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Veronique Enos Kaefer:

Welcome to a recap of our latest Third Thursday Webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at [michaeljfox.org](http://michaeljfox.org).

María De León, MD:

Welcome to our Third Thursday Webinar, When Parkinson's Hurts: Treatments for Managing Pain. My name is María de León, I'm a movement disorder specialist. I'm also a Parkinson's advocate and I'm a council member of the Michael J. Fox. I was diagnosed with early Parkinson's nearly 17 years ago. And it's great to be here. I am a veteran of this topic. I've had different types of pain over the last journey of my journey of Parkinson's. Today we'll discuss Parkinson's and pain and how it can impact your lives. Parkinson's can cause different types of pain, and so we're here to discuss how we can manage it better today with different lifestyle changes, medications and so on. We got a lot to discuss, and we have an excellent panel today.

Let me introduce our panelists. First I'd like to introduce Ethan Henderson, who is a member of the Michael J. Fox Foundation Patient Council. And he too was diagnosed with early-onset Parkinson's disease in 2016. He is also a senior associate director of Advancement at the Michael J. Fox Foundation, and a Parkinson's policy advocate. Welcome, Ethan, thank you for being here.

Ethan Henderson:

Thank you.

María De León, MD:

We also have Dr. Lillie Rosenthal. She is a physical medicine and rehabilitation physician in New York City. She's an expert in lifestyle management for injury prevention, pain management, and integrative health. She's also a consulting physician for the New York City Ballet, that is just wonderful, Metropolitan Opera and more. Welcome, Dr. Rosenthal.

Lillie Rosenthal, DO:

Thank you.

María De León, MD:

And we also may be joining a little bit later by Dr. Indu Subramanian. She is a movement disorder specialist and clinical professor of neurology at UCLA. She is a neurologist with the VA and director of the Southwest PADRECC Center of Excellence in Parkinson's disease. Dr. Subramanian is also co-chair of the Wellness Task Force of the Movement Disorder Society.

Thank you very much, I think we're ready to proceed. For many of us living with Parkinson's, myself included, pain can be a part of experience. And for myself it was the beginning of all my problems. 75 of people with Parkinson's report having pain at one time or another. And pain can occur in the early stages, mid-stages and late stages. And unfortunately, because we don't have a good scale or because sometimes it's invisible, pain can be often unrecognized and untreated. What we're going to do is then ask some of our wonderful panelists how they've had their interactions with pain. Ethan, what has been your experience with pain and how has it changed over time?

Ethan Henderson:

Yeah, so thankfully I had been trying to figure out what the pain in my neck was for a long time and I went to a pain specialist. And she was the one that first floated the idea that I may have Parkinson's. And so I got to see movement disorder specialist quickly and received my diagnosis. That neck pain has not gone away in the eight years now that I've had the diagnosis. It's also expanded out into the shoulders and I've had other pains of my body that I can manage, but it's always part of my everyday life.

María De León, MD:

I'm sorry to hear you're having pain. I know the feeling, I started with pain too. Well, I'm glad that you got a diagnosis after recognizing and somebody recognized those parts. Dr. Rosenthal, what kinds of pain do your Parkinson's patients report besides what Ethan has mentioned to us?

Lillie Rosenthal, DO:

Yeah, pain, I just want to give an overview. We often think of pain as the diagnosis, but I'd like to open up and rethink the idea of pain. Pain is really a signal, and I also, when I see patients in pain, Parkinson's, non-Parkinson's patients, I think of pain and I like alliteration. I think of pain as a puzzle, something to figure out. The real trick of figuring out pain, managing it well, removing it, hopefully eliminating it is to figure out what is the root cause and what are the root causes of pain. Pain for all of my patients, often it's tremendous friction in life. As we all know, pain is also an experience, right? Pain is an emotion. Pain isolates us as we know. In my practice and especially with Parkinson's patients, pain can come from multifactorial reasons. It could be musculoskeletal, it could also be the pain of stiff joints. It could also be pain of constipation.

I want to really open the idea that pain is not something just to be suppressed. But also that pain is not just something that should be passively managed by your physician. Even though I am a physician, I really take very seriously the conversation of what patients can do that's safe, effective, that works. And there are so many things which I'm excited to share that have no side effects that can actually change the game and the lane of pain. Some of the things I see often, things like frozen shoulder, stiff joints, headache, things that can or cannot be directly related to Parkinson's. I'm excited to have this conversation and really hopefully will empower people to make very significant effective changes.

María De León, MD:

Thank you, Dr. Rosenthal. It is so true that pain is amalgam of things. And it's not just a diagnosis, but it's also a symptom. And as I've often told my patients, a symptom of Parkinson's, just like the tremors or the stiffness. And so we need to figure out how to treat it and how that is part of the Parkinson's? But I like to know how do you differentiate, is this a pain from Parkinson's versus a pain related to other old age, arthritis, some other systemic problems? Because I think some of our patients have that conundrum, "Do I go to my neurologist or do I go to my primary care doctor or somebody else?"

