



**The Victory Summit® Virtual Event:
The Parkinson's You Don't See: When Your
Autonomic System Goes Off-Track**
"Managing Pain in Parkinson's"
Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

I would love to welcome Dr. Jori Fleisher to the stage. The last time we saw one another was at World Parkinson Congress in Kyoto, and we shared dinner and I listened to stories and I thought this woman, we gotta get her on the virtual stage. Well, I didn't know we were gonna be doing virtual. I thought we've gotta get her on the stage and present her or to the community. So here is finally our chance to welcome Dr. Fleisher to talk about one of the autonomic symptoms of Parkinson's that really doesn't get discussed much, which is pain in Parkinson's. Dr. Fleisher is an associate professor of neurological sciences at Rush University Medical Center in Chicago. She's a movement disorder neurologist and an epidemiologist who leads the Rush Advanced Interdisciplinary Movement Disorder Supportive Care Clinic. That's a mouthful. And a ,huge biography to go alongside that. So in your program books, folks, please look up her biography and you'll know so much more about why she really is an expert in this field. So, I'm gonna turn it over to you. I'm gonna go off video and let you have the stage for your presentation, and I'll be back for Q and A afterwards.

Jori Fleisher, MD, MSCE (Associate Professor, Department of Neurological Sciences, Rush Medical College):

Wonderful. Thank you so much Polly for that really kind introduction. I cannot believe how long it's been since we were in Kyoto. And thank you for the opportunity to speak this morning. Thank you to Connie and Davis for the incredibly inspiring welcome. And to all of you who logged in this morning, this is a victory, right? You are educating yourselves already. You have made the choice to learn about things that as Connie mentioned may never be relevant for you or your loved one, but are out there in the Parkinson's community. And if you'll forgive, I really, really love corny analogies, but one of the analogies that I have, that's been well received at least in our support groups is, having Parkinson's can be like going to the cheesecake factory, right? You could know someone who's gone to the cheesecake factory and never have eaten, you know, all the things that they've chosen off that ginormous novel of a menu.

Right. And you could go every week for a year and you still might never order the chicken teriyaki hawaiian egg rolls. Right. even, though you've been there so many times, so I kind of think of Parkinson's like a cheesecake factory menu, just because you see it and you've read about it does not mean that you necessarily are going to order that thing, but you're kind of

better off knowing what's out there. So that just in case someone shows up with that wrong order, you know what to do about it, right? So, with that in mind, let me quickly share my screen.

You can see the pretty slides instead of my messy office. And so, it is my privilege to talk with you about pain and Parkinson's, and I will disclose that I do not think of myself in any way as an expert in pain in Parkinson's and really diving into this topic like so many other things came from patients and caregivers, care partners affected by Parkinson's saying, is this part of it? Why are we having this? Please tell me more about this and really trying to dig in and figure out what's out there. So, what I wanna say about pain to start with is 15 to 20 years ago, if you would've asked a movement disorder specialist you know, how much is pain a part of Parkinson's, they would've told you, yeah no, not really. But it's a really important symptom. It's part of why we're here this morning.

So, these are my disclosures. I have no relevant financial disclosures related to this talk today. But do wanna shout out that there are no FDA approved medications specifically for Parkinson's related pain. So, any medications that we talk about for Parkinson's related pain today are technically off-label. But based on research. So, our goals for the day are to understand the prevalence of pain in Parkinson's, to identify and describe the different types of pain commonly experienced in Parkinson's and there are about four different types that we know of, at least today, this could change in a year. This could change tomorrow. But the state of the science right now is there at least four different types, to learn about current treatments for pain in Parkinson's including both pharmacologic, so medication, and non-pharmacologic options. So, this is kind of a cartoon of the pain pathway, right?

So, when we say pain, what do we mean? There are people whose lives are focused on understanding the details of the pathways of pain in the nervous system. So, this is just a really quick overview. But pain is really defined as an unpleasant, sensory and emotional experience associated with actual tissue injury or potential tissue injury, right. If you've ever almost hurt yourself on something, you know, that kind of moment of ah! So that kind of falls into this idea of pain and it suggests that it's not that there's other domains like emotion and cognition, so memory and thinking that can be involved in the origin of pain and how we manage pain. So how does this come to be? So, our skin, our joints and many of our organs all contain millions and millions of nerve fibers whose job it is to detect injury of different kinds.

