



## **The Parkinson's Podcast**

The What and Why of Parkinson's Motor Symptoms and How to Manage Them  
Davis Phinney Foundation

Jackie Hanson (Program Manager – Video and Audio Production, Davis Phinney Foundation):  
Hello everyone and welcome to the Parkinson's Podcast. This podcast is brought to you by the Davis Phinney Foundation and brings you experts from the around the country as well as additional educational and inspirational resources to help you live well today with Parkinson's.

Welcome everybody, we are so glad you're here. My name is Jackie Hanson and I'm the Program Manager of Video and Audio Production here at the Davis Phinney Foundation and I am very glad you are listening today! If this is your first joining us, I want to first say, welcome. We are very grateful you've found us and I hope you find some value in this episode today and other episodes on our podcast. Please feel free to reach out at anytime to [blog@dpf.org](mailto:blog@dpf.org). This can just be to say hello or if you are looking for an episode or any of our resources on a particular topic, we would love to help guide you in that direction, so again, feel free to reach out to us at anytime, [blog@dpf.org](mailto:blog@dpf.org). Myself or one of our other amazing staff members will respond to you as soon as we can.

If you missed our episode last week be sure and check it out. It was the second episode of a mini 2 episode series geared more toward the care partners for people with Parkinson's, but believe me when I say that everyone out there could benefit from our last episode which was an interview with author, film producer and director, and retired broadcast journalist Dave Iverson who moved in with his mother at age 59 to be full-time caregiver and did so for ten years until she passed at age 105. It's a moving, and wonderfully genuine conversation and I highly recommend it.

This week we are shifting gears and looking at the motor symptoms of Parkinson's. Dr. Suketu Khandhar, a movement disorder specialist at Kaiser Permanente in northern California, first breaks down the basics of motor symptoms: like what are the main ones, why do they occur, etc, but then also discusses ways to treat them and also the latest research on things you can do to potentially slow down the progression of motor symptoms.

A quick note that this conversation was originally from a live Virtual Victory Summit event, and during these events we always highly encourage audience members to ask questions in the chat, so you will hear Suketu and the moderator Polly reference the chat every now and then.

So, with that here is Polly Dawkins, the executive director of the Davis Phinney Foundation, to start us off.

Polly Dawkins (Executive Director, Davis Phinney Foundation):

So, to start off, we have such a wide range of people here with different years of diagnosis and obviously coming in from all different parts of the country and beyond, but can you start by telling us what's happening in the brain with someone with Parkinson's and how does it affect the movement and the motor side of Parkinson's?

Suketu M. Khandhar, MD (Medical Director, Kaiser Permanente Northern California Movement Disorders Program, Kaiser Permanente Sacramento Medical Center):

Sure. Happy to do so. So deep within the brain, there's an area called the basal ganglia. And within that area, there's a little factory called the substantia nigra and that factory produces a chemical called dopamine. Now under normal circumstances, dopamine, when produced allows us to initiate, maintain, and steady our movements. However, if that factory, the substantia nigra no longer is able to create as much dopamine as it used to we start to develop stiffness, slowed movements, and ultimately a tremor. And so that really forms the chemical understanding as to why somebody starts to have pathology in Parkinson's disease is really this difficulty in being able to produce and utilize this chemical called dopamine.

Polly Dawkins:

That's super helpful. So, stiffness, tremor...

Suketu M. Khandhar:

And slowed movements.

Polly Dawkins:

Slowed movements. So those are the primary motor symptoms of Parkinson's, or would you add others?

Suketu M. Khandhar:

I would add others, but let's start focusing on just those three first, right? So, you know, in medical school, we always think about the triad of Parkinson's disease, being tremor, slowed movements, and stiff movements. And, you know, we're talking about rigidity, bradykinesia, and a resting tremor. Many people associate the condition with the resting tremor only and the reality is not everybody with Parkinson's will develop resting tremor, a good 70% do, but what about the other one third? But what everyone does really ultimately develop is bradykinesia. In fact, the hallmark of the condition is bradykinesia or slowed movements. If you think about everybody that you know in your support network, everybody you know in your community with Parkinson's disease, or anyone you've ever seen with Parkinson's disease, they're going to be slow in what they do. They're going to have processing issues when it comes to motor ability to do things, their dexterity is a little bit off. They may be not having the normal arm swing or normal stride. All of that really revolves around those slow movements. You add a bit of rigidity to it, or the muscles just being tight and stiff. It makes with those movements to even be more difficult. And then a tremor of course, is one of the most visible of all Parkinson's symptoms.

Polly Dawkins:

Yeah. So, focusing on bradykinesia for a minute. As I understand it, but you could tell us better, that affects everything in your body, correct?