Lillie Rosenthal, DO:

100%, and that's a great question, because we want to know if we're going to dig down as investigative reporters of what symptoms are due to what? Often there's overlap, so I just want to say that. And which doctor to go to, right? When we tend to just, any chronic disease, and Parkinson's is definitely in that bucket of a chronic disease, we tend to overemphasize that everything is due to Parkinson's disease, or Alzheimer's, or diabetes, or any chronic disease, so I want to open up the conversation. But the questions to ask, and I get so much of my information from basically this is pretty old-fashioned, but it still works, a very good history, and a very good physical examination. Because just because you have Parkinson's doesn't mean you can have a frozen shoulder from something else, or back pain from poor posture, or a stiff joint from being less active.

María De León, MD:

Exactly. Thank you. And this is where having a good history and always keeping a journal, and I think Ethan does this. Your doctor asks you to keep a journal of your pain symptoms so that we can figure out is there any connections to the Parkinson's, the medications and your routine? What have you discovered about that, Ethan?

Ethan Henderson:

I wish there was a golden nugget answer, but we've been keeping track of when it's off periods and when it arises, whether it's I'm doing physical activity or if I'm just sedentary. There is not a strong answer. I will say that more times than not it is when I'm in my off periods from my medications. But to go back to the question you were saying, "How does it differ between PD and others?" Pain that I feel now is quite different than what I felt when I was young and I was active and just lots of bumps and bruises from being a young kid. These are quite different and they shown up in different areas of my body. Also with muscles cramping and other things like that. I exercise all the time but it does not completely alleviate, and so I have other ways to deal with that.

María De León, MD:

And we will get back into that lifestyle, and I appreciate it. And you guys have really shown us how there may be different types of pain, how people manifest differently and feel differently and we have to think about it not just in isolation but also in conjunction with the Parkinson's and other symptoms and what's going on. We're going to proceed right now to look at a video. Pain from Parkinson's can have a variety of causes as we discuss, and we'll get more into it later. We thought we will show you this video that Dr. Rachel Dolhun has provided for the Michael J. Fox Foundation. Our main causes and most common treatments for Parkinson's pain. Right after the video we'll do a deeper dive into the treatments and lifestyle changes for living with pain and discussing what Dr. Rosenthal, Ethan and myself have done to deal with this and what we have found works and doesn't work. And we'll try to answer as many questions as we can.

Rachel Dolhun, MD:

Many people wonder if pain can be part of Parkinson's. It can be, and there are many different types, which have different causes. First, pain can come from movement symptoms. Parkinson's movement symptoms such as rigidity or stiffness and slowness of movement can lead to muscle pain and joint stiffness and aches. This is called musculoskeletal pain. Dystonia, which is an involuntary muscle spasm is also a common cause of painful cramping, typically in the legs, feet, or toes. If dystonia occurs, it's often when medication wears off between doses or before you take the first dose of medication in the morning. Pain can also come from Parkinson's disease itself. Because Parkinson's affects areas of the brain that process sensation and pain, some people experience pain from the disease itself. This can sometimes be hard for patients to describe and for doctors to diagnose, because it can cause many different types of pain. It might be numbness, tingling, burning, or sharp stabbing pain. And different may experience it in different areas of the body.

Lastly, pain might be caused by conditions other than Parkinson's. Other diseases such as lower back problems, pinched nerves, arthritis and even depression and anxiety can also cause pain. Many of these conditions become more common as we get older. Because the pain in these conditions is similar to the pain in Parkinson's, people often ask, "How do I know if it's age or Parkinson's?" Both arthritis and Parkinson's, for example, can cause stiffness and difficulty moving, especially in the morning, and one can worsen the other. Joint pain from arthritis can make slow movement from Parkinson's even slower, and moving slowly or less with Parkinson's can make stiff joints from arthritis even stiffer. No matter the cause, pain can contribute to mood and sleep changes and decrease quality of life.

It may be helpful to keep a log of when your pain comes on, especially in relation to when you take your Parkinson's medications. And to note where you feel it, what it feels like, and how long it lasts. This can help you and your doctor figure out the cause and the best treatment plan. Whatever you do, don't automatically assume pain is or isn't part of Parkinson's or that nothing can be done to ease it. There are multiple options for treating pain. With your personal physician you might adjust your Parkinson's medications. If movement symptoms or dystonia are causing or contributing to pain, your doctor may change the dose or timing of your medications. For dystonia botulinum toxin injections such as Botox can temporarily relax certain muscles and decrease cramping and pain. There are also non-medication strategies you can use. People find pain relief through many different routes, including massage, meditation and acupuncture.

Although most of these techniques do not yet have rigorous scientific evidence to support them, careful and cautious practice if your personal physician approves may be helpful. Exercise or physical therapy are other options. It can be hard to want to move when you're in pain. But activities such as yoga, walking, or stretching are helpful for many types of pain. A physical therapist can direct you to the best program for you and your symptoms. And sometimes pain medication is necessary. Depending on what is causing your pain and how severe it is, your doctor might suggest you take an over-the-counter anti-inflammatory or a prescription drug. Always talk with your physician before starting any medication.