So, there are some nerve fibers that are sensitive to heat. There are some that are sensitive to pressure. There are some that are sensitive to vibration, some that are sensitive to light touch and sort of where things are in space. If your neurologist has ever like poked you with a you know, little safety pin or something like that, it's because they're checking these different things. They're not trying to torture you. And so, all of these different nerve fibers that are all

over the body sort of coalesce and send information back up to the brain through different pathways. And there's really, there's a medial system what's called the affective or cognitive evaluative dimension of pain. This is the system that links the physical sensation of pain to an emotional response, and also to memory. The second system is a lateral system or the sensory discriminative system.

And this tells you where that pain is located and how long it lasts. So, both systems in the brain and throughout the nervous system are sort of receiving information at the same time and just kind of sorting it a little bit differently, sending it on to different way stations, but helping sort of altogether, that helps you process what we label pain. So, for example, imagine that you are a curious toddler, and you just think that this unchild-proof little electrical socket over there is really interesting, right? You just have to touch it as part of your exploration of the world. So, when you touch it, the nerve fibers in your finger will register that electrical shock. They will send that information in milliseconds up the nerves from your finger to your arm, to your spinal cord, up through your brain stem and to the medial and lateral pain systems.

Why is this important? So, the lateral pain system quickly tells you, ah! That sensation is coming from this finger, so that you can pull that finger away and get out of harms way, right? The medial system, since you're a toddler, and this is all new might first register the emotion of surprise and then connect that sensation to unhappiness or fear and lead you to cry. But what it will also do is link that sensation so that there's the connection between finger plus socket equals pain. This is not good. And it will actually store that as a memory for the future. So, all of these things are incredibly connected, which is why pain is so complex. So, how common is pain in Parkinson's? Even Dr. Parkinson recognized it. So, 1817, described what we now refer to as Parkinson's. He even mentioned at that time that he had some patients who had pain extending down the arms and fingers.

So, there are various studies showing that in Parkinson's, pain is associated with the worst quality of life, regardless of any other symptoms. We also know that it's very common. So mostly through research studies, and it's estimated about 40% of people who have pain don't even mention it to their doctor. Cause if we don't think about pain as a symptom of Parkinson's, you might not tell your Parkinson's specialist that you have pain, right? It's like you might not tell them that you're constipated if you didn't know that constipation was a really important symptom in Parkinson's. So, depending on the pain type and the way that we ask, up to 90% of people with Parkinson's can report pain at some point, granted, this could be, we ask someone with Parkinson's have you had any pain in last week and maybe they had a migraine, maybe they stub their toe, right?

So how we ask is really important, but we do know that chronic pain is twice as common in people with Parkinson's than in people who don't have it, but it's often not discussed. So,

bottom line you are not alone. This is really common. Ask for help, if you take nothing else away from this talk. When, when does pain happen in Parkinson's? Like so many other things, it could be across the entire spectrum of the disease process. So, in early Parkinson's there's some evidence that suggests that pain may be the most bothersome non-motor symptom in adults, early on in the disease. And in studies that look at folks with more advanced or late-stage Parkinson's, pain was rated as the sixth most troubling symptom. And so even early on in Parkinson's like, why is this happening? We see that there are changes in the nerve endings and there changes in the spinal cord and the brain stem in those medial and lateral pathways that process and regulate pain, those are happening even early on.

So, I mentioned that there are four types of pain, so there's musculoskeletal, dystonic, radicular, or neuropathic and central. And we'll talk a little bit about each of these. So, musculoskeletal pain, you've probably experienced this at some point in your life, right? If you biked too vigorously, if you really hit the gym hard, if you stubbed your toe, right. If you, you know, cracked your shin on something and you've got, you know, a big bruise, right. People can have problems in the muscles or bones, but in Parkinson's, we can also see this in relation to rigidity, that sort of involuntary stiffness and muscles decreased movement and some arthritis, right? So, our colleagues in rheumatology sort of the joint specialists will say, you know, if you don't use it, you lose it. And if you have arthritis, as much as that joint hurts to move, you gotta keep it moving.

You gotta keep the joints lubricated. And it's similar with muscles. And it's especially true in Parkinson's is that if you're not moving, you're gonna lose more ability to move. And so, the less you move, the more stiff you get, the more painful the muscles can be, which of course then makes you not wanna move anymore. One really, really common symptom beyond the muscle cramps and tightness that people can feel often in their calves and that can be present for years before Parkinson's. So, a Charlie horse or cramps in the calves that wake people up from sleep, cramps in the toes, sort of curling up in the middle of the night, waking people up from sleep. We can see that in other conditions, but we can also see that very commonly in Parkinson's early on. And one of the most common things that we see over and over and over, and I hear in clinic constantly is asymmetric or unilateral one side shoulder pain, shoulder stiffness.