Suketu M. Khandhar:

That is correct. So, if you think about what this dopamine is doing in the brain, you know, if we have an idea that we want to move, there has to be some planning involved in how we want to move and if that dopamine isn't there, that motor planning, that motor initiation, that ability to make the movement all is somewhat compromised. And this is why we're a lot slower at what we do. It's not just that you don't have enough gas in your gas tank. It's the fact that even the whole system itself is just a bit rusty and just a bit slower. And we'll probably circle back to that in just a bit, because that's why exercise is so important and Davis said it so nicely, just a few moments ago, about how that really is sort of one of the cornerstones of treatment is exercise.

Polly Dawkins:

So, is it when we hear from our community that you all in the audience experience slowness of gut and digestion, is that considered bradykinesia as well? Or is that completely unrelated?

Suketu M. Khandhar:

I think, so for me, it's related. And the main reason is because if you think about how the gut moves, the gut is kind of like a toothpaste container, right? You kind of push from the bottom and ultimately something comes out the end, right? Along the length of the gut, there are these bands of muscular tissue that basically work in synchronicity to push, you know, whatever's within the gut along. And so, if those movements are somewhat slow, you're really not gonna be able to move that along. You're really not gonna be able to clear your gut. You're really not gonna be able to absorb anything afterwards, simply because you are impacted. And so, for me that slow gut motility has almost everything to do with processing of gut muscles and that synchronicity that's supposed to occur otherwise.

Polly Dawkins:

Got it. A question from the chat that somebody has asked, is the basal ganglia affected by Parkinson's and does it affect movement?

Suketu M. Khandhar:

So, the answer is yes, part of the basal ganglia is the substantia nigra and all the connections that it basically projects to. The basal ganglia is a collection of a lot of nerve cells and a lot of nerve sort of collections. And one of them happens to be the substantia nigra, but so is the subthalamic nucleus, so is the globus pallidus internus, so is the caudate, all these areas work in conjunction in order for us to be able to sort of do things and maintain our movement. So, is the basal ganglia affected in Parkinson's? Absolutely. Where is the seat of where it's being affected? It's the substantia nigra, but also everything that the substantia nigra projects to.

Polly Dawkins:

Got it. Thank you. We're focusing on movement today and motor symptoms, but since you're first expert, I'm gonna go into some basics, a little bit of basics of Parkinson's as well. So, can you tell us are there various subtypes of Parkinson's and how do you categorize the individuals who come to see you?

Suketu M. Khandhar:

So, it's a good question. And, you know, for me, Parkinson's isn't just one diagnosis. It's a collection of diagnosis that are all sort of have common threads to them. And the common threads really being bradykinesia, the rigidity, and then also tremor, there is a fourth motor condition, by the way. And that's postural instability, the inability to be able to maintain your posture and be able to stand upright and not be stooped over or not be at a risk or propensity to fall. So, when I see a patient with Parkinson's, I have to recognize that they're gonna fall somewhere along that spectrum. And are they someone who has classic garden variety type Parkinson's disease, which is kind of what Dr. James Parkinson first described back in 1817 when he published his manuscript, the Shaking Palsy in the Lancet. And that's really where somebody has for the most part equal parts tremor, equal parts rigidity, and equal parts bradykinesia.

But what about those folks who don't have tremor at all? And they have a lot more in the way of bradykinesia and rigidity. And that's what we like to call akinetic rigid syndrome. They're a lot slower, a lot stiffer, and there are times where they just simply cannot move. Then there's people who have only tremor and yet for the most part, their dexterity is relatively spared and they're able to get around and move around and walk around. And they don't really have a lot in the way of postural instability. And they don't have a lot in the way of motor instability, but they do have quite a bit of tremor. In fact, tremor is the predominant symptom. And so that subtype is gonna be tremor predominant Parkinson's. And then there's a third or a fourth subtype rather, it's something called postural instability in gait syndrome. It's where rigidity and bradykinesia is absolutely there, tremor may or may not be there, but early on in the course of the condition, they're so much more plagued by the propensity to fall. In fact, that may be the presenting symptom for them. That may be why they ended up going to the emergency room or to their primary care physician.

So, to summarize, when I see somebody in with Parkinson's disease, for a second opinion or even really, a first encounter, I'll try to subcategorize them into one of four categories. Do they have that classic Parkinson's picture where everything's about equal? Do they have that more tremor predominant picture? Do they have more of an akinetic rigid without much tremor picture? Or are they more plagued by their instability in gait syndrome?

Polly Dawkins:

Got it. So then as a clinician and a provider, you try to figure out which sort of subcategory, do you treat people differently depending on which subcategory they fall into in your mind, or is there a path that's different for one person versus the next?