María De León, MD:

Wonderful. I hope that was a great overview of the PD pain. Dr. Subramanian, Rachel mentioned a few medical options for treating pain. Why does adjustment in PD meds or use in Botox help with pain?

Indu Subramanian, MD:

As part of the off symptoms of Parkinson's disease, especially with that stiffness aspect, you can sometimes get muscle cramping as part of your cardinal Parkinson's symptoms itself. And so with that cramping there can be sometimes painful cramping that happens. People can feel stiffness in their joints that can be coded as pain, which can sometimes even exacerbate other existing pain. If you have back pain and you have an off sort of medication timeframe, sometimes the back pain or the hip pain or the knee pain can get worse. And so I think the first thing that we try to do is make sure that the fluctuations, the motor fluctuations are stable, so we have not much dopamine fluctuations. And so we can adjust the baseline Parkinson's medicines and see where we get with the pain complaints. This can also be quite effective for people who have early morning off periods or stiffness, cramping overnight, adding sometimes some long-acting levodopa preparations overnight at bedtime can help with that as well.

María De León, MD:

Wonderful, thank you very much for your expertise. But I'm really curious, Ethan, you said you began with pain, did you notice any improvement or change when you started treating the Parkinson's when you got diagnosed and started on actual PD treatment? Was the pain any different, or?

Ethan Henderson:

I'll be honest, I didn't notice a difference in the amount of pain, but the severity, yes. The [inaudible 00:16:24] levodopa certainly has helped. And as just mentioned, because of my cramping is in the middle of the night, my movement disorder specialist has instructed me to take my last pill right before bed, so that helps. But it certainly has not reduced the frequency, but the severity, definitely yes.

María De León, MD:

But it's helped. Okay. Yeah, just a personal note. I began, as I said earlier with pain, and as you've heard from the panelists and also from the video, there's different types of pain that you can see in Parkinson's,

central pain, radicular pain, musculoskeletal pain, and all of these types of pain can occur in every patient at different times, so it's always important to know. But the one thing that I've discovered, I had severe central pain that felt like acid was being poured on my body when I was touched or showered. And when I started the Parkinson's medication my symptoms went away. Fortunately for me, the pain symptoms, the central pain responded. It may not always be true, but I think it's always important to not only think about other possibilities of pain, but also always think that treat the symptom of pain like you treat the motor symptoms or the other symptoms of Parkinson's to try to see if we can get improvement. Moving on, that's just been my experience. And I'm glad you got some relief, but maybe some other things will come up.

Dr. Subramanian, we have a lot of questions about DBS and pain relief. Can you tell us more how DBS can reduce pain for Parkinson's and what types of pain for Parkinson's does DBS work best for?

Indu Subramanian, MD:

In my experience, DBS works best for, again, those on-off fluctuations. We can't get you any better than usually how you best feel on levodopa when you're in the on state without dyskinesia. If we can reduce those fluctuations, and some people code when they're turning off or when they're off that they have pain that re-emerges. If that sort of pain responds to levodopa and when you're in the best on time your pain is reduced or you're pain free, then that gives us an indication that DBS may be a good option for you. DBS is something that can help smooth things out in the 24-hour cycle. It may help get people sleeping better, that sort of off pain in the middle of the night or in the early morning cramping, those things can certainly respond to DBS. And I think DBS also can help quality of life in general.

When people can feel globally better, often their mood improves, they feel like they can get back to doing their activities of daily living, they can start sometimes doing some of the wellness stuff that we all feel is helpful. Things like starting to exercise more is, starting to connect more socially, starting to get more out in their communities and feel like their old selves. And all of this can feed forward into feeling like the pain is overall better.

María De León, MD:

Thank you very much. But one quick question, not everybody knows what DBS is. If you can just briefly tell us what DBS is for those people in the audience they're not sure what that is?

Indu Subramanian, MD:

Sure. Deep Brain Stimulation or Deep Brain Surgery sometimes is what the S stands for. We're able to implant electrodes into the brain to change the circuitry that is abnormal in people living with Parkinson's disease. We're not 100% sure how exactly this works. It sort of jams the circuits a little bit, but we seem to see benefits especially in the motor symptoms of Parkinson's we're able to implant these electrodes in specific parts of the brain, depending on what your Parkinson's symptoms are and then program these electrodes to give stimulation into the brain. And we can help with the cardinal symptoms, usually motor symptoms of Parkinson's and to help improve dyskinesia and to keep people more in the best on state.