And for a lot of our folks, especially if they've been athletes, this gets blamed on, you know, well, you know, you play baseball, you know, you threw your arm out too many times. Like it's arthritis from that, or you've got a frozen shoulder or, you know, people get sent to physical therapy, physical therapy over and over again. And they might wind up getting sent for injections of that shoulder or getting sent for surgery of that shoulder for shoulder replacements. But in the end, this was actually the stiffness and the slowness contributing from Parkinson's that was leading to that shoulder being frozen. So, the surgery isn't gonna fix it, treating the Parkinson's is gonna fix it. But for many people that unilateral one sided really stiff

shoulder can be the thing that brings them to medical care that gets them the diagnosis of Parkinson's, it's really common.

And I'm gonna come back around once we describe these kinds of pain, then I'm gonna talk about what we do. So, I don't want you to think that I'm holding out on you. We're gonna get to the treatments. So, let's talk about dystonic pain. So, this is also pretty common. What does dystonia mean? It's a fancy word to describe muscles that are fighting against each other, or one is contracting and pulling the limb and another muscle or muscle group is pulling in a different direction. So, if you imagine that you are doing a bicep curl and you wanna, you know, flex your muscle, you have to, there are other muscles that need to be a little bit activated just to make sure that you don't kind of whack yourself, right? If those other muscles though are overactivated and pulling. And so, you can't pull the bicep the way you need to, we get these twisting, you know, strange movements of the muscles that are involuntary or unintentional.

So, people with Parkinson's can experience repetitive, patterned postures of dystonia. So, it's often the same things. It might be a foot that's turned in or pointed down, or both. It might be toes that are kind of curled or cramped. These can cause, sometimes it's not painful at all, but sometimes these can be painful. They are paroxysmal, which means they come and go. They can be spontaneous, they can be triggered by movement. They can occur early in Parkinson's just as part of the disease. They can also occur later in the disease where we see that certain forms of dystonia are better when medicines are working and as medicines are wearing off, the dystonia comes back out. So, some OFF dystonia, and you can imagine that if the muscles are cramping and curling in ways that they shouldn't, that could be painful.

So foot dystonia, as I mentioned, is among the most common forms. So, we often describe this as plantar flexion, which means pointing your toes down, think about ballerinas and foot inversion. So, sort of tilting in and that may occur early. Sometimes that can be a presenting symptom for people, especially in folks with early onset Parkinson's and certain genetic forms of Parkinson's. More often, we see it as a complication of treatment, as I mentioned. So, I know a lot of my folks struggle with, you know, their meds are working during the day. They're doing pretty well, but they wake up first thing in the morning. They've got no medicine in their system. They're just trying to get their day going. They're trying to get to the bathroom, get dressed and do all the things. And their foot is just curled up.

Those toes are curled up or the foot is curled in. It makes it really hard to get your day going. That's often a symptom of being at your lowest dopamine point for the day. For other people, they can have what are called dysphasic dystonia or peak dose dystonia, which means they may have some dystonia when the meds have worn off, but they may all also have dystonia often in the face and the neck where you get kind of pulling postures. Those can happen when the medicines are working, sort of at their highest levels in the system. So, it can be pretty

complicated. So radicular or neuropathic pain is another type. This is seen in about 5 - 20% of folks. I just yesterday told someone who said, yeah, I got this sciatica thing, but that's not in your area. Yeah, it is.

So, what is radicular or neuropathic pain? If you take a look at this diagram on the side. So, this is sort of a cross-sectional view as if we were looking down into the spinal column and looking at how the vertebrae lineup. And so, this is a disc. When people talk about herniating a disc, a disc is almost like if you imagine a jelly donut, there's sort of a harder outside and a very squishy inside. As we age, that squishy, this outside of the donut gets kind of stale and so you smush it a little bit too much, and the jelly can kind of come out the side and that jelly comes out the side essentially, and smushes onto the nerves that are coming off of the spinal cord at every level and need to go out through tiny little tunnels.

But instead they're getting pushed by that gel from the inside of the disc. Oftentimes people have some arthritis that makes the little tunnel that the nerve needs to go through even tighter. So, you have this tiny, tiny, fragile nerve that's getting sort of crushed by different things. And when a nerve gets crushed, it causes a really specific kind of pain, which can be a sharp, shooting, electrical kind of pain. If you've ever had sciatica, if you've ever actually bumped your funny bone, you get that zing sort of sharp pain, that's neuropathic pain. You're getting that, cause there's a nerve that runs right here just where you like to put your elbow down. Right? And so, in people's back, if they're having dystonia, if their posture is a little bit off, if they're stooped forward and they're crunching their spinal column in different ways, if they have other changes to their spinal column, just from arthritis or from older age, we can see that those nerves get crushed more often.

