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Rachel Dolhun, MD: Welcome to The Michael J. Fox Foundation Parkinson's podcast. I'm your guest

> host, Dr. Rachel Dolhun. I'm a movement disorders neurologist, a lifestyle medicine physician and principal medical advisor at The Michael J. Fox Foundation. I'm also a mindfulness enthusiast, even if sometimes I feel like I have more enthusiasm for it than I do actual practice. That's our topic for today, mindfulness, meditation and Parkinson's. These are important tools for managing life and for life With Parkinson's. We're going to talk about what these practices are, how they can help all of us, but especially people and families with Parkinson's and what the research shows. Let's introduce our guests. Dr. Sarah Mulukutla is an integrative neurologist and founder of Mindful Neurology. She

teaches mind-body strategies and researches the effect they have on people with

Parkinson's. Sarah, thank you for being here.

Sarah Mulukutla, MD: It's great to be here. Thanks for having me.

Rachel Dolhun, MD: Sree Sripathy is a Bay Area-based photographer, writer and creator. She was

diagnosed with Parkinson's in 2015. She's a practitioner of mindfulness and

meditation and sometimes yoga as well. Welcome, Sree.

Sree Sripathy: Thank you. It's lovely to be here.

Rachel Dolhun, MD: And last but not least, Ken Hill is a semi-retired IT professional and volunteer

> firefighter living in the Portland area with his wife Kat, who was diagnosed with Parkinson's also in 2015. Ken has reading, walking, and other mindfulness practices that support him in daily life. We're glad to have you with us, Ken.

Ken Hill: Thank you. It's my pleasure to be here.

Let's dive right in. Sree, I'm going to start with you. Can you tell us how you use Rachel Dolhun, MD:

mindfulness in your life with Parkinson's and some of the benefits that you see

from doing so?

Sree Sripathy: I use mindfulness on a daily basis in the sense of being aware of where my body

> is in time and space. With Parkinson's, I find that all of the things that I used to do that came naturally to me no longer do. Walking, eating, talking, cutting things. I really have to focus on the moment, which is really what the basis of mindfulness is all about, being present in every moment and just being aware of what you're doing, whether I want to or not, that's what I have to do. I was hoping mindfulness would come into my life a different way, but it came in

through the vehicle of Parkinson's. But the way that helps me is when I am able to do it, which is more often than not, is it allows me to slow down to decrease my anxiety. It allows me to not worry about the Parkinson's as much, just focus on each moment when I'm cutting a cucumber or stir frying some cashews or anything like that. And it really helps me just settle into my day. It's a gift. It's a gift.

Rachel Dolhun, MD:

That's such a beautiful way of seeing it and the Parkinson's forced you into mindfulness, but the mindfulness is so helpful and I hear this a lot from people too, that it's helpful in understanding your Parkinson's and understanding how it's changing, which of course is so helpful in having conversations with your doctor, who's asking you how you're doing or how are things changing and how should we adjust your treatments?

Sree Sripathy:

Yes, particularly when it comes to dyskinesia, I get dyskinesia very easily on very little medication. When I'm dyskinetic, I'm often very anxious and stressed out. I have to learn to focus and take deep breaths and just focus on what my body is doing. And sometimes that allows me to relax and relieve the dyskinesia a bit. Sometimes it doesn't at all, but it allows me to at least not be as stressed and anxious about what my body is doing, just to be one with it. I can't really escape it. It's with me. I've got to learn to live with it.

Rachel Dolhun, MD:

And just for our audience, dyskinesia is that extra involuntary movement that can sometimes come along with many years of life with Parkinson's and taking the medications for Parkinson's. But we'll get more into some of these symptoms like dyskinesia and anxiety and some of the other motor and non-motor symptoms with Parkinson's that mindfulness and meditation can really help with. Ken, I'll turn to you now. How do you use mindfulness in your daily life and especially in daily life as a care partner to someone who has Parkinson's that over nine, 10 years is of course changing?