Suketu M. Khandhar:

Absolutely. And so, I think this is important to express to the audience is that, you know, you can't treat every individual the same way, right? This is a designer disease. And therefore, our approach to treatment has to also be equally designed or tailored. And so, if we as the clinician can be a bit more precise on what subtype of Parkinson's you may have, then we might be a bit more precise on what types of treatments and more effective treatments can help them achieve a better quality of life. Now, why is this important? It's important because our job as providers, you know, in a world where we currently do not have a cure for Parkinson's is not to help you be rid of the Parkinson's, but make sure it's manageable for you, make sure that you recognize that there are ways in which we can actually improve your quality of life and help you engage in life in a much better, more meaningful way.

So, let's give a couple of examples. Somebody who's got that classic Parkinson's picture where everything's about equal. They tend to respond pretty favorably to medications. They're the ones who ultimately get that really robust ON response. They're someone who actually may notice when the medications wear OFF. And so when we talk about that ON OFF phenomenon and, you know, people wanna feel that that medication's doing something for them, and if they really do get that, it's more likely that it's gonna be classic Parkinson's disease, somebody with tremor predominant Parkinson's, no matter what you throw at the tremor, tremor tends to be pretty stubborn, may not always respond to medications, may not always respond to a variety of medications. And therefore, thinking that if tremor is gonna be that stubborn, we may consider after a few trials of medications, maybe considering early, you know, sort of thoughts about deep brain stimulation.

I mean, the fact that deep brain stimulation even came to existence was because tremor tended to be quite stubborn. In fact, if you were to go to Europe and ask many of the specialists who practice in the movement disorder space, many of them will say that tremor is just resistant to meds, cycle through the meds pretty quickly, and consider surgery early. Then somebody with akinetic rigid syndrome may have a chance to respond to medications, but you're really gonna wanna focus quite a bit on the physical therapy piece. And then somebody with that postural instability and gait disorder hardly ever will respond to medications. And this is where you really need to capture the attention of the physical therapist early on and help them understand what types of postural exercises they need to do. How can they keep and maintain their upright position? How is it that they should exercise and maybe more aggressively, or do they need an assisted device, like a walker or maybe a specialty walker to help them reduce the probability of them falling? So again, you know, really tailoring how we treat people is gonna be really contingent on how we diagnose somebody.

Polly Dawkins:

Yeah. That's really helpful. Somebody has asked about postural instability. They've said that their podiatrist said that their toes and toenails have been affected by postural instability. Can you explain what's going on with the toes and the feet in Parkinson's?

Suketu M. Khandhar:

I'm assuming that this audience member probably is developing something called toe curling dystonia. If you think about it, when we stand up, we're putting all of our body weight and all of our center of gravity on two little areas of surface areas, right? Just whatever's on the sole of our feet. And if you happen to have high arches, it's even less surface area than that. It's really remarkable that we, as humans can actually even stand upright, right? Maybe opposed to other animals in the animal kingdom. And so, if our instability, or if our postural stability is off, right, we have to rely on quite a bit to help grip the ground or feel like we're gripping the ground in order to maintain that stability. And so, our toes will naturally curl under, right, in order to actually feel like we're keeping ourselves upright.

A lot of patients with Parkinson's will actually have toe curling dystonia first thing in the morning before they take their first dose of levodopa or other medications. So, it's very common for that toe curling to occur. And when that happens, it can be quite painful because you start having your toes stay in those positions, not to mention it's difficult to actually do the hygienic nail cutting or clipping. And then those toes kind of dig to the ground and then gives a lot of people, quite a bit of pain. So, recognizing that there's toe curling dystonia and trying to treat and target that is really important, kudos to the podiatrist for calling it out.

Polly Dawkins:

Yeah. What are, any ideas strategies that people can use for toe curling dystonia?

Suketu M. Khandhar:

If it's responsive to medications, it may require just an adjustment to medications. For a lot of my patients who have it early morning, who cannot wait for their oral levodopa to kick in quick enough, I might use an inhaled version of levodopa because it kicks in a lot quicker. I might give them a long-acting levodopa at nighttime or in the middle of the night so it still stays on board when they wake up in the morning. But let's say it's not responsive to medication, then physical therapy and stretching out those toes. Sometimes a simple method of if you were to take one of those therabands, you know, those rubber bands that people use for rehab and kind of rope it over your foot while you're sitting and then pull back on it as if you're, you know, trying to reign in a horse, that sometimes helps to stretch out the sole of the foot. This was a technique that was taught to me by an old school physical therapist and it's amazing how much our physical therapist have learned over the years and what they can impart to us and we're always learning. And then the last thing, if those things are not successful is to consider botulinum toxin injection, and inject that into the sole of the foot, which of course can be painful, but also can relax the muscles that tend to be curling under.