And what that leads to is often this pain that kind of shoots down the back of the leg. It can go into the buttocks, it can go down the side of the leg. It can go down the back of the calf, even all the way into the foot. So, if this is happening, we don't instantly blame it on Parkinson's. We wanna make sure there are no other causes. If there's a disc that's gone awry, if that jelly has squished out, our neurosurgery colleagues can do surgeries when it's appropriate to try to kind of clean out the gunk, make a little bit more space, leave some room for that nerve to heal. We can do neurophysiological testing to see if there's some other reason for that nerve being injured. And it may be due to postural changes, right? As I mentioned, it may be due to all kinds of other things.

So, we sort of go through why is this nerve being injured? And then we can try and attack that with treatments. The last kind of pain is central pain. So, this is the rarest form we think. But this occurs in probably 10 - 12% of people. This can be poorly localized. What does that mean? Usually when we ask people, where does it hurt, right? You should be able to point and say, it's you know, in my buttocks, it's radiating down my leg or it's, you know, in my toes that are

cramped up. I have folks that will say I just hurt. Everything just hurts. And it's hard to describe pain. It's just sort of all over and nowhere all at once. It's vague, it's not sharp. It's not dull. It's not achy. It's just hard to say what it is, but it's pain.

Right? So, this can happen in Parkinson's, and this is very, very tricky, as you can imagine, it kind of sounds like, where is this coming from? We know in general, where in the brain, this sensation is sort of coming from, but how to treat it can be very tricky. And sometimes this show up in more unusual ways, so people can have burning sensations, like burning sensations in their mouth, in their genitals, rectal pain, again, very uncommon. But if this happens, we know what to call it and we know to at least bring it up to our Parkinson's specialist. So, speaking of that, recognizing that you have pain, recognizing that it could be related to your Parkinson's, step one, you're done, you've got it, right? Now, who do you go to and what do you talk, what do you say?

So, you know, I love this. When will it get better? I don't even know what it is yet. Right? We have to describe what it is as far as the symptoms to know how to get help. So, I put on here, this is the little thing that we are taught in med school about how to take a history, right? You're supposed to ask these questions and the acronym is old carts. What is the onset of the pain? When did it start? Where is it? How long has it been going on? Or if it comes and goes, when it's there, how long does it last? I have radiating pain down the back of my leg. It started a month ago. It's there for seconds at a time. And then it goes away, but it's sharp. It's shooty or it's achy or it's crampy. These are all of these things that if you can think about these before your appointment, it will absolutely help your doctor or your healthcare provider to really think through where is this coming from and what do I need to do about it?

Aggravating and alleviating factors are very fancy medical ways to say what makes it better? What makes it worse? Right? Are there positions, putting your feet up on a coffee table, leaning back, turning over in bed? What makes it better? What makes it worse? Heat packs, ice packs, massage. All of these things are really important to know. So that's sort of the general, this is a helpful way to think about things. But in the last couple of years, there's been more of an effort to try to come up with tools specifically for pain in Parkinson's to help us report what's going on. So, this Parkinson's pain questionnaire, happy to share my slides, and this is accessible online. So, if you wanted to, you could even print this out. If you are experiencing pain before your next visit with your Parkinson's specialist and check off, sort of come in ready, you're ready to go.

With this King's Parkinson's disease pain questionnaire. So, it's a 14 item Parkinson's specific screening tool. Check off, here's what I'm experiencing. And then you can hand it to your doc and say, this is what's bothering me the most today. I wanna focus on this, right? That can really help us on the other side of the encounter understand what's most important to you today and

really drill down to that. So, the other things to do, write it down. This applies to, I would say anything, not just pain. This is if you're having fluctuations, if you're having dyskinesias, if you're having drops in blood pressure, keep a diary, does not have to be detailed, but keep a diary for three days before your visit. And it will do worlds of good. What do I mean by a diary? Okay. What you wanna keep track of is what you actually did, when you actually took each medication that you're supposed to, do not write down every day for three days in a row that you took your 8:00 AM at 8:00, because I will tell you that for most people, that is just simply not true, right?