Ken Hill:

Sure. I had struggled at first with trying to figure out a consistent practice and tool for mindfulness and meditation. And what I've started with reading books and following some webinars and some YouTube videos on how to meditate and the actual traditional meditation techniques of trying to focus on your breathing and listening to some nature music never really worked for me. And what I just really found, it is very similar to what Sree just described is I try to take my everyday activities and just turn that into a mindfulness exercise. I also have learned to really carve out dedicated time in the morning and in the evening to really focus on some meditative techniques. In the morning it could be while I'm having my first cup of coffee, I do a daily reading. Some people would call them a devotional reading, but there's usually, I have a series of books that I've been reading over the past several years that just give me a thought for the day to think about and try to practice and focus on throughout the day.

And then in the evening when I'm getting myself ready for bed, I revisit that reading and I try to reflect on how I did throughout my day. I used to write it down in a journal, but now I really don't. I just think about it and store it in my brain. One of my biggest useful Meditation techniques is actually walking. I try to get outside every day regardless of the weather. I live in the Pacific Northwest,

so most of the time it's pretty rainy and chilly and I just put on a parka and I go outside and I go for a walk and I use the sounds of nature around me to just focus on the hearing, the raindrops, the puddles that I'm walking through and do that for about 20 to 30 minutes a day to just focus myself and my attention away from my care partnering role, the fact that I'm living with Parkinson's with my wife for the rest of our journey, and it really helps.

Rachel Dolhun, MD:

I love that both you and Sree talked about how it's just part of your daily life. I think a lot of the hesitation with some of these practices is you have to sit on a cushion for 30 minutes in a quiet place. And really this is something we can bring in our day to day and you can focus, Ken you mentioned hearing, looking at the sounds of nature around you, feeling. It's really just about tapping into our senses and using what's around us to be here. And the other point I wanted to underscore is you use the word struggle. And I think for a lot of people, that can be what it feels like at first and we have to experiment with different things to see what works and what doesn't and what fits into our lives. And that may be different from day to day or with what you're going through. That one meditative or mindfulness practice might not be what works best for you today or for what you're going through today. Sarah, using those experiences from Ken and from Sree as a starting point, tell us a little bit more specifically what are meditation and mindfulness?

Sarah Mulukutla, MD: Yeah. And there's a lot there that both Sree and Ken mentioned. I'll start by just defining mindfulness since it has come up already. But mindfulness is a mindset. It's a little bit of an ironic name because to be honest, our minds are full all of the time. The best way to start to think about meditation and mindfulness is the understanding that the human brain is incredibly active all the time, including thoughts and an inner dialogue or we're constantly holding within our minds our experiences. We could be driving to work and preparing for a work meeting at the same time and not even realize making that turn, stopping at the light. Part of our brain operates on automatic, and yet we're very present with these thoughts in our mind, and that can be memories and emotional anxiety. It's so hard to get out when you're anxious about something.

> It is just so present in our awareness. Sree mentioned needing to focus on what her body is doing. And that is a strategy of meditation and mindfulness where you intentionally train your mind to do what you want it to do. And both Sree and Ken talked about being present to the moment, and that really is the definition of mindfulness. There's a little bit of an attitude about it too that not only do you have to be present, but you have to be accepting. You have to be okay with what is. A lot of times you feel pain and right away, oh man, my day is going to be ruined. Man, should I take medicine or not? I mean, we just go into this cascade right away instead of feeling a pain, experiencing it and seeing if there's something you can do in the moment to make it better.

That's a little bit of the mindset aspect of it. Now, what we do with meditation, there's three steps that we do with meditation. And I'll get to the whole cushion part of it in just a second because I do think that we need to start by sitting and intentionally taking some time to practice this. First of all, you decide that you're going to meditate and you're going to choose one thing to focus on. Let's say it's

a body sensations and you can do it while chopping cucumbers. I'm going to experience every sensation of chopping cucumbers, the sound that it makes, the smell that it makes. I'm going to be seeing what my fingers are doing and feeling that cucumber, feeling one hand holding the cucumber, the other hand, gripping the knife. That's paying attention to it. And most likely if you can do it, you won't cut yourself.