María De León, MD:

Thank you so much. We're going to move on to, because we still have a lot to learn about Parkinson's, we would like for you to consider being part of our study, the PPMI study. That's the landmark research study that looks at the Parkinson's Progression Markers Initiative. We are recruiting volunteers both with and without Parkinson's to try to follow participants over time. And this information can really help us determine better treatments, understanding of the disease, and lead to better care for the patient, better resources. I hope you think about joining and this could help you and others in the future. Moving on, non-medication strategies for pain. As we've discussed, pain in Parkinson's can manifest in various many

forms and we have to consider also other medical issues. And so just like every Parkinson's is different in every individual, so is pain and the management. We're going to go to Dr. Rosenthal a bit to get what does she do, especially how does she approach this acupuncture, massage, physical therapy for people that have pain?

Lillie Rosenthal, DO:

Yeah, sure, sure. These are science-based strategies. I want to put a giant highlight around what's on the slide and some other evidence-based treatments for pain. And I want to emphasize with no side effects, positive side effects, and it could also improve your health and well-being generally. Usually we're all kind of seduced by high-tech. DBS is high-tech and it's a great option and we're waiting for a cure for Parkinson's disease. But in the meantime, and it's not secondary, it's actually I'd like everybody on the call to consider how much they can do, and think about medicine as a verb. I'll say that again. Something that you can do actively, not just take your medicine. And I'm not at all discounting the adjustments of dosaging of Parkinson's medications, nor the need at times to take a pill. But I want to really carve out a giant space to consider what can be done front and center to alleviate pain. Again, with positive side effects, that may be new language for people.

As an osteopathic physician and a specialist in physical medicine and rehabilitation, I do hands-on manual work in my office in New York City. Meaning, as sometimes, and there is some overlap with a physical therapist, even though I'm a physician, it's part of what I do. Going to the root cause of joint and muscular issues, which can actually help the body heal itself. Because we know there's movement disorders and challenges, we want to keep moving. Not at any cost, but find a sweet spot of passive manual work, which is helpful, as well as active, which is exercise, which I know we're going to be speaking about. Massage is another way that we can help with circulation and oxygenation and reduce pain. Acupuncture, I'm not an acupuncturist, but that helps some people. I don't know when you want me to talk about, but I see some questions here. Medical cannabis is something that I do prescribe in New York City as a New York City certified physician that prescribes medical cannabis-

María De León, MD:

We'll discuss that later on. We'll move that and discussing the lifestyle. I just wanted to ... Thank you, I wanted to just discuss some of those in general. And I wanted to ask Ethan that I know that he's tried some non-medication strategies for pain and I wanted to know what he has tried and what he find works and doesn't work for him?

Ethan Henderson:

I have benefited greatly from aqua therapy. I do a lot of work in the pool. A lot of it has that, the gentleness of the water, being able to move. I can do my exercises, I do my physical therapy stretches in the pool. Having that resistance is really, really helpful to me.

María De León, MD:

Do you find that it works better in the deep end or shallow end?

Ethan Henderson:

Deep end. Deep end, because there's more resistance there, because I'm fighting against my whole body is, that has been really a game changer for me. Along those lines I use a heating pad when I have the muscle cramps, I use stretching. I'm a marathon runner, so I definitely stretch a lot and I've tried to ... Don't do yoga, because I can't, my balance is not great, but I do yoga nidra.

María De León, MD:

Me either.

Ethan Henderson:

Yeah, but yoga nidra is just like yoga but lying down. Things like that have been extraordinarily helpful for me.

María De León, MD:

That's wonderful. Thank you. And I too agree. I have found that water therapy is wonderful and for me, like you, deep end therapy is a lot better than the shallow end doesn't really help with the pain. It helps with the rigidity and the stiffness and also the actual muscles with your balance, so I really like that. And thank you for sharing. Dr. Subramanian, I wanted to ask, people have wondered, what is the difference between complementary treatment versus alternative treatment?

Indu Subramanian, MD:

Complementary and alternative medicine was the old description of what we now, I guess would say is integrative medicine. And I think that alternative medicine makes it seem like it's other than or separate from. And that you choose either Western approaches that are standardized and the Western medical approaches I would say versus alternative medicine. Then the concept of complementary medicine came in where you use each to compliment each other. And I think now we've moved onto the word integrative medicine. And my approach to this is that we really, I am a Western trained neurologist who's been in practice for over 20 years. I think that levodopa is an amazing medication, as are many medications that replace dopamine therapy, especially for motor symptoms. I think the surgeries are really mind-blowing some of the effects that we can get from those. But we have a very complex disease with a lot of non-motor issues, a lot of mental health issues, and we don't have a way to even scratch the surface in terms of quality of life for many of our people living with Parkinson's in this regard.

I think we just have to be really honest about what we have in our armamentarium. And so opening our minds to integrative medicine, lifestyle approaches is really key I think in helping people to live better and to also become the agent of their own destiny. And so I think offering patients lifestyle choices, including things in the exercise realm, sleep is important, dietary choices, mind-body approaches, which you've mentioned a little bit about yoga, things like meditation, prayer. These are all things that can actually help our patients in the non-motor realm, especially with mood. And then we have social connection, which I think many of us didn't realize was part of the medicine until we lost it during the pandemic. And this is actually something that is a passion area of mind. Loneliness is something that really affects our patients. And so thinking about how we can really intentionally create social connection and support for people going through this from diagnosis even.