Polly Dawkins:

Does that make your feet less responsive or numb, and therefore harder to actually walk because you've had botox injections in your feet?

Suketu M. Khandhar:

Not necessarily. What makes Botox lead to numbness is when you're injecting it subdermally and not into the muscle. This is where you wanna inject it directly into the muscle, thereby relaxing the muscle. And therefore, you shouldn't really get a lot of numbness from that. So, it really depends on the skillset of the individual who's doing the injection. Sometimes it could be a podiatrist. Sometimes it could be a rehab physician, and sometimes it could be the movement disorder specialist. Typically, general neurologists, unless you're in an area where the general neurologist kind of is a Jack of all trades and master of all trades as well. They do it, but in most large volume centers, the general neurologist usually does not.

Polly Dawkins:

I'd like to back up a tiny bit to the beginning of your relationship with a person with Parkinson's and your diagnosis. What would you recommend to your patients or to our audience members that they can do to best prepare to meet with you the first or second or every time they meet with you? Cause you get 15 minutes, right? Maybe half an hour, if you're really lucky and it's a couple times a year?

Suketu M. Khandhar:

Correct. So, for me, and I'm gonna, let's say, so we're basically talking about somebody who's already been diagnosed, right? And so if they're already diagnosed and they understand their Parkinson's a little bit, I think it's always important for you as the patient, as well as your care partner, your loved one, your spouse, your child, your friend, to understand what are the symptoms over the last X number of months, or a certain amount of time that have been plaguing you the most? Is it the tremor? Is it the postural instability? Is it that toe curling dystonia? Or is it a non-motor symptom? Oftentimes we tend to focus on the motor symptoms because they're the most obvious. And then we monopolize all of our time in the office with the motor symptoms and therefore we never get a chance to talk about the non-motor symptoms, which sometimes are quite a bit more challenging and even a little bit more difficult to treat.

What about that fragmented sleep? What about that swallowing difficulty? What about that constipation? What about that pain in the feet? Or what about urinary dysfunction or how about a mental health issue such as apathy or depression? So, my suggestion is if you have limited time, you wanna make sure that you optimize your time with the specialist. You optimize your time there in the office, and you probably list off the, you know, top three to five questions. Gosh, I can tell you how often I tell this to patients. And of course they come in with 45 questions and we never have enough time for 45 questions, but the top three to five

questions that I want to have these answered by the end of the visit, I really need to have a better understanding from this, or I need to know where I can go to get good information on this.

And so, part of the empowerment that patients and their loved ones should have before they come in to see the doctor is to understand their own condition, go to the Davis Phinney website, go to other Parkinson advocacy websites, understand Parkinson's disease and see where your problems are plaguing you the most and ask the questions that you need to ask. But if you focus yourself a little bit during the office visit, and you have these questions already prepopulated before you go in, then it's going to make for so much more of a meaningful visit, you're gonna walk away satisfied rather than kind of feeling, gosh, I wish I had written that question down, or it happens all the time, it's Murphy's law where you go in there and you're like, I had a question to ask, oh, I'll remember it afterwards. And of course, hardly ever, does anyone email me afterwards to say, oh, this is the question I wanted to ask.

Polly Dawkins:

Oh yeah. So, going back to motor symptoms is there a link between the severity of motor symptoms that some people with Parkinson's experience and the non-motor symptoms that they experience?

Suketu M. Khandhar:

In my experience, I've noticed both progress with time, but both won't necessarily progress in the same fashion. Sometimes the tremor can be relatively stable for a few years, particularly if you are treating it right. If you're on medications for these things, you know, and most of our medications for Parkinson's kind of focus on the motor, well, maybe we don't see much change in the motor aspect, but now we see quite a bit of change in the non-motor aspect. So, what I see is someone who's relatively well treated from a motor perspective and they're exercising and they're, you know, having a good, positive attitude. It's really the non-motor symptoms that then get ahead of them. And so, most of our attention then is focused on the non-motor piece. It does not necessarily mean that the non-motor is progressing quicker. It just means that the motor is being treated and therefore now the non-motor kind of, you know, sort of takes over. So, I don't necessarily see the two progress in the same fashion. I see them progress independently, but they progress nonetheless. And I think for the audience to appreciate that there are non-motor symptoms of Parkinson's, you know, and if you're not sure whether something is related to Parkinson's or not, it's not a typical symptom that you associated with Parkinson's just ask, hey, is this constipation part of my Parkinson's? You may end up asking your primary. You may end up asking your neurologist, but just ask.