If you're doing this while washing dishes, you won't slip and break that glass. Just going back, so you decide you're going to focus on something and you do it, you focus on it, but inevitably spontaneous thoughts arise and that is the human mind. In meditation practice, you catch these thoughts that arise because you're focused on it and then you go back to what you're focusing on. Sometimes it's easier to do that while sitting where you make an attention to just do nothing else but catch the mind wandering, go back to your focus. It could be the breath, it could be an inner word that you silently repeat like Herbert Benson told as his technique from the relaxation response 20 years ago. Once you start, we all inevitably realize our minds are so busy and that's why we have to practice this. so that when we're out walking or getting dressed or doing our daily, then we catch our minds wandering or thinking or being stressful or anxious, and we decide to bring it back to the present moment.

Just to answer the first question that the first definition of meditation is when you decide you're going to train your mind to focus on something. This is true for all of us, whether we have Parkinson's or not. It is so helpful to train your attention to realize that you can focus on what you want to focus. And then if you do that continuously, then you develop mindfulness, which is the capacity to be aware of this, to have this mindset, to observe the mind and the body ongoing basis. And then mindfulness becomes present in your daily life. It does require a little bit of effort in the beginning

Rachel Dolhun, MD:

And one reinforcing and one question. The acceptance part of it, or sometimes this is talked about as non-judgmental, so it's not you catch yourself thinking about something and start beating yourself up that, oh, I had that thought again or I had... It's really, as you said, it's accepting what comes up. But then a misconception I think that a lot of people have about meditation is it's really not about totally emptying your mind or clearing of all thoughts, right? You said it's about observing and seeing what comes up and naming that.

Sarah Mulukutla, MD: Meditation is a very active process. When we sit down, we work hard to train our mind, and it's a great feeling to just focus intentionally. It's brain exercise, it's exercise for your brain muscles. The amazing part is when you start to do this, there is incredible physical biological changes.

Rachel Dolhun, MD:

Why are they good for us? What are these doing to our bodies and our brains?

Sarah Mulukutla, MD:

Yeah. The first aspect is that when you do this practice, which is inherently a safe practice for the body, you are paying attention to something repetitive and you're disregarding spontaneous thoughts. Oftentimes these thoughts are stressful for us. Like many of us have negative thoughts. I mean, I would say majority of people. If you think about what's going through our minds, it's things that we perceive as

stressors. We're choosing to disregard them, but we're also doing something repetitive, calming, and the body responds, it triggers the parasympathetic response. We can define that term. There's a part of the nervous system that is designated to trigger or to signal whether we need to be alert. That's the fight or flight, the arousal mechanism or the parasympathetic, the rest, digest and repair. If you take as little as 10 minutes every day to intentionally create a safe calming spot, this actually changes the whole signaling of the body.

First of all, you strengthen these repair signaling of the body. The immune system changes. You see genetic changes, epigenetic changes that can happen as little as a couple of weeks after starting this practice. From the brain perspective, you start to gain insights because I think the key for meditation is choosing to focus on your internal body sensations. You really do have to be willing to observe your thoughts and be okay with the fact that you have these repetitive thoughts that you may not want. Whereas Ken decided, that was a great example of bring it in. He reads a passage and decides that's how he wants the day to go or how he would like to act that day. And at the end of the day, he reflects. You have to be aware throughout the day what your mind is doing in order to regulate.

What happens is first you take this time to set the body up for calming the body, which by the way, with my work with Parkinson's, I found that during the meditation practice, rigidity will reduce, movements increase. If they're in that calm state, they don't experience freezing of gait because they're setting their body up to be optimized. And in our research, we're actually looking at the neural connectivity. We think that by doing this practice and disregarding spontaneous thoughts, quieting the thinking networks, our hypothesis that we're currently examining is whether that neural connectivity actually improves. But for all of us, we can be more clear and we create a direction, a compass for our day that we want the rest of the day to go that way. And at the end of the day, we reflect. And if it went that way, that's great. If it didn't, this is a journey. We try again tomorrow 'cause we have our goals. We've started to observe our body and we're okay with our patterns as they were in their past, but we also have the power to change our patterns in the future.