This is a very stigmatized disease. How can we build that support, help people get cheerleaders in from the get-go to really support them? I think that the kind of concepts that we're talking about, whether it's what we call historically alternative and complementary medicine, integrative medicine, lifestyle medicine, these are all things that I think we can open our minds to using alongside of our standard Western approaches. And hopefully under the guidance of a neurologist with a team of other folks that can be implemented.

María De León, MD:

Thank you so much. And you're absolutely right, I think that integrative medicine is much better, because I think that takes into account the holistic approach of a person, not just the neurological or not just we look into the spiritual, the psyche and all that. And certainly we are meant to be social being. The more we engage, the better we feel. And so some of these activities, the more you do it in a group, I think the better, it provides both benefits. But moving on to the lifestyle approaches to reduce pain, you might be

wondering if there's anything I can do. I know we've talked about a lot of things. We scratched the surface on a lot of things. We can talk about any one topic for a whole hour, I realize that. And you may have lots of questions and you can find lots of information on the Michael J. Fox Foundation websites.

Is there anything that a patient can do, Dr. Subramanian before their next doctor's appointment to help them discuss the pain issues, to help them ... The doctor target exactly what the problem is? I know Ethan is already keeping a journal doing that, talking about their diet, doing yoga and therapy. Anything else that we can do to help ourselves when we go to our doctor to discuss what we can do next to improve our pain?

Indu Subramanian, MD:

I think if pain is a key issue for you, it's important to make the topic that you want to focus on at the next visit. I think doctors are ever busy and we have less and less time and more documentation needs. I think you going in with one or two key things that you want to drive in for that appointment, maybe write it down, take a friend or a loved one who can really advocate for you. I think a lot of my patients come in by themselves. I have a lot of women, for example, that come all by themselves and then get flustered sometimes and are like, "Oh, I forgot to ask you something and I can't even remember what it is now." I think in the heat of that moment that kind of what's important goes out the window, so write it down and think about what you've already tried.

Being systematic, if you've tried a couple of approaches, make sure you write them down and say, "I failed these things. I did try these things. This is when it occurs, how it feels." Being able to describe it well. Telling what helps, what causes it, if something triggers it. All of these things are very helpful with respect to pain. If you've already been able to, like you were saying with Ethan, keep a diary if things fluctuate, depending on if you took your medicine late, if you had a good night's sleep, if it happens before or after you eat, before or after when your next medicine is. All of these things are actually very helpful to us as your neurologist or treating physicians to pinpoint what may help you.

And certainly, I think if it's important to you, you want to bring that up first and foremost. Say, "There's something really important I wanted to try to ask you today, just want to make sure I get just a time to mention it. Please let me know when you'd like to hear about my problem." That way the doctor can know that before your hand's on the door to leave and you then mention it and there isn't enough time to handle it.

María De León, MD:

Yeah, thank you. And we know as you mentioned, life's still going on, so you have stress, lack of sleep, did you eat, did you not eat, what you ate? And we're going, moving on to the diet, how important is diet, Dr. Rosenthal, what do you recommend and how do you see the diet affect the Parkinson's pain in your patients?

Lillie Rosenthal, DO:

Food, one of my favorite subjects, food as medicine specifically. First of all, I always-

María De León, MD:

Not my chocolate.

Lillie Rosenthal, DO:

Not my chocolate. Okay, we'll talk about that. But food, I always preface with, I am not the food police. However, the science is not confused. On all humans, the closer you can get to something called, and I will decode this, a whole foods plant-based diet. In regular language, the more fruits, vegetables, beans,



nuts and whole grains, none if little processed food, meat not so good. Basically the Mediterranean Anti-Inflammatory Diet. And this is very confusing, I know. There are influencers, there are politics around food. But we do know scientifically there's a big word that's coming around a lot, which is called the microbiome. We know that the gut and the brain, and the brain is where we all experience pain, are very, very connected. And specifically with Parkinson's, a lower protein, high fiber diet, and what I just mentioned will cover those things.

And I can't emphasize enough. And I know that it's cultural and it's normalized to not think about that, but I always give my patients a challenge of try for a week or two. Because food is really information for ourselves. I know that sounds clinical and I get it that food is pleasurable. I can't wait to blend up my acai bowl after this talk. There should be joy around food, but you want to be creating less friction. And especially for pain, we know the science again is not confused, that foods that fight pain are things that grow and mostly fruit, when in doubt more fruits and vegetables. I cannot emphasize that enough as a master key for general health and also fighting pain.

María De León, MD:

Thank you, yes. And one thing I want to add is that we really have to consider also the culture. Because us in Hispanic culture, we tend to have dinner at nine o'clock. And as we get older, the digestive system is already slower as you get older and with the constipation and everything. Sometimes not just what you eat, but the times that you eat. And also, sometimes we think raw vegetables or the fruits are better, but we also have to think about how easily digestible they are. Especially if you're dealing with constipation. Things like the skin of the apple may be harder to digest, so better to do a puree or peel it before, or maybe the carrots better, they're absorbed more easily if you cook them a little bit, they're softer, things like that. We need to talk to maybe a dietician to our doctors about what is best for your situation.