We know that medication adherence is really challenging, especially in a condition where you have to take meds sometimes multiple times a day. We also know doctors are the worst patients that if we're supposed to take something at eight, you know, one day maybe we took it 7 45, one day we took it at 8:30. When you keep a diary to try to track these really finicky Parkinson's related symptoms, write down when you actually took it, because on my end, I'm gonna make medication adjustments, potentially, based on what I think the pattern of your symptom is in relation to the timing of the medicine, but if the timing of the medicine isn't actually what you wrote down, then my changes might go the complete wrong direction, right? So, honesty is by far the best policy. Your doctor should not be giving you any hard time if you're taking your medicines late or early, if they are, maybe you need to find another doctor.

Alright, so say for example, here's just an idea. You know, here's Monday. I took my levodopa at 8:03. It was ON for most of the day. Oops. I forgot my evening dose. But I was doing pretty well. Monday was a good day, but on Tuesday I had really bad toe curling. So that dystonic pain right, before the meds, took that medicine late. So, hey, I look at this and then I say, wait a minute, this looks like early morning OFF dystonia. They're getting this problem before their meds are kicked in. Okay. They took their medicine late. Maybe they took it with food. Maybe there is an interaction, but things were going pretty well. And then we got some muscle stiffness later and then the meds went back ON and the person was feeling good. This is so, so helpful and will get you the results that you want sooner.

So, contrary to popular belief and this cartoon, there is no one size fits all approach to pain in Parkinson's. Just like any other symptom, no two people experiencing a symptom in Parkinson's are experiencing exactly the same thing. So, what do we do? Multidisciplinary approach is our answer. There is no one answer except this, which is we need to pull on all of the resources that we have. So, exercise, exercise, exercise, physical therapy will be huge. They've been demonstrated to help maintain range of motion, prevent falls, prevent contractures fractures. We know, in early disease this is true. We also know in later Parkinson's that interdisciplinary, palliative interventions have shown that pain is both one of the most common symptoms, but is also one of the most treatable. I will tell you, in my own work, doing home visits with folks who

are home bound with Parkinson's, that we found over a year, that we could improve bodily discomfort.

The assumption is everything's gonna get worse, right? Wrong. We can improve bodily discomfort, and it's not through any magic it's through recognizing pain and using really simple, straightforward things. Often over the counter to try to address it. Sadly, only three drugs have ever been studied for pain in Parkinson's in really rigorous randomized control trials. And none of those seem to show a difference. Does that mean that we don't use them? No. We use what we've got and we try our best and we base it on clinical experience. So specifically for musculoskeletal pain, usually physical therapy is our number one. It's gonna be the bedrock of any treatment, learning how to use those muscles more efficiently, how to use them better, how to stretch plus minus medications. So, heat, ice, massage, you know, Icyhot, Bengay, Arnicare gel, all these things that are out there can all be used together.

If pain is due mostly to rigidity, that stiffness, or to bradykinesia, the slowness of movement, sometimes adjusting the dopamine replacement, the dopamine agonists may help. So, this might be in the form of levodopa or dopamine agonist, this be therapies to extend how long those other medications are working. And there's some early evidence that one newer Parkinson's medicine safinamide may show some improvement in the use of pain medications. If someone has rheumatologic disease. So rheumatoid arthritis, if they have orthopedic issues, then things like nonsteroidal anti-inflammatories like ibuprofen or Naproxen can be helpful. And if there's really significant joint injuries, if someone's got a really bum knee, and they can't exercise, they can't do all their Parkinson stuff cause they just can't bear weight on that knee, well, then we need to fix the knee, and sometimes that's just what you gotta do.

In the setting of that ridiculous or neuropathic pain, that sharp shooting, zinging pain, that's coming from a nerve being crunched. We wanna avoid overuse and poor posture. So, if, because you're sitting at your desk like me and you're hunched over all day, you're crunching a nerve in your back. Well then we get a little lumbar support pillow, or then we work with physical therapy on being big and being tall. Sometimes this can require surgery to sort of open up the space around that nerve, but there are many options in terms of medications that specifically work on that nerve related pain. So, we can use things all across the spectrum from low dose antidepressants that work on these pathways including tricyclics and selective serotonin or selective serotonin norepinephrine reuptake inhibitors. These are things like duloxetine certain anti-epileptic, medications, Gabapentin, pregabalin. These are really effective for neuropathic pain. You don't have to have seizures to use them. They're not going to give you seizures from using them and things like NSAIDs, like ibuprofen and in rare cases, sometimes we need to escalate and use opioid analgesics like morphine or codeine.