Polly Dawkins:

Yeah. Good point. So, staying with the progression question, because we get so many questions about, and it's such a big concern for our community, when it comes to motor symptoms, do all motor symptoms get worse?

Suketu M. Khandhar:

The answer is yes, and some motor symptoms are more worrisome than others. So, the bradykinesia or the rigidity or the tremor doesn't worry me as much as the postural instability does because with postural instability, it doesn't respond very well to medication. It requires a good physical therapist or a good exercise program to really achieve some degree of input and improvement. But that's what is ultimately gonna lead to a fall. And sometimes a fall is a ticket to the hospital. Sometimes a fall, you know, warrants a need to be in a skilled nursing facility for a while. And those things change people. They change people from a mental health perspective. They change people from a motor perspective. So, are all motor symptoms of Parkinson's equal? No, not necessarily. For me, postural instability is the one that I personally tend to focus on a lot more simply because it's the one that I worry about that if not treated well, if not addressed early, then we're gonna see fall risk.

Polly Dawkins:

Yeah. So, let's focus on one of the things that you said at the beginning. Let's talk about the complimentary therapies or treatments that don't involve medications that can help people improve their motor symptoms. And I know one of the first things you said was exercise and Davis talked about exercise.

Suketu M. Khandhar:

That is correct.

Polly Dawkins:

Tell us what things people can do.

Suketu M. Khandhar:

So, let's start with the exercise piece, because we all hear about how important exercise is. We all hear about exercise potentially being neuroprotective. We all hear about exercise potentially slowing the progression of the disease, and maybe the only thing to do so, but how much exercise, what kind of exercise and the reality here is that there's a lot to choose from, right? If you look at the sort of evolution of Parkinson related exercise from the John Argue method to LSVT to LSVT Big to PWR to Boot Camp, to tai chi to yoga, to, you know, rock steady boxing, right, or cycling, all these things have been deployed in the use of Parkinson's disease. And when we do research, we try to look at one aspect of exercise and its impact is on somebody. But reality here is that you could do any of these things. And you could do a combination of these things. The studies usually out of Europe, maybe out of the Cleveland Clinic and a few places in the states, oh, dance as well. I see that in there as well. My apologies. So, all of these are wonderful, but the recommendation is 40 minutes of high intensity or aggressive exercise, six days out of the week.

Wow. So that's the numbers that I give my patients. And when they ask what is high intensity exercise, it can involve any of those things that I just mentioned, but it has to be high intensity. So, what is exactly high intensity? It's when you're doing these exercises, you cannot carry normal conversation during that time. Okay? So, think about that brisk walk that you might take with a pal as you go around the block and you're chitchatting the whole way through, that's not high intensity, it may be a brisk walk, but it's still not high intensity. You should not be able to carry normal conversation during that time. So, if you are able to do that 40 minutes out of the day, six days out of the week, that's what the studies have shown that will alter the change sort of the trajectory of Parkinson's care.

Other complimentary treatment...

Polly Dawkins:  
Can I ask question?

Suketu M. Khandhar:  
Oh please.

Polly Dawkins:  
So that feels inaccessible to some folks I'm sure and that feels really aspirational as well. Do you have suggestions or ideas that you talk with your patients about how to get started on that on cause starting with six days a week, 40 minutes a day is hard.

Suketu M. Khandhar:  
It is, you're right. And like anything that you do that involves exercise, you're gonna wanna start slow. And you wanna start at something that is achievable, right. Make a goal that's within reach. And when you reach that goal, make another goal that's within reach. And then ultimately the aspiration is to get up to 40 minutes, if you can. I have some patients doing quite a bit more, but I've seen folks who were so dependent on their walker. So dependent on needing a wheelchair to get from the hospital parking lot to my office, who after kind of deploying these ideas a year later are able to walk in unassisted. So...

Polly Dawkins:  
That's powerful.

Suketu M. Khandhar:  
You know, correct. It is powerful, right? And when you start seeing these improvements, you start having more of a positive attitude. You start having that light go off in the back of your head going, oh my gosh, I can do this. And you start feeling better about yourself. Maybe mood is also lifted as well. Of course, along the way, you're gonna have to talk to your neurologist about what kind of medication adjustments are required and things of that nature. So, it's not just exercise, it's exercise plus the meds.

Polly Dawkins:

Yeah. Somebody asked, can too much exercise be, let me look at the question. I think it was something like does is too much exercise a bad thing for Parkinson's?

