



Victory Summit: Sleep and Living Well with Parkinson's

Welcome with Davis Phinney

Davis Phinney Foundation

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

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

Hi, Davis.

Davis Phinney (Founder, Davis Phinney Foundation):

Hello, Polly.

Polly Dawkins:

Welcome to the virtual stage.

Davis Phinney:

Thank you.

Polly Dawkins:

So, our organization started not quite 20 years ago, and we've all learned so much in that time, you with your lived experience and that's alongside you and alongside our community, learning and researching and understanding what it takes to live well with Parkinson's, and sleep is such an important part of that.

Davis Phinney:

Yes. Sleep is one of the absolute keys to every living moment with Parkinson's

Polly Dawkins:

Yeah. So, Davis, how did you sleep last night?

Davis Phinney:

I mean, I slept okay. Not great. I don't know if I was worried about speaking this morning or I'll just, you know, some of my bad sleep behaviors cropping up. Like yesterday, I took a nap, which is typical for me, but I took a too long nap, I would say. And then last night I had an extra glass of wine, which is never really conducive to good sleep.



Polly Dawkins:

Right.

Davis Phinney:

But I still try to follow my main pre-bedtime ritual, which is to get in bed fairly early, say nine or nine-thirty, because my wife likes to go to bed early and she gets up early, earlier than me in general. But also, one thing I did last night, which would, was not as helpful with, was that I didn't construct, constrain my fluid intake. So, I had to get up to pee three or four times, which is one of my banes of good sleep.

Polly Dawkins:

Yeah. You know, I wonder, Davis, at a previous event like this, at a Victory Summit, we learned about red light. So, when you get up, not to turn on the lights and wake your body back up, but to have a red light that might be less disruptive. Is that something you've done at home?

Davis Phinney:

Yeah. We have a little bathroom light that actually goes green or blue, and that, so that I have a point of reference which is how I get to my bathroom, not waking up, stumbling around in my closet, which is pretty fun. That's there.

Polly Dawkins:

Yeah. Yeah. You know, I few years ago my mom gave me a light that you could put inside your toilet, and it illuminates the toilet so that you don't, which I have not used yet, but I wonder if that would be a good thing to do to, so you know where you're going, where you're aiming.

Davis Phinney:

Yeah. Possibly. I mean, ours is right next to our toilet, so it works well.

Polly Dawkins:

Yeah.

Davis Phinney:

But one of the things that've I done to improve sleep time, like getting bed. There's been a big one because I was having some REM sleep disorder, bad behavior things where I was punching my wife and whatnot when we were sharing a bed and all of those have pretty much gone away with the separation of bed. And so-



Polly Dawkins:

That's a good idea. So, you mentioned REM sleep behavior disorder. We have some good resources written about that for folks who are tuning in and don't know what that is. I'm sure one of my colleagues will drop that in the chat. So, you mentioned that having separate beds has helped you.

Davis Phinney:

Yeah. And then reading a book on Kindle, which allows me to stay up later because the light doesn't bother my wife. And so that's a good ritual. And then the bad aspect for me is that I'll frequently check my phone for an Instagram post for my kids, which I follow religiously. And that then sucks me down the whole Instagram rabbit hole. Oh. You know, end up with way too much screen time on like my phone, which is just not, not very conducive to good behaviors.

Polly Dawkins:

Yeah. So, limiting screen time before bed or in bed is a good practice.

Davis Phinney:

Oh, right. Yeah. And the kinds of screens, too, but it doesn't have the effect as like your laptop or your phone. Yeah. It's not so bright. Yeah. And that's much better for healthy. Some of the other things that I do are that I always need to, to manage the temperature of our and keep my legs cool. Because if my legs get hot, then I'll having restless and that's a good sleep. Sleep is rest of leg syndrome.

Polly Dawkins:

Yeah.

Davis Phinney:

And that's another reason that having separate beds works well for us, because my wife will sleep with two down comforters on, so I'll sleep with the sheet. We

Polly Dawkins:

Be hanging out-

Davis Phinney:

Yeah. With my feet hanging out. Exactly.

Polly Dawkins:



Another thing that I know you've talked about, and one of our speakers at another event used to sing a song to this concept, which is to stop watching the news before bed.

Davis Phinney:

Yeah. Stop watching the news-

Polly Dawkins:

Exactly. It's making you sad.