For dystonic pain, that crunching, curling, often when the medication is worn off. That's why we wanna keep that diary and see, where is this in relation to when you're taking your meds? We adjust the dosage, it might be adjusting the dose, it might be adjusting the timing, the frequency, getting you longer formulations. There's some evidence that rotigotine, which is a dopamine agonist patch, improves some of that fluctuation related pain in two studies. For folks who have really that focal dystonia, where it's one area or one limb, using botulin toxin injections to sort of relax those muscles a little bit can be very helpful. And there's some studies that have shown deep brain stimulation can improve, certainly can improve dystonia, and so when people with dystonic pain, this may be a really good option for them. So central pain that's hard to describe, vague, it's everywhere, it's nowhere all at once pain. This is the challenge. We always start by trying to adjust the dopamine therapies to see if we can get a handle there. But then we have this whole other list of things that we try to use. And there's really no textbook for this. It is a bit of the art and science and clinical expertise.

I do wanna hit on a couple of other things that are really important considerations in the treatment of pain in Parkinson's. So, depression is critical to think about, and it's not a straightforward association. People with chronic pain in general are more likely to be depressed than people without chronic pain. That seems to make sense. And people who are depressed are more likely to have chronic pain than people who are not depressed. Plus, people with PD, with Parkinson's are more likely to be depressed regardless of pain than people who don't have Parkinson's because there are chemical changes in those circuits as well. We also know that people who are depressed have a very hard time with sticking to their medication regimens, whatever that is. So, they often miss doses. They're often stopping medications sometimes without telling their loved ones that they've stopped a medicine. And this can lead to these vicious cycles of frustration where the family says, but you're supposed to be taking and the person says, but I don't wanna take, I don't think it's helping, maybe because they're not taking it the way they're supposed to take it. Right.

And then they go to the doctor and they say, well, this medicine isn't working and the doctor goes, oh man, I really wanna help. Okay, well let's, maybe we need to increase the dose of that medicine. Maybe we need to add another medicine on top of it. And meanwhile, this is all sort of piling on and getting out of control. And the depression is underneath. It's sort of catalyzing all of this. So really, really critical to be thinking about that as a contributor, it's not the only answer, but it can be a contributor. If someone has diabetes, if they have other conditions that put them at risk for kinds of pain, we wanna make sure we treat that. Osteoporosis, rheumatologic diseases as well.

I mentioned very quickly deep brain stimulation. So, this has been studied in relation to pain in multiple studies and most studies primarily looking at STN or sub thalamic nucleus deep brain stimulation, show improvement in pain symptoms with stimulation. There's still a lot of work

going on, but DBS may help with pain in some folks. So, what about alternative treatments? Right. We often refer to alternative treatments as complimentary and that's because at least 40% of people with Parkinson's use one of these in addition to more standard Western medical treatments. Though only half of people who use alternative treatments, tell their physician that they're using them. So, A, please tell us everything that you're using so we can make sure stuff isn't interacting. We are not going to judge you. And again, I say, if someone's judging you, maybe that's not the right person for you, find someone else.

But I just like to give a little bit of background on, you know, well, my doctor doesn't, you know, tell me about any herbal therapies or any, you know, things like that. Part of that is training in Western medicine is there's this very heavy reliance on first do no harm. And the way that that is often interpreted is if we are going to recommend something, we need to know enough about it, to know and be able to counsel you. Here's what you can expect that it will do for you that's good. Here are the benefits and here are the harms. And for a lot of alternative treatments, they may be studied, they may not be studied in the most rigorous scientific Western medicine standards. And so, we might have a study that says, hey, I did this thing in 10 people and they all said that they felt better, but there's no reporting on like, well, did they have any side effects?

We don't know. So it's challenging sometimes to be able to fully endorse something if we don't have all the data in front of us, that doesn't mean it doesn't work. We just might still be waiting for more information. So, there's some information that suggests that acupuncture certainly is helpful in other pain conditions and maybe helpful in pain in the setting of Parkinson's. It tends to be well tolerated. There tends to be very few side effects. Maybe find a more reliable acupuncturist than our friend in the cartoon. What about medical marijuana? This is a constant, constant discussion. So, here's the challenge with talking about medical marijuana. Aspirin is one chemical. We know a lot about aspirin and yet if you follow the news, it seems like every other week there's some new study that's like, aspirin is good for you.