Rachel Dolhun, MD:

And we're not judging the day at the end of the day when we reflect and go, oh gosh, that didn't go quite as planned. Or we miss our meditation. I think one of the things that really spoke to me is that these practices can have benefit even if we fall away from them and we don't practice them every single day, that every little bit counts, but Sree, I want to turn back to you. When you heard Sarah talking about some of the benefits and things that she's heard from other people with Parkinson's about when they practice and symptoms decreasing or falling away. What has been your experience?

Sree Sripathy:

My experience has been that when I'm able to focus on the moment and do some deep breathing and meditation, maybe not the motor symptoms as much sometimes, that can be a little bit iffy, but definitely the more emotional symptoms like anxiety, depression, things like that tend to be a lot better for me. And anxiety is one of my biggest non-motor symptoms with Parkinson's disease. And I could be anxious, for instance, about being on this call. And then that anxiety increases my dyskinesia. Excitement also increases my dyskinesia, but

then when I focus on my breath or focus on the sound of a fan or maybe the flickering of a light against the wall, anything 'cause sometimes the breath is very hard to focus on. I need to find something more physical, more material to focus on, and then I'm able to slowly calm down and I feel actually many times my dyskinesia gets slower, it gets reduced, I find the anxiety is less, and I find that I'm actually able to go about my day in a much more purposeful way. Now, I'm not saying that works 100% of the time, but I've noticed that it actually works more often than not. It doesn't get rid of my dyskinesia at all. It just helps me not get dyskinetic about my dyskinesia, if that makes sense.

Rachel Dolhun, MD:

Yeah, that's a great way of putting it. And it also is an important point that these tools may not be the be-all end-all. You're using them in conjunction with, I'm sure medication or exercise or trying to get the best sleep you can. All of these other treatment tools for Parkinson's, but they're a good thing in your toolkit that you have at your fingertips to practice.

Sree Sripathy:

Absolutely. And the nice thing about mindfulness and meditation is I don't need any device. It's just me and my mind and my breath. It travels with me wherever I go. It carries no extra weight and it just brings me benefits.

Rachel Dolhun, MD:

And it has very low risk of side effects.

Sree Sripathy:

Low risk of side effects, yes.

Rachel Dolhun, MD:

And Ken back to you, because the word we didn't say out loud, but Sarah you were alluding to, is stress. We all have it in different ways, whether we have Parkinson's or not. We know people with Parkinson's do report feeling more stress than people without. And Sree, you talked about how it impacts your symptoms and can exacerbate them, but Ken, we all have life and life with stress. And so how do you find that mindfulness and meditation help you manage that?

Ken Hill:

Well, it helps me organize accomplishments because as a care partner, I've noticed my stress level with just going throughout my day much more stressful. And what I have found by focusing specific time intervals throughout the day to doing something that I can say at the end of the day, hey, I accomplished this. And then the next day I can go, I can feel better that I'm at least accomplishing something. Because for myself, when I'm dealing the stress, I feel like I'm not worth anything. I feel worthless, I feel sluggish. When I started my meditation journey and trying to figure out how to do this, I came across a YouTube video of a Navy Admiral giving some graduation speech, I think it was for a boot camp for a bunch of Navy SEALs. And what this Admiral said was he has told troops and his Navy SEALs every morning, make your bed because when you are done at the end of the day, you can say at least you accomplish something.

And so I started doing that. I never made our bed, and then I started doing that. And amazingly, after doing that for about a week or two, my stress level just dropped. And it was before I did any kind of more focused meditation practices. And so I just kept doing that. And there's going to be days where I forget it and those days that I forget it, I come into bed and when I go to bed at night, I go, oh, I didn't do that, but I can let it go. For myself, if I have found a way to just carve

out focus time and I can pick away a little daily accomplishments, I can really handle my stress better.

Rachel Dolhun, MD:

That's so interesting. And it shows us how it's so different for different people. Now I'll say I do make my bed every single morning, but for me, I don't know, maybe it's doing something, but I don't really feel what you're describing, but for me, maybe it's writing and that's my meditative practice and where I can carve out 15 minutes in the morning to just get my words out on the page, hear what myself is telling me and write for myself. That's my meditation and my reflective practice. It just speaks to how many different tools there are and you have to try and experiment with many different tools to see which ones work for you. But speaking of that, Sarah, we were going to take a short break and do an actual short practice because we're talking a lot about this, but a lot of times just actually experiencing it tells you a whole lot more. Take us through a short exercise.

