, it drives your energy level, it drives your cognitive function.

I just think that people just say, I can't sleep, and they're tired all the time, and you really need to try to find that solution that works that works for you.

Heather Kennedy:

Has anybody tried ASMR, it's Autonomic Sensory Meridian Response and there's these whisper stories, I'm going to get myself in trouble here because they use this particular technology for other things that we won't go into here on our show today, but there is a podcast of this for just sleeping, where it's mimicking the sounds you hear in the womb.

That's very calming it's just like a slight rustle of a microphone or paper or someone whispering very slowly, very softly and for some people it works, they get some squishy headphones. They're out like a light.

Gaynor Edwards:

It's like mindfulness or, you know, sea noises and stuff like that, or rain or whatever, although at the moment here, you don't need those.

Amy Montemarano:

So, my two magic bullets are listening to guided meditations on an app and, you know, some of them are really really good. I don't remember the app that I use. But the other thing that usually helps me is if I clean up before I go to bed. If I can declutter like the space around me because I'm a pretty sloppy person. I find when I clean up a little bit before I go to bed that somehow, I just it declutters my mind as well.

Gaynor Edwards:

But you haven't got that nagging happening all night that I've got to do this when I get up. Do you still set an alarm?

Amy Montemarano:

I haven't set my alarm in 20 years.

Gaynor Edwards:

Because you don't need it or are you anti-alarms?

Amy Montemarano:

Yeah, I just don't need it. I mean, I was always a light sleeper right, so even yeah, I didn't really need it. The sun came up and I would wake up.

Gaynor Edwards:

Yeah, it's just whole idea of having a clock in the bedroom is so negative isn't it, you clock watch and you're almost dreading the alarm and waiting for it to go off, so I think throwing that out is a very good thing to do.

Melani Dizon:

One of the podcasts I listen to, it's called, "Sleep with Me" and it's very similar but it's just this person that is in a monotone voice for just 3 hours, and he talks nonsense. And I haven't slept since I was born, pretty much, so this has just been a constant problem for me.

And I have really restless legs, I've terrible cramping, and got all this crazy stuff but this one will quiet my mind. And like I don't even know, it's nonsense, but it's mesmerizing.

The other thing my doctors were like, you know, just kind of running through all the different things to try and I was like I'm really worried about taking anything even an over the counter sleep thing to help me sleep and they were like, well your side effects are so much worse, of not sleeping than anything you would get from this over the counter thing like if you could get yourself to actually sleep, I don't care about that like and it's true. If somebody says you know you're going to lose a couple of years off your life, I'm like I don't care if I can sleep.

But the only thing that's really, you know, that's really helped me is, I found this one CBD product that I tried probably 100 and I tried other things and it is literally the only thing that's ever helped me sleep.

Heather Kennedy:

And I think you may have just touched on some of the questions that I saw when I first popped into the chat too.

Melani Dizon:

Oh, restless legs?

Heather Kennedy:

Yeah. So, for people with restless legs, has anyone tried gabapentin, which is, you'll see they have a rap sheet this long, they kind of cover everything like do you have an itch? Gabapentin. Are you restless? Gabapentin. Are you nervous? Gabapentin. But anyway, it's supposed to be good for restless legs and I've had decent luck with it.

Melani Dizon:

It's so different for each person right, like you just have to find your special cocktail.

Amy Montemarano:

So, it's worth saying that not everything is Parkinson's related.

Gaynor Edwards:

No, exactly.

Amy Montemarano:

So, you know, it doesn't necessarily affect all of us and it doesn't necessarily not affect us because of PD either. So yeah, it's a problem, I think of aging as well.

Kevin Kwok:

Yeah, I think the other issue is, whatever we're using it's not just the quantity or hours of sleep. It's the quality of sleep. You know, back in the days when we could sleep and then just go deep into sleep for even a few hours, and you wake up fully rested. I find that even if I get seven good hours, seven long hours of sleep, I'm still waking up tired, you know, I don't know if others feel the same way, but I mean I can fall asleep in the most embarrassing places. I'm not sure if others have the same issue.

Heather Kennedy:

I'm not gonna say some of the places I've fallen asleep in.

Melani Dizon:

You know, it's interesting because so we had Dr. Postuma I want to say it was probably a year ago, he's a sleep specialist, we did a webinar and Leigh, if you haven't already dropped that in there, we can drop it in. And so, a couple of things that he mentioned that I thought were super interesting and hopefully useful is that some people talk about, you know, they're afraid to nap.

And they're afraid to try and like catch up. And his thought is, yes, just do it, like just don't stop if you, you know if you can nap, nap, because it's not like if you nap, you're not going to get your sleep. You're not getting your sleep at night anyway, so any place that you can get your sleep, it's really important to get it so if you have any issues with insomnia, restless leg, RBD, that webinar is really really great, so I highly recommend watching that.