Suketu M. Khandhar:

In theory no, but the reality is it's gonna fatigue you. So, know what your limits are, right. If you start off the bat with an hour of exercise and you know, you end up becoming that weekend warrior, you know, you're gonna be down for the count on Monday. I'd rather be that you don't be down for the count on Monday. I'd rather it be that you achieve something that's achievable. Feel good about yourself. Feel like you did something, accomplish something, and slowly work your way up. But if you overdo it just like any of us, if we overdo it, we're gonna need a couple days of rest. And I'd rather that you don't take the couple days of rest. I'd rather that you actually keep up at that same pace. So yes, there is a limit to what you can achieve and what you can do. So certainly, know what your limits are.

Polly Dawkins:

Okay. Super. So, I interrupted you as you were about to talk about the next thing.

Suketu M. Khandhar:

I think one thing we don't often talk about, or maybe sometimes providers feel that they don't know enough about is basically supplements, supplements and good eats, right? I mean, we all talk about healthy diets. We all talk about wanting to eat more of that Mediterranean type style diet, you know maybe everything in moderation, not too much of anything, you know, fresh fruits, fresh vegetables, try to avoid the dairy a little bit, try to avoid red meat. We all know most of that. Right. And I'm not gonna reiterate that, but I think it is important to kind of monitor. Drinking plenty of water. That's also really important, right? I mean, particularly like, I'm in Northern California, it's gonna be a hundred degrees here today. Drink a lot of water, you know, more than you think you need and monitor it, right.

Measure how much you're drinking, how much you're eating and what you're eating. You'll be surprised because you think you might be doing well. And maybe you have a little bit of a, you know, room for improvement. When it comes to supplements, I always tell patients, you should take basically a multivitamin with a B complex, B as in boy, simply because most of the B vitamins really encourage good spinal function. And that's something that you're gonna need as you sort of embark on your exercise program. The other thing is vitamin D, D as in dog, I think that a lot of us have been dissuaded from going outside because of the, you know, sort of this risk of skin cancer and exposure to sun. And so, we slather ourselves with a million SPF and we try to avoid that. But the reality is many of us actually do have low vitamin D levels, but vitamin D is required not just for bone growth and matrix, but it's also good for memory.

And so, I always encourage patients, you know, get your vitamin D checked and actually see if it's low. And if it is, go ahead and take a supplement of vitamin D. Taking vitamin C very helpful, particularly if you're on levodopa, because it helps to encourage the absorption of it. If you were, so those are things I usually recommend. There are a few other supplements that are not commonly spoken about like coenzyme Q10 or glutathione, particularly intranasal, and a few others that also might be, you know, might be helpful in Parkinson's, there's some data to support it. Not a lot of data though, but these are also relatively safe. And so, these are things I probably would encourage that if you are interested in talk to your neurologist and see if it's something that they've had experience in and just have that healthy conversation, if it's something that you should try yourself.

Polly Dawkins:

Thank you. Looking back through all of the years that you've been doing this work, Suketu, when you think about, is there a theme or a trend to people who are doing better with Parkinson's? What are they doing to live better?

Suketu M. Khandhar:

That's actually a good question. I think they're the folks that basically deploy a strategy of three things. And I think I've given this talk before, around this topic to the National Parkinson Foundation. And those three things are the right medications, and remember more is not always better. So, the mark of a good provider is not just the fact that you can prescribe, but recognizing when you're not supposed to. And so, one third of this sort of strategy is to make sure you're on the right dose of meds. One third of a strategy is to make sure you're on the right therapy program, exercise program, activity program, but one third involves positive attitude and empowerment. And that might mean you gotta go look up some stuff that might mean you need to understand what your condition's about. That might mean you wanna engage in a support network locally. I mean, you actually go to the Davis Phinney Foundation. There's so much information that's out there that's wonderfully vetted by experts. And those patients who use that strategy of the right dose of meds, the right therapy program, and self-empowerment do a lot better than those who don't.

Polly Dawkins:

That's powerful as well. Yeah. I'm gonna take some questions from the audience since there are so many. Back to your recommendation or what the literature says about exercise. Can you break up the 40 minutes as you're trying to aspirationally get to that? Could you break it up into chunks, a couple of 20-minute chunks or a couple of 10-minute chunks?

Suketu M. Khandhar:

The answer is yes, but no study has really shown where there are four, 10-minute chunks are better than one 40-minute chunk. The studies almost always look at the 40-minute chunk or a longer stretch. I can only imagine however that the four, 10-minute chunks are probably going to be helpful. I don't know for sure if it's gonna be as helpful, but I think you can break it up.

And I think that if you require some rest time or downtime in between those times, that's perfectly fine with me.

Polly Dawkins:

Great. There's quite a few questions about fatigue and energy levels. Some folks who are dealing with post Covid, fatigue and saying short nap, but is there anything that people can do to sort of decrease the frequency of those energy crashes or the fatigue?