Davis Phinney:

Yeah. No, that's true. And that's one thing that I constantly don't do is follow too many news threads or if I'm on my phone or I'll, or else we just, as the couple don't watch the news after 6:00 PM. Yeah.

Polly Dawkins:

Yeah. Because it just sort of gets you worked up and-

Davis Phinney:

Yeah.

Polly Dawkins:

Yeah. Anxiety around what's going on in the world.

Davis Phinney:

Yeah, that's right.

Polly Dawkins:

Yeah.

Davis Phinney:

That's right.

Polly Dawkins:

So, Davis, you've mentioned so many different strategies that you use. You've mentioned reducing your intake of fluids before, before you go to sleep, reducing your alcohol, bringing



screen time down, not watching the news before bed temperature control in your bedroom, separate beds. You've also mentioned before about that all of the things you do in the day are sort of interconnected

Davis Phinney:

Yeah.

Polly Dawkins:

To how you sleep and how you sleep. Really. Tell us a little bit about that.

Davis Phinney:

And I think that that starts in the morning when you wake up is whether you've had a good sleep or a bad sleep, you've got give yourself the intention that it's going to be a good day. And so that's very important just to start with an intention that today is going to kick. And even if you don't feel it's important to say it and then get up and if you can get outside even better and just, you know, arms up baby. Yeah. Because that's the, the key to starting your day out. Right. And then if you can exercise by all means, exercise is very important to, to your overall body health and your, and your sleep eventually as well. Yeah. As well.

Polly Dawkins:

You've also talked about sort of quieting your mind down.

Davis Phinney:

Yeah. Well, and that's part of my own sort of advice to people about meditation is that that I'll meditate in a less formal way that many people do, but I'll still have a procedure for when I wake up or when I'm try trying to go to sleep, which is to just lay on my back and quietly, listen to my breathing and count your breaths up to 10 repeatedly. And that, because I've done that for a few years now, that's proven a good method for calming my voices in my head that would otherwise be telling me to get up. You got to worry about this. You got to worry about that. You know? And so, I'll just lay back and,

Polly Dawkins:

And that helps.

Davis Phinney:

Yeah. Because it's like a signal to my brain to shut down. And so that that's very good for me. But as you said, Polly, I think the key to sleep is there, the reason that we need sleep is because

it's so good for our whole body. And if our whole body is getting rest and recovered and having its neurological responses fulfill in that way, then we're going to be healthier and better in the long run. Yeah. Then, but I should add one more thing about sleep, which is that the timing of your meds are so important. And so, for me, I'll take a long-lasting one, from retiring right before bed. And even if I'm waking up or early in feeling sort of agitated, I'll take that same pill in the middle of the night just to hack my system and support it so that I can sleep into the morning a little bit more.

Polly Dawkins:

Yeah. That's such a critical piece of, and there's so many pieces to this puzzle.

Davis Phinney:

Yeah. And it

Polly Dawkins:

It's probably changed over the years for you. And it's probably different from when you before you had deep brain stimulation to after.

Davis Phinney:

Oh yeah. I mean, deep brain stimulation has culled my tremor now for nearly 15 years. Yeah. And that's been the biggest sleep enhancement that I could have ever imagined because pre-DBS, I was sleeping maybe max 15 or 20 minutes at a time. And that just crush time.

Polly Dawkins:

Yeah. I mean, that's how wolves sleep, but our humans aren't meant to sleep that way.

Davis Phinney:

No. Well, and then when you wake up and you're immediately tremor in your hands doing this, and so you're paining your arm now trying to go to sleep while activating actively depressing, your tr that's not helpful or good,

Polly Dawkins:

Not at all.

Davis Phinney:

And so not having to deal with the tremor aspect has been so such a godsend for sure.



Polly Dawkins:

David, you, and I could talk about sleep for a long time, because it's certainly not one of my superpowers either. But we've got some great experts who are going to come on and you and I can come back at the end and catch up and send people off onto their days. If that works for you,

Davis Phinney:

That works for me. Let's get to it!

Polly Dawkins:

Let's get to it. Super. Well, thanks everybody for logging in, telling us who you are. Thank you, Davis, for sharing your own personal sleep and Parkinson's journey. And we'll call you back on the stage in a bit.

Davis Phinney:

All right. Thank you. Thank you, Polly.