Aspirin is bad for you. You should take aspirin. You should not take aspirin. Aspirin is one chemical, marijuana contains at least 60 active chemicals, including THC, which has psychoactive effects. That's what makes people trippy. That's what can cause hallucinations, CBD has the potential therapeutic effects. So, in lab and basic science studies, there are any number of pathways by which it makes sense that the compounds in marijuana could affect pain circuits. So, these receptors are all throughout the nervous system, especially in the basal ganglia where Parkinson's tends to really affect, but they have a lot of different effects. And so, there are many, many surveys. There are some studies that have been done in Parkinson's, the data we still don't know yet. So, there's a survey of 339 people. That sounds awesome. 25% said that they used marijuana, not in a medical context, 46% of those people with Parkinson's described some benefit to their Parkinson's symptoms.

Here's why understanding the science is really critical. 339 people. That sounds amazing. Turns out only 54% of those people actually completed the survey. So, 183 people filled out the survey, 46 people, people said that they used marijuana and 21 people said that it helped. Those actual numbers seem quite different from what's reported, right? That's often we get these nice headlines in the news. When you drill down to like the real deal, what happened to actual people like me, it gets a little bit more complicated. There have been small studies where people knew what they were getting. So, there's a placebo effect, involved, subjective improvement in some symptoms, not so much in others and in four well designed controlled clinical trials, no significant benefit was found. And in a study that looked at whether medical marijuana was helping with dyskinesias, that actually showed a trend towards worsening.

So, if you choose to go this direction, if you're in a place where it is legal, either recreationally or you get a medical marijuana card, just keep in mind that we know some side effects, which can be low blood pressure. So, hang tight to that for future talks this morning, dizziness, hallucinations, sleepiness, confusion. Bottom line is the current research right now suggests that cannabinoids are probably ineffective for both levodopa induced dyskinesias and motor symptoms, but we need further rigorous studies to really answer this question. So, in summary, pain disorders in Parkinson's are common. They are underrecognized, they are underreported, but they are detrimental to wellbeing, and they are manageable. Early asymmetric, stiff, or painful shoulder is a common and often misdiagnosed presenting symptom of Parkinson's, talk with your neurologist. Talk with your movement disorder specialist before you let someone take you to the operating room and open up that shoulder. Pain in Parkinson's can be categorized as musculoskeletal, dystonic, neuropathic, or central.

You can have some from every column, but we can address them. So, paying attention to the timing, the quality, the relation to medication doses is really important. Keep that diary. Think about those OLD CARTS, the onset, location, all these things that will help you have a better conversation and get to a better treatment with your treating provider. Always, always, always ask about a multidisciplinary approach. If someone says you should try this medicine. Awesome. Should I also be doing physical therapy? Should I also be thinking about acupuncture, should I also be stretching, give me some resources for that they're out there. Okay. So physical therapy and exercise really help improve mobility, prevent contractures, maintain range of motion. And we wanna tailor the medication therapy if we need it to the type of pain that's involved. Right now, there's no proven benefit for medical marijuana or other alternative in the setting of pain in Parkinson's. Please stay tuned. So, with that, I think those are my references. And thank you so much for the opportunity to speak with you this morning.

Polly Dawkins:

Thank you. Thank you, Dr. Fleisher. That was incredible. If you are ever feeling low and you need some upbeat feedback, the comments from the chat about how terrific this presentation



was, we'll compile those for you. And you can just put 'em on your wall and look at them anytime you're feeling like, am I making a difference? Cause this was terrific. People loved it.

Jori Fleisher :

Thank you so much.

Polly Dawkins:

There's one comment from, I think it was Betty Shapiro who misses you in Pennsylvania, she misses you. So, that was fun to see. I have time for just a few questions from the audience. Your slides were so complete. I'd like the audience to know that we will send your slides and a recording of this so people can watch it again and fast forward, slow down, rewind so they can see it in the future and share it with others. So don't worry. We'll be sending that. Couple of questions, Kevin asks, does mindfulness practice actually reduce pain or just allow one to tolerate it?

Jori Fleisher :

That's a really good question. I don't know if we know and I don't know if we know whether those two things are separate, right? Because if it improves your ability to tolerate pain, because pain is so multi component multifactorial and there is this emotion component, if you can tolerate it more, I would argue, then that means that you're actually changing how you perceive pain. Right. So yes and no, and all of the above. And that's a great question. And there are people that are spending their lives, both scientists and physicians, and probably philosophers trying to answer that question. So.

Polly Dawkins:

Yeah. Thank you. Thank you. You mentioned a pain diary tracking. Do you know if there's first an app or any digital way to do that?