Suketu M. Khandhar:

There's actually quite a few things. So, fatigue is something that's just gonna come along with Parkinson's, it's one of the more common non-motor symptoms, and just to kind of break it down, the reason why it happens is if you think about the circuitry that's off in the brain, right? That basal ganglia circuitry that's affected by Parkinson's disease. Your brain is trying real hard to reconcile, is trying real hard to compensate for the problem. And that's fatiguing in and of itself. Right, somebody with Parkinson's is working a lot harder than somebody who doesn't have Parkinson's to achieve the same thing. And at some point it's going to compromise them and be fatiguable. What was it? The Michael J. Fox had said that don't mistake my bad days for a sign of weakness. Those are the days I'm fighting the hardest. And so, fatigue just comes with the territory.

Now, are there things that we can do to help improve fatigue? The answer is, yes. Let's look at our sleep pattern. Are we sleeping well? Do you have REM sleep behavior disorder, which is where people actively act after their dreams? And there are treatments for that. There are medications you can take at nighttime for that. Are you actually not able to toss and turn in the middle of the night because you're so stiff and your dopaminergic medications have worn off. Do you need an adjustment to your medications, particularly something given at night? Do you need to have a rescue therapy if you wake up in the middle of the night to go to the bathroom? Are you having fragmented sleep because you do end up going to the bathroom so many times in the middle of the night? And can that be treated? Are you having difficulty during the day because you are go, go, go like, you know, our American psyche is such that we always are on at 60 miles an hour. But have you slowed yourself down a little bit? Have you broken up your day into certain chunks? You know, are you doing your exercise program when you expect your meds to be on board rather than when your meds are wearing off? And is that fatiguing you? Are you drinking plenty of water? You know, so these are all things that if fatigue is a big issue for you, can we recognize certain things that are contributing to it that we actually have control over?

Polly Dawkins:

Yeah, it they're so interrelated, aren't they? Yeah. I think about the advice that Davis and his wife Connie give me sometimes, which is you gotta rest, right athletes rest. And this disorder, this Parkinson's condition requires so much output of energy that rest is a critical component to recovery and being able to continue to...

Suketu M. Khandhar:

You know, Connie said something to me a couple years ago when we did that that Shelter in Place podcast series that I did back when the pandemic first began and Connie was a guest speaker and she gave a tip that I use in my own life and my own family is that, you know, fatigue is something that's not just motor, it's also mental, right? So, if you have mental fatigue, that's also gonna wear you out just as much as motor fatigue will. Well, mental fatigue comes from the fact that we're thinking all the time, right? And so, what Connie does, and I know Davis is on the call as well. So, he probably will attest to this is that after 6:00 PM, they don't watch any news. They don't watch anything that's too activating. Certainly, there's a lot going on in the world.

There's a lot of angst and there's a lot of worrisome things that happen in the world right now. And so, if you monopolize your mind with all that in the evening, you're gonna have a hard time sleeping. You're gonna have a hard time, you know, feeling like you can get to a place where you can sleep more soundly. And so, I thought that was a brilliant thing. So even in my family, with my kids and my wife, we don't watch the news. We don't read the news after 6:00 PM, we'll do it in the morning, you know, understand what's going on, but we don't do that. You know and then I think what Connie said, she watches, what is it, Seinfeld or 30 rock or one of those, you know, those wonderful shows. Yes. Wonderful shows that are just funny. Exactly. Yeah. And I think that can be helpful too.

Polly Dawkins:

Great. I'm looking at some of the questions here. While, they may not be related to motor symptoms, I'd love to ask you them because you're here.

Suketu M. Khandhar:

Sure. Of course.

Polly Dawkins:

One is about double vision and Parkinson's, and the person says, who cares for eyes with Parkinson's? Who should you see? Who should be on your team?

Suketu M. Khandhar:

Good question. The easy answer is an optometrist, not necessarily an ophthalmologist, which is an eye surgeon, but an optometrist. And the main reason is because if you think about it, your eyes are moving synchronously because of the eye muscles behind it. Well, those muscles are not spared by Parkinson's. They also are gonna be having some degree of fatigue ability, some degree of rigidity, some degree of bradykinesia and may or may not respond to medications. So sometimes if the eyes are not moving in sync, you're going to have one eye that's moving a little bit differently than the other eyes moving. No different than maybe your arm swing being a little bit off one side from the other. So, if that happens, whatever field of view, that one

eyeball is picking up is gonna be a little different than the field of view that another eyeball is picking up.