Sarah Mulukutla, MD: That sounds great. Let's do a mindful moment. And I use those words in particular because oftentimes people hear that and right away they fix their posture and they sit up straight. And the point I want to make is that, well, this is case in point that you weren't doing that before you were reminded to. This is why we need the reminder. I'm going to start with a body scan. Being connected to the body is a very important skill that we can develop, and we do this by intentionally focusing on the body. I invite everybody listening, bring your attention to your right foot. Just start to see if you can feel anything coming from your big toe. See if you can feel toes two, three, four, five. Can you make out in your, just by sensing, you can close your eyes if you feel comfortable 'cause I want you to really tap into what you possibly can feel. Can you feel those toes touching the ground or any cloth around the foot?

> This might be hard for people if you are not used to doing it. We'll move on to some of the bigger parts. Now, just gently bring your attention up towards to the right ankle and see if you can just scan. Just see if you can feel the chin, the calves, and come up to the knee. Just by feeling it, but it may help by looking at it. Can you feel the leg in its current bending position? Go up to the hips. The hips are an even easier place to feel. The hips are the heaviest part of the body. If you're sitting right now, feel the hips supported by the surface beneath you. Can you outline the contact of your buttocks? Whatever part of your body is sitting, can you feel where that contact begins and ends for that surface that is supporting you? And just stay there. You are bringing your body into your awareness, and this alone should be a relaxing signal to your body, to your nervous system. I'm just going to bring attention to the breath if it feels comfortable for you.

But just if you can find it, just see if you can start to observe the normal inhale and exhale as it is occurring. And try and see if it feels comfortable. Keep your attention there. See if you can trace the whole inhale. And then it transitions, slows down and the exhale begins naturally. And when you start to try and intentionally keep something in your focus, that's when you might start to notice your mind wandering. I'm going to just go with one sound to finish our meditation, but I'm going to hit a bowl and in case the breath is not comfortable for you, why don't we bring in listening as both Sree and Ken mentioned,

sometimes you can just find sound to listen to. Here is a bowl, and see if you can listen to the very end of the sound. And when that bowl ends, we'll end this meditation and then you can release your focus. But first here is the bell. All right, you can go ahead and release your focus and gently come back to the podcast in the room around you.

Rachel Dolhun, MD:

Thank you so much. Just taking those couple of moments, you can feel so refreshed and just ready to jump back in. And I think that's helpful in the workday too. I find that even if I'm feeling overwhelmed or things are going in a different direction and I can just pause for two minutes and I can rub my fingertips together with really, really strong intention or focus on the sights and sounds I'm seeing in the room around me. It really just gives us this renewed focus and energy for going back to what we were doing. Sree, I'm going to go back to you and ask, when you tell people that you practice meditation or mindfulness, what are some of the responses you get or maybe misconceptions that you hear?

Sree Sripathy: I don't actually think I tell anybody.

Rachel Dolhun, MD: Well, now you have, you've told the world.

Sree Sripathy: Now I told the world. I think the question I get is, oh, that must be because you're

Indian, or that must be because of your religious background or your cultural background. And I don't think that's quite true. I didn't grow up with mindfulness. I did grow up with meditation. Mindfulness, I mean in the sense that any parent would tell their child, don't talk while eating. Don't watch TV while eating, all that stuff. Pay attention to what you're doing, which is actually very interesting because a lot of the stuff my parents told me when I was a kid actually very much applies to mindfulness and to meditation. But the other thing I get is often, what is that? And oh, I can't be mindful. I can't meditate because I have to sit down and clear my mind and I can't sit for 20 minutes or 30 minutes.