Jori Fleisher :

That's a great question. I know that there are many different apps out there for tracking symptoms. I don't know if things like Empower, which I know is like one of the popular ones for Parkinson's symptoms. I don't know if it has pain on there. I would be surprised if it wasn't, but it may just be like one question here or there. So, I'm not aware of any that are specific to that

Polly Dawkins:

Super. And we at the Davis Phinney Foundation will take what you've created, if we don't already have a worksheet, we'll create a paper one that you can download after this presentation so people can track their pain and use that. So, thanks for that idea. You've

answered so many of these questions... is severe neuropathy in the feet, and could that be an early symptom of Parkinson's?

Jori Fleisher :

That's a really good question. So there's a lot of kind of conflicting evidence about if you just have neuropathy where like you have numbness or you have tingling, or you have sort of heightened sensation or pain where there shouldn't be pain that starts kind of in both feet, you know, and gradually works its way up. We often think about neuropathy like that in terms of diabetes, but there's evidence that maybe this can be part of Parkinson's and is it the Parkinson's itself? Could it be the treatments? Could it be the treatments are causing a vitamin deficiency and that's what's causing the neuropathy? The research is still ongoing. Right now, there isn't a recommendation to say like, well, you should replace your B12 even if your B12 levels are low. I would say having that as a presenting early symptom, I would worry that we're missing something else. That would be my take on it is we would wanna go through sort of a regular neuropathy workup, and there's a lot of labs that we tend to send off just in general neurology to say, could it be thyroid? Could it be, you know, do you, could you have diabetes that's undiagnosed? I've certainly had people, you know, there's a lot of other things that can cause burning or neuropathic pain that we wanna exclude, especially cause they're treatable.

Polly Dawkins:

Got it. One last question and the audience just has so many great questions here. Again, your presentation really covered so many of them, but last question and we can follow up with links about sleep, but there are many questions about uncomfortable restlessness and sleep. And could that be, why does that happen? And is there anything to do about that?

Jori Fleisher :

So that sounds like it could be, not necessarily, but it could be restless leg syndrome which is really common in Parkinson's and outside of Parkinson's. But it's this uncomfortable creepy crawly sensation. It's not necessarily pain, but sometimes it can be hard to distinguish and pain is so subjective. Right. But it's this like feeling that begins usually in the legs that you just need to move. So, we see this in Parkinson's, we can see it on its own. We always, always, always want to make sure that someone isn't iron deficient because that's a very common trigger for restless leg syndrome and treatable. So, if you have a, you know, if you have restless leg and someone has just sort of said, yeah, while you're have Parkinson's, so restless leg goes with that. Yes. And let's make sure you're not iron deficient.

And why is that important, this is a question that we often give to our med students, is iron deficiency in an adult can often be a sign of blood loss. Right. And we might, we might write it off. But there are certainly people where, you know, they could have a cancer, they could have something else. And some other reason that they're iron deficient that's causing them to have

what seems like a plain old Parkinson's symptom. And sometimes we focus so much on Parkinson's and there's so many things Parkinson's can do that we are just like, yeah. That's Parkinson's yep. Yeah. That's Parkinson's and we kind of, we take our eyes off of the other things that it could be, and we don't wanna miss those things. So, check your iron levels. If you have to take iron, take iron, it will help your restless leg take something to treat the constipation that the iron is gonna worsen. That's gonna worsen your Parkinson's constipation. So, it does get a little, you know, taking something to treat the side effects of something else, but it's really important and getting good sleep will help all of the other kinds of pain also.

Polly Dawkins:

You've set us up for so many other conversations that we need to have and bring to the community. We will be doing a Victory Summit event in, I think it's in September all about sleep. So yes. So that will delve into that. We do have many resources on sleep, but thank you for addressing that. I've never heard about the iron deficiency causing restless leg. So that's a really interesting...

Jori Fleisher :

I did just see a really quick questions pop up that I wanna address cause it was a great question, but I can't take iron if I'm on levodopa, don't take them at the same time, but you can take them separated in time. So that is not a contraindication. You just, the iron, if you take iron at the same time, I mean, literally think of it as like iron man's, it's like no levodopas getting into your gut right now, but let the iron pass. Right. And then you can take your levodopa later. So just keep them separated out in time.

Polly Dawkins:

Great strategy. Great strategy.

Want to Watch a Recording of the Webinar?

You can access the recording [here](#).

Want More Practical Articles Like This?

Much more can be found in the Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action.

[Request Your Manual Now](#)

Thank you to our Peak Partners, Amneal, Kyowa Kirin, and Sunovion for making it possible for us to print, distribute, and ship the Every Victory Counts manual