And when those images become super imposed on each other in the back of the brain where our visual cortex is, it will not be the same image. It will be a slightly off, and this is why people develop a little bit of double vision. And so double vision is so common in Parkinson's, you know, whether you wanna call it conversions insufficiency, or there's a risk for other high disorders, like glaucoma, cataracts, things like that as we age. I think it's important for everybody, every year to see an optometrist, see whether glasses would be helpful, particularly with prisms in them to be able to reduce some of that convergence insufficiency. And if there is glaucoma or there is cataracts, then seeing an ophthalmologist. So, the Parkinson's specialist, the neurologist, they may be able to explain some of this, but when it comes to treatment and better understanding visual issues, it's really an optometrist that's gonna be the first place that you're gonna visit.

Polly Dawkins:

And is there a specialty of a neuro optometrist who really specializes in the connection between the brain and the eyes? Or is that not a...

Suketu M. Khandhar:

No, there is a neuro ophthalmologist, and these are basically some folks who have done an ophthalmology residency and then a fellowship in neuro or sometimes neurologists who then did a fellowship in ophthalmology. Oftentimes they can really better parse out what exactly is going on. But many times, the answer still falls back on, hey, I need prisms or I might need surgery, or I might need, you know, cataracts to be removed. So, for me, it's almost always best to start with the optometrist and then move to an ophthalmologist. Also, the thing is an ophthalmologist, particularly neuro-ophthalmologist, they're not in every location, and they're pretty rare to come by. They're even more rare than a movement disorder specialist. So, for example, in our network, in Northern California Kaiser with nearly 10,000 physicians, we only have two neuro ophthalmologists in the whole organization. Academic centers may only have one or two, depending on the, you know, how large their facility is. And so, you know, I think that maybe the more complicated cases certainly should go to a neuro ophthalmologist but starting with an optometrist and then a regular ophthalmologist is probably fine with most people.

Polly Dawkins:

Got it. This might have been answered with your last question, but somebody asked, could you discuss visual spatial problems related to Parkinson's?

Suketu M. Khandhar:

Yeah, and I think that's goes along the lines of what I said before is that if you're picking up a little bit something different on one eye, you're gonna pick up something a little different on

the other eye and your visual spatial will be a little bit off. It's not uncommon for Parkinson patients, if they're trying to step off the curb for them to miss that fall because of it. Visual spatial issues also, I think think kind of lends to freezing of gait and difficulty with that. So again, seeing an optometrist, seeing whether you need glasses, seeing whether we can reshape what it is that you're seeing in your field of view can be very helpful. So visual spatial issues, unfortunately, are quite problematic with many of our patients, particularly when it comes to them wanting to walk or them feeling comfortable when they do so and not falling.

Polly Dawkins:

Yeah. Last question for you. And even though there's a zillion questions from the audience, we will get to most of them. So, you talked about low dopamine and being a hallmark of Parkinson's, can low dopamine levels cause muscle or ligament or tendon injuries to heal more slowly?

Suketu M. Khandhar:

Not necessarily. It's just that you don't have the muscle strength to be able to recover so well. And so, I think optimally treated patients will recover better than non-optimally treated patients. So, if somebody has low dopamine and they're not on a high dose of, or a good dose, not high dose, a good dose of dopaminergic medications, trying to recover from an injury is gonna be a little bit more challenging. You know, for me, optimal treatment is not just about getting through your day but making sure if something were to occur, some crisis situation, that you also can recover from that as well. So, for example, I try to optimize patient medications just before they go in for that typical knee replacement surgery, or before they go in for that hip replacement surgery, because many of our patients do require those things but if you're not well treated before that, how do we expect to recover well after that?

Polly Dawkins:

Good point. We could carry on this conversation for another half hour. I'd like to ask you, would you be willing to come back sometime and speak to our audience again?

Suketu M. Khandhar:

Absolutely. It's always a pleasure.

Polly Dawkins:

We really appreciate your time and your expertise and the commitment that you have to helping people with Parkinson's live well today.

Jackie Hanson:

Thank you so much for listening to today's episode. If you enjoy this podcast, please consider subscribing, leaving a review or giving us four stars. We ask for these things, because these really do help us, they improve our ratings in the podcast charts and help expose our free resources to more and more people in the Parkinson's community.



A big thank you to Dr. Suketu Khandhar for taking the time to have this interview with us. You can find out more about Suketu on the accompanying blog post for this episode. Also on that blog post, you will find any mentioned resources in this episode along with additional resources on this topic area in case you are ready to dive in further.

Last but not least, please remember that this is just one of the many free offerings from the Davis Phinney Foundation. Not only do we have countless additional resources to help you live well with Parkinson's through our blog, YouTube channel, live events, and more, but we also have ambassadors all around the country ready to help YOU. These are people with Parkinson's, care partners for people with Parkinson's, and medical professionals, ready to help guide you through the complexities of this diagnosis.

Thanks everyone so much for being here, and we will see you next week.