And again, there's so much information and you can go to the links and Dr. Rosenthal can give us more information later. But also, we talked about exercises, we talked about yoga, and why did you ask Ethan about meditation? I think that you do some meditation for your pain. What can you tell us about that? How has that worked? How did you get into that?

Ethan Henderson:

I got into it because my wife had been practicing it. I'll readily admit, at first I poo-pooed it. I didn't think it was something that would help me. And after I started doing it, I practice meditation twice a day right when I get up and then sometime during the day when I'm starting to feel, get stress or something coming on. It's a wonderful way just to center myself, to relax, to try to just turn off all or put my electronics away and go to a separate place. The deep breathing, the calmness that helps just relax my body, relax my muscles is really a fantastic benefit to me. And I know others that have had benefit as well. There's some fantastic free apps that people can get or online that walk you through it, or they're guided meditations that incorporate breathing and other types of mindfulness that you can include. I really, really can't stress how much it's helped.

María De León, MD:

Awesome. Yes, I agree. I have found myself too that when I feel really stressed or I go to a dark, quiet, cool place and just try to stretch, lay down and try to watch my breathing until I can calm it down. If it seems very agitated, try to calm down my heart rate, and that seems to really help. But the one thing we haven't mentioned is sleep. We all know that Parkinson's patients have trouble sleeping. And we sleep very little. But I have found myself that a good night's sleep where you get into deep sleep is better than so many medications and so many treatments to decrease the pain. Dr. Subramanian, what do you think about recommendations for sleep and making sure that the sleep patterns are well fostered in patients, especially patients that have pain?

Indu Subramanian, MD:

Sleep is really important. Getting a good night's sleep all consolidated if possible. If you can aim for eight hours, that's great. We see that a lot of these lifestyle choices impact each other. If you exercise, especially in daylight, get sun exposure first thing in the morning, set the tone of the day with some sun exposure, it's good. Taking away those electronics and artificial light towards bedtime. If you can keep off those devices for two hours, read an old school paper book if you're still needing something to settle you down. Sort of having a routine where you wind down in the evening, sometimes breathing, sometimes some gentle stretches, sometimes chamomile tea or something. Having a routine to set you into a pattern of getting restful sleep. And then trying, if you do wake up in the middle of the night to try to go back to sleep, don't, people get in habits where they start eating or walking around their house and watching TV and get back into bed and try to fall asleep again. That can be helpful.

And I think meditation and yoga are very helpful, especially the breath work and yoga, those long exhalations can really get people into a relaxed state. Can cause the parasympathetic nervous system, which is the calming nervous system that balances out that fight or flight sympathetic nervous system that gets us anxious and on edge. You can increase that parasympathetic drive through breath work and meditation can definitely be helpful too. It's actually very helpful. Just a minute, just to clarify from my end about diet, since people had mentioned it. I think since there's so many nuances, I think working with a dietitian is actually really helpful and certainly in some instances we actually do increased protein sometimes towards the end of the day. Our medications are not well absorbed with protein exactly taken at the same time. So, if we can move protein sometimes to the evening, but taking away protein in some people who may be malnourished, especially our women who get dyskinetic and then very skinny and then can lose bone mass as well, can sometimes not be a good thing.

I think this is very nuanced and certainly from a cultural standpoint, sometimes also working with a dietitian who can help you to guide in your own culture and what your food groups might be that you love how to get some of this appropriate nutrition, I think is definitely very helpful.

María De León, MD:

Absolutely agree, thank you for that. And as someone said, sometimes you get into vicious cycle, you do one thing, you don't sleep well, you get more pain, you get more pain so that you don't sleep well. We need to find ways to break those cycles and figure out exactly what the root cause is. And so I'd like to ask each one of you, what is the one tip that someone can start trying today to manage their pain? Dr. Rosenthal, let's start with you. What is one thing you would recommend for somebody? I know it's just kind of a general, there's so many things.

Lillie Rosenthal, DO:

So many things. I'm going to cheat a little. I'm just going to say that recognize you have tools. That doesn't count as my one. And the real one I don't think it's going to come as a surprise, but breakfast, lunch and or dinner can be opportunities to feed yourselves in a way. And we're talking about the nuances, which I completely agree, but you really want to stay. You want to eat real food and you want to be nourished. Ultra processed food, high sugar, inflammatory diet is not going to help anybody, Parkinson's or no Parkinson's. That's something I would say. And you have an opportunity three times a day to either help yourself or harm yourself in certain ways. And that's something that we can control. Agreed, being culturally sensitive and beans, Dr. De León are the best thing, going for a great bioavailable protein source. That's a culturally appropriate thing for lots of cultures.