And what I often tell them is, you don't have to sit for 20 or 30 minutes. I told my sister the other day, if you can take even 30 seconds, she has two young kids. If you can just take 30 seconds in the bathroom while brushing your teeth, just 30 seconds, that is enough for one day. If that's all you can get, that's 30 seconds where you are present, where you were calm. Don't stress yourself by going for 30 minutes or 10 minutes. That might be too much, but 30 seconds I think you can do. And so that's helped her as a mom most of the time.

Rachel Dolhun, MD: And Sarah?

Sarah Mulukutla, MD: I just want to add to that. By doing that, by making that choice to change what

you're focusing on, the brain really can and the nervous system really can respond that quickly. Of course, it might take a little practice to get there also, but just be encouraging that the body responds so quickly to what's in the mind, and we mostly see it in the opposite direction. You have a stressful thought, we can feel it right away, but we should all be encouraged that we can intentionally put ourselves into this more present and relaxed moment. And that's a wish that I

have for everybody to learn that. Thank you for bringing that up, that it can happen quickly.

Sree Sripathy:

This is a quick present example. On this call I've been very dyskinetic, but when I remember to bring my attention back to my breath, I've noticed that the dyskinesia calms down, and that happened just a few minutes ago. It's happening now, but it requires me to constantly be focused back on my breath or something. And so then I noticed that the movements of dyskinesia are less and I'm able to speak more clearly and I'm able to focus more clearly. It's happening as we speak right now that I'm seeing the positive effects of that.

Rachel Dolhun, MD:

Yeah. And thank you for saying that because I think that too, that being present and mindful in our conversations helps so much with connecting with other people and building those positive connections that are so important for our brain health. But so important when we're living with Parkinson's especially, and we're always multitasking, and I guess it's, I have to be doing it right now, leading the podcast, but when you're talking with someone, how can you really be listening to what they're saying, looking in their eyes, looking at the color of their sweater so that you're so here and now and you can respond to what they're saying because you've truly heard it. You're not just waiting to jump in and say what you want to say. Ken, I want to go back to you and talk a little bit more about this misconception about the religious potential ties to meditation or mindfulness that may make some people hesitate when coming to meditation or mindfulness.

Ken Hill:

A lot of people that I've met in my journey on this planet, they say that prayer and meditation are the same thing, and they can be. When you talk about prayer, people think you're a religious person, but when you talk about meditation, people don't think you're religious for some reason. That's been my experience. And I actually think they're very, very similar. And it's just a focus on how you want to live your life. And I don't know if I'm making a coherent answer or not, but from my perspective, it doesn't matter. If it works for you, it works. And don't worry about how other people are going to perceive what you're doing.

Rachel Dolhun, MD:

I think that was a very coherent answer, and I love the honesty of it, and I loved too how you ended that this is for you. Back to my writing. I write and I write for myself. Nobody else is going to see that. And so it helps me be open and honest. And same thing with other practices of meditation and mindfulness. But Sarah, I'll ask if you have anything to add onto that.

Sarah Mulukutla, MD: We have learned just how this affects the body and the brain, and that has helped many more of us understand that you can do something to modulate your biology. I would say that these traditions initially emerged from spiritual disciplines, which is another interesting top philosophical discussion in and of itself. But John Kabat-Zinn back in the 1980s was the first to make this truly secular and to show that just there's this concept of learning to observe your brain, and you don't have to include a spiritual or a devotional object of focus. Originally it was, but we can replace it with anything. Herbert Benson, also MindBody Institute, a physician. Just by inhaling, exhaling the word one silently to yourself is enough to get the results. I think that's what has helped also. Prayer and devotion are a form of meditation. You are intentionally bringing your

awareness to a spiritual concept. They fall into meditation, and yet meditation is much broader. And as you said, find something that works for you that really feels settling, centering as your object of focus. And that's when you can start to do this really regularly.

Ken Hill:

This concept of spiritual practices in a daily life, I mean, one of my favorite spiritual practices, it's my default go-to. It's the Serenity prayer, and I am not a religious person. You can use some spiritual prayers like the Serenity Prayer to just get rid of stress and to pass all of that energy to some other object. It could be your conception of God, it could be your conception of the master universe. I know in twelve-step recovery programs, they call that a higher power, and that works for me because I can just take that and pass it along to somebody else because it doesn't work when I have to try to process it myself.