Steve Hovey:

I totally agree with that. I think if you're sleep deprived you need to get it somehow. You know, and if that means taking a nap at one o'clock in the afternoon, then do it.

Gaynor Edwards:

I think Amy too, would advocate that in the office.

Melani Dizon:

So, the other thing that I would like to mention that is possibly unhelpful for some, hopefully helpful for some, is to change the way you talk about it like "I sleep fine." "How do you sleep?" "I sleep fine."

Because we really do like, we confirm and reconfirm and tell everybody that we don't sleep and we just constantly, we don't sleep and then we don't sleep, not saying that like, just say it and it will come, but there is a powerful, there's something powerful in saying, I'm a fine sleeper.

Amy Montemarano:

Change your script. It is very powerful.

Melani Dizon:

But it is sort of weird like somebody says, "How did you sleep?" and even if I sleep terrible which is, you know, I'm just like, "It was great." And it really has changed things, so again, it's something to try, it's not going to help everybody, but it might help some people.

Heather Kennedy:

And how many couples have had partners who have said can we get a separate bedroom, please?

Gaynor Edwards:

I just like the idea of, you know, the monotone bloke, and the product's called "Sleep with Me."
It's just this idea of the dull man with this monotone voice.

Amy Montemarano:

Or if you can't sleep you can always call Gaynor because she's going to be awake.

Melani Dizon:

Not only is she seven or eight hours ahead of you, but she's also not sleeping.

Amy Montemarano:

She's always there for us.

Gaynor Edwards:

Always at your service.

So, what about the other side of that which is like this sudden onset of sleepiness? I mean, has anyone been called out and felt themselves going in the car, that's the really scary thing if you, you know, you worry about that.

Kevin Kwok:

It's interesting, you know, as a passenger in a car I'm always asleep. The same as in a plane, almost instantly I'll fall asleep.

Heather Kennedy:

On a plane?

Kevin Kwok:

Oh, on a plane, those are my best sleeping hours. There's something about that falling asleep. I mean my kids you select that I could be watching the most exciting adventure movie and I'm snoring in the corner right.

Heather Kennedy:

You're just resting your eyes, Dad, you're just resting your eyes.

Gaynor Edwards:

But is Robert De Niro in it?

Kevin Kwok:

Definitely not.

Amy Montemarano:

That's the key. That's the key question.

Melani Dizon:

Does anybody watching have any questions about the things that we've talked about?

Gaynor Edwards:

They're all sleeping. Don't wake them up. Don't wake them up.

Heather Kennedy:

You're getting very sleepy...

Gaynor Edwards:

I used to do I used to have a five o'clock sleepy time, which applied wherever I was in the world. So, if I went over to the States, it would still be, you know, no jet lag or anything, irrelevant of what jet like did five o'clock was sleepy time. 5pm that is not am, and it's like being a baby sometimes isn't it, oh leave her alone, oh she's having a little nap.

Melani Dizon:

There's a great question. Does anybody have any experience around the connection between sleep disturbances and depression? Has anybody found that their actual depression, also increases as their sleep decreases or is there vivid dreams or anything like that is happening?

Heather Kennedy:

It ruins everything. I mean, your gut goes offline, your meds aren't hitting whatever meds may be, you don't feel like doing much so you have that slight apathy or that you're dragging knuckles feeling. You feel like there's somebody hanging on each of your appendages and on your back, just kind of weighing you down and everybody else is like come on, come play, and the more you're around them and the more tired you get the more you're like overwhelmed and over stimulated. And I think what happens is that you get really bummed out because it's isolating to be up all night alone.

Nighttime is when all the dark, deep dark thoughts come to spend more time in the underworld like Persephone. When you do up you know Hades me alone kick Hades down a little bit, I want to spend some time in the sunshine again.

Amy Montemarano:

Heather, I think you have an online, was it a Facebook thing where you're pretending to be Parkinson's waking you up all night?

Heather Kennedy:

Yes. It was on YouTube under Kathleen Kiddo's YouTube.

Melani Dizon:

Leigh will have it in just one second. Just wait.

Amy Montemarano:

Yeah, that was awesome.

Gaynor Edwards:

There's also something about being uncomfortable isn't there so whether you've got restless leg or whether you can't turn in bed, it's you know, how to get yourself in that comfortable position, so that you've even got a fighting chance of going to sleep.

There was some, I think it was in Portland, there were these some sheets for sale which was, I don't know the brand make so I won't endorse the product anyway but it's like it had a silk central bit...

Melani Dizon:

Yeah, it's like a satin internal thing you can...