María De León, MD:

Exactly, thank you. And the one thing before I go to Ethan then Dr. Subramanian, one thing I have learned or observed, including in myself that when people with Parkinson's start gravitating to sugary

foods and caffeine, is that they are very low on levodopa and they need to be adjusted. Once that's adjusted the cravings for any sugar decreases completely. It's like they're wearing off sooner. Anyway, that's just my personal observation. Ethan so what do you recommend, especially when you're having bad days? And we all know that we can have bad days with ... Even if we don't have Parkinson's, we just didn't sleep well, we got the crud, whatever. Of course, that's going to make our pain worse. What do you recommend or what do you do that may try to alleviate some of those things people could do to jump in the pool?

Ethan Henderson:

I will use a phrase my father, who also had Parkinson's embrace and now I embrace is to expect the unexpected. Every day is going to be different. And when you have a great day, celebrate it. When you have a bad day, acknowledge it, recognize it, but then put it in a box and try to have a better day. I don't mean to sound flippant, but it's working with what you have, the tools you have, the body you have. Making sure that you are eating, that you're staying mentally aware of your surroundings. And doing some exercise, getting some kind of exercise every single day really helps me on my bad days. I think all those combined would be my advice.

María De León, MD:

Wonderful tips. And now last but not least, Dr. Subramanian, what is your one thing or little tips that you recommend for someone to try to improve their pain?

Indu Subramanian, MD:

I mean, I think pain is very connected to mood in my opinion. And I think that if you can kind of separate the pain, so there is pain, but then sometimes there's a reaction to pain and people ... Because sometimes can catastrophize and they say, "Oh, what if it gets worse, then I'm going to be stuck here and then I'm really going to have a bad day." And there's this extra stuff that comes along with it. And sometimes people get anxious, sometimes people get quite depressed. And so I think really understanding, yes, pain may be at the core, but then it sets into this reactionary amount of things that then also fuel people to feel not good. And so I think if you can bring attention to that extra mental health component, whether it be an anxious component or a premeditated, sort of, "I'm already catastrophizing about how bad this could be, and it's not even that bad yet."

And then we can unwind that and just stay in the present moment. And then is there something that we can just stay here maybe and incorporate breathing, incorporate something that might be delicious or beautiful that we can bring our minds too instead? Or if you have a beautiful pet in your home or a baby or something that you can pet or something to bring your attention to, it can sometimes take you away from that extra winding up into this other place that often people get into, that that is much harder to get away from. I think I really am a huge believer in the sense of our approach, our attitude can make a huge difference. That's the secret sauce that is helping Ethan to do well right now.

And you as well Mari-a, even on those bad days, thinking about the good days and bringing focus on what we're grateful for and what is beautiful around us. Even though it may sound trite, I think these are things that actually do work, even in my own experience. And I think that, again, if there are extra mental health issues that you're also dealing with depression, anxiety, apathy, additional sleep issues that are just not letting you get a good night's sleep at all. If you can work with your team to help treat those, sometimes the pain can actually get better as a result.

María De León, MD:

It's true. Thank you so much, yes. Again, the holistic approach and looking at what exactly is the root cause and what we can do to improve it. I know that everyone has a question about cannabis, so we're

going to go back to Dr. Rosenthal, so she can talk to us about cannabis in the treatment and management of pain with Parkinson's in this case. What are your recommendations, what you discovered?

Lillie Rosenthal, DO:

Yeah. My approach to pain generally is the most efficacious options with the least amount of side effects. Cannabis is, at least in New York state, and I mentioned I'm a New York State certified physician that prescribes cannabis. Because my thought, when patients come in, I mean this may be counterintuitive and it sounds like, oh, marijuana, cannabis, and doctors are extremely generally conservative. We want to follow the science, but we also to be, we should be very thoughtful. Somebody taking even an over-the-counter Advil or Naproxen, and you can have a bleeding ulcer right there. You can have kidney issues. I just want to sort of, Cannabis is one of these things that I have found particularly in Parkinson's that could help coming off the conversation about stress. If it could help with sleep, it could help with tremors, it could help with stress, it could help with mood, and it could dull the pain. It could help with neuropathy.

This is never my first line, nor is even a painkiller my first line. My first line is lifestyle changes. But I do have the conversations, if patients are optimized on their movement, they're exercising, they're stretching, they're eating well, they just can't do it. It is a very low-risk option. And I want to emphasize that cannabis is a sexy but often misunderstood. And we still don't know a lot about it. Research, it's schedule one, we're looking to federally have it be schedule three, we need more research on it. However, nobody's ever died of cannabis poisoning. So, I just want to put that as an option of a conversation to have with a physician and not just run to your local dispensary maybe who may not know enough or be considering your general health issues. I think it is a worthwhile conversation with a physician who has some experience in this area.

María De León, MD:

Thank you. Well, there have been some reports, and I don't enough, forgive me if I don't remember, for severe nausea or hemorrhage or the GI system with people that took cannabis. But yes, the Fox Inside show that about 70% of respondents have tried cannabis. The problem is that it's not yet been proven, like you said. Has there been any control studies? Because unfortunately there's so many different ties, people manufacture it differently, synthetically for different things, and smoke versus inhale versus, so that is the problem. We don't have any information but the best ... Yes, go ahead.

Lillie Rosenthal, DO:

Yeah, I'd like to say, as a physician, I never recommend smoking nor vaping of cannabis, because we need to protect our lungs. Doing this on your own as a trial is not a good idea. In New York State we have dispensaries with pharmacists that are pharmacists that exclusively work with cannabis and your other medications. It is certainly not frontline, not because it's not valuable, but I would say the same thing about any pain medication.

María De León, MD:

I appreciate it. Yeah, no, it's important to keep. And always, always, I recommend before you make any changes, take any decisions about adding, taking away, any alternative or complimentary or to always discuss with your team and your neurologist to figure out what is the best approach for you. And we've talked a lot about different approaches and lifestyle changes and integrative medicine, but the problem that many of us have is that some of these alternative or integrated services like massage and acupuncture and things, they're very costly and they're not covered by insurance. In some places I know that some acupuncturists are covered in some massage, but there's very few and far apart, physical therapy is. What do you recommend in those cases you like to have? And I know at the beginning when I first started

having a lot of stiffness and pain in my legs, initially I was just getting a massage because the stress of being a physician.

But when my pain began and the stiffness began, I mean I was going two, three times a week to get a massage, because I was in so much ... My muscles was so tight, so tense that I just needed to have that. So yes, that's very costly. What do you do? Recommendations. One thing I found was the water therapy, like Ethan said, that really helped. But other suggestions?

Lillie Rosenthal, DO:

There are many things that are free and they're not suboptimal, they're actually optimal. Things like Dr. Subramanian mentioned, getting outside, taking a walk, vitamin D, sunlight, breathing, free. Beans and bananas. I don't say that as a joke, I say that correct. They are cheap and good and can actually help with the pain mechanism. Shutting off your screens before, the lifestyle fact, shutting off your screens before bed so you're not waking up the brain. These things need to be optimized and everybody has a different budget.

And believe me, if I can revamp the American healthcare system, but I'm going to say something I said at the beginning, which I feel is very, very important, and I'm not just giving it lip service, but this is true. Every single person, patient needs to take control over their own healthcare. And ask the questions to your doctors, "What can I do to help myself?" And hopefully we're giving you some very good information on this, not wait on this webinar and conversation, not just waiting for the cure or the magic pill or the magic procedure. That is a misguided way to go. I hope we have given some practical advice. And these things are basically free. And the passive things cannot ... A one-hour massage or an hour with me doing manual therapy, people go home and then they have to live their lives for the rest of 23 hours. That stuff matters. I cannot emphasize that enough.

María De León, MD:

And one thing that I found that there may be, as you're talking about free services. If you live in an area where they have a physical therapy training or they have massage therapy training, acupuncture, a lot of those because they have to train. As you train physicians so on, then you may be able to get a volunteer and get a free massage, get a free treatment. So there's always something to look at if you have one way to do it. Anyway, we've covered a lot and I hate that we always come to the end, and I know we have a lot of questions, but dealing with pain is hard. Living with pain is hard. And I know that for myself and a lot of people that have pain. When you're hurting, you're not yourself. And if it becomes an unbroken cycle, that's when it leads to hopelessness and helplessness and isolation, so we really need to be aggressive about treating the pain and finding the source.

But it can make you very irritable. I don't know about you, Ethan, but my family, I try to stay away from everybody when I'm in pain, because otherwise I'm grouchy. And so they know if I'm alone, then leave me alone because I'm not ... What do you do Ethan? How do you deal when your pain is really hard? How do you do, your family? How do you approach, "Hey, I'm hurting." Or how do you have those tough conversations to get them engaged to help you and so on?

Ethan Henderson:

Yeah, sometimes people without Parkinson's don't understand that we are having pain. And sometimes it's just passed off as, "Oh, you're getting old, or you overworked, or you carried something you shouldn't, Ethan." Those are going to be the questions, the statements you're going to hear sometimes. And just, I've tried to remain calm and just even headed and tried to just say, "No, this is different and I'm sorry you don't understand, but please know that what I'm feeling is quite different than what you're feeling. And give me time, give me the space and give me the area to feel safe and be able to have these conversations

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and feel the way I do." So, they're challenging at times, but I think looking at it in big picture and just being, trying to remain as calm as possible with those kind of conversations.

María De León, MD:

Thank you. The one thing I say, just sometimes it takes one breath at a time, one minute at a time. That's all you can do. Unfortunately, we come to an end. I want to thank the wonderful panelists for all the wonderful input. Thank you for the Michael J. Fox Foundation and all our sponsors. Thank you so much. Have a wonderful rest of the afternoon and wonderful weekend. Thank you.

Ethan Henderson:

Thank you.

Lillie Rosenthal, DO:

Thank you.

Veronique Enos Kaefer:

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