Gaynor Edwards:

Yeah, yeah. So, I mean ideally if you were in those with satin pajamas that's gonna help.

Amy Montemarano:

I don't really know anybody who sleeps well after a certain age.

Gaynor Edwards:

My sleep's improved since I've gone on Sinemet. I was on the agonist before, and I think Sinemet has actually helped.

Steve Hovey:

Yeah, well I just read that the agonist actually work can work against you when it comes to sleep. But yeah, I agree, again taking that Sinemet at night has really helped me a lot.

But you know, you joke about the satin sheets and the satin like silk pajamas. But I've heard that actually can be helpful for folks that have a hard time, like turning, you know like people they have a hard time, turning when they go to bed.

Gaynor Edwards:

Yeah, I'm joking, it doesn't mean I don't believe in it.

Heather Kennedy:

That's definitely a problem for me. Sometimes I feel like I can't turn around. Someone gave me a gravity blanket and I thought I was dead. Those heavy ones are a nightmare for a Parkie. Have you ever tried to use a gravity blanket? They're scary.

Melani Dizon:

I use it every night, I can't sleep without it.

Gaynor Edwards:

I guess that's because you've gone OFF in the morning anyway, so you can't, it just feels like extra weight. Yeah. It's just more constricting for us maybe. Whereas, Mel, it's probably a comfort, isn't it?

Melani Dizon:

Yes.

Heather Kennedy:

So, what's everybody doing for fun?

Gaynor Edwards:

Satin pajamas and silk sheets.

Heather Kennedy:

I just want more of it. Seriously I want more sleep in my life.

Amy Montemarano:

Maybe we should have a sleep retreat.

Gaynor Edwards:

The ultimate sleep over in Barcelona.

Kevin Kwok:

There won't be much sleep. There will be a party in Barcelona.

Gaynor Edwards:

Yeah, but you have to sleep at some point.

Heather Kennedy:

Kevin, are we allowed to talk about our sleep study a little bit?

Kevin Kwok:

You can chat a little bit about it. Sure.

Heather Kennedy:

I won't give the details. It's just being monitored about how DBS affects sleep, and so it's something that they're trying to discern whether it's actually making me sleepy or because I have the device or because I'm still recovering from the surgery or how that sort of works specifically. My autoimmune system was tested against DBS as well so I've done two studies since having DBS that I've started the second one now, and I can't wait to go to sleep thing where they put all those things all over, what do you call those? Electrodes on your head?

Melani Dizon:

So, is it part of a clinical trial or is this a different study?

Heather Kennedy:

Yeah, it's a clinical trial, has anybody done that before?

Kevin Kwok:

Yeah, I think it's really worthwhile they get a sleep assessment. If you haven't done it.

Steve Hovey:

Yeah, I was I was amazed I actually slept. When they wired me up, I'm like, forget it I'm never gonna fall asleep, how am I going to turn over, you know, but I actually slept pretty well that night.

Melani Dizon:

Alright we are almost at the top of the hour, and I have a couple of things that I want to share but so the first thing is I want to make sure that I get the link up for everybody. So, if you have a moment after this session, you know to click that link and then share some topic ideas that you have or any feedback you have about the council.

And then the other thing is, as we talked about, a challenge that we would love to have everybody do over the next month and then come back next month and report and see how it went.

So, here's the challenge: to use sunlight to boost your sleep quality.

Dr. Andrew Huberman, we've gotten a lot of links from him, he's an amazing sleep guy and light therapy, he suggests exposing your eyes to natural light early in the day, even just two to 10 minutes of sunlight can ensure photons get through, even if there is cloud cover. Seeking out the sun in the evening is important as well. If you expose your eyes to the sun when it is setting it will set the appropriate timing of secretion of the hormone cortisol, which will make you alert at the right times during the day. So, spend two to 10 minutes again exposing your eyes to the



sun as it is setting. If you're unable to do that, for whatever reason, you could also do you know try five to 10 minutes outside in nature, on the grass, next to a tree with a friend. Try to get some of that vitamin D without sunscreen and then put sunscreen on if you're going to be out longer for sure but you want to have some of that be able to absorb.

So, that is your challenge, if you did it, if you do it every day, and then see what happens experiment with other things but let us know how it goes for sure.

Anybody else want to share a couple of quick, fast tips that people can try out for this month?

Kevin Kwok:
Exercise.

Steve Hovey:
And try to do it outside.

Gaynor Edwards:
If you can. Look at this. Rain, rain, the whole week. Don't come to England.

Melani Dizon:
Good. Well, thank you everybody for being here as usual, we love this monthly this monthly Council and please provide your feedback and we look forward to seeing you all in July. I will provide the audio, video, transcript, and show notes, so you'll get all those in the next week or so.

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