Rachel Dolhun, MD:

This is such great conversation, and I just want to say out loud that this is not discounting or undermining people who do have strong religious ties or faith practices. For a lot of people, those are absolutely their mindfulness and their meditation and their hope and all of those things. Again, it's just back to finding what works best for you and for your life. And I'll stick with you for a moment. You mentioned how mindfulness and meditation can help you get away from Parkinson's for a little bit, and that's important, having that life and that time away from Parkinson's and being a care partner. I'll ask you two questions. One, for a lot of care partners that can feel impossible, like you don't have time, or if you do take the time, you feel guilty. One, how do you navigate that? And two, how does taking time like that away help you be more present in your role as a care partner?

Ken Hill:

Yeah, what it has really helped me to do is to realize and to get a sense of a forgiveness around Parkinson's in my life. And realizing that I can't control what Parkinson's is going to do in my life, but I can control how I respond to it, how I can react to it, and it has helped me to stop figuring out what is going to be the next stage of Parkinson's. As a care partner, my wife, Kat, the diagnosis was 10 years ago, but we know most of it is people show symptoms way before that. And that was our experience. And I have always been in the earlier stages of our journey with Parkinson's, is trying to figure out what's next as a care partner, what's going to be her next symptom of progression and how do I have to prepare for that?

And I've gotten to a point with my meditative practices is that I've stopped figuring out the why or the how Parkinson's is going to be in my next year, five years from now or 10 years from now. It's given me confidence to know that whatever's presented to me, I'm going to be able to tackle it. Whatever's presented to Kat in Parkinson's as a new symptom, we'll be able to figure it out because we've been successful the past 10 years plus. I attribute that to focusing on some of my own needs as an individual outside of Parkinson's. I went on a fabulous salmon fishing trip this past weekend. It was helpful to get me away from the day to day Parkinson's and then I can come back and I can reengage.

Rachel Dolhun, MD:

Yeah. It's like, this is going to sound like a terrible comparison, but just having a weekend off from work. If I'm trying to continue to work during the weekend,

I'm half there and then I'm annoyed that I am having to work on my weekend. But if I really take the full weekend, I arrive on Monday ready to tackle, to use your word, to tackle what's ahead of me. But Sree, I'll ask you, as somebody living with Parkinson's, does what Ken said about being more able to face what's in front of you, does that resonate?

Sree Sripathy:

That's interesting because while he was saying that I was thinking about my father. My father has Parkinson's disease, so he was diagnosed about eight years after I was diagnosed. He got diagnosed at 78, he's now 80. And my mother told me the other day, or maybe it was a week ago, she's like, I don't know what's worse, your father having Parkinson's or you constantly talking about what he needs to do about Parkinson's. And so that brought a little light bulb to my brain to say, you know what? Let's not overwhelm my dad with all the things that are going on with Parkinson's and all the things that could happen. We'll just take it each day as it comes, and I will look out for things and I'll give suggestions as needed, but I just need to slow down and really chill out and just be more mindful of the stress that I might be placing on them by constantly mentioning it or being aware or not wanting my dad to go through maybe something that I went through or not wanting to understand.

For me, that was very much an awareness of that, letting the Parkinson's be where it needs to be. I mean, a lot of people say, Parkinson's is not me, or it's not who I am. I don't know about all of that, but I do know that it is possible for me and many people I know to take a break from it, whether it's by reading a book, whether it's by doing some deep breathing, listening to music, closing your eyes and taking a nap. You get a few moments at least in a day where if you're lucky, it's possible to feel normal again and to feel separate from it. And that's what I have found that helps.

Rachel Dolhun, MD:

Michael says something very similar that he lets Parkinson's take the space it's going to take and no more. It's about what both you and Ken are saying, putting it in its place. Sarah, we mentioned some names of practitioners and gurus in the fields, and how can people find tools if they're new to this or might feel like it's maybe not as accessible? What are some of the tips you would give people on getting started and other resources that are out there?

Sarah Mulukutla, MD: I have a couple, I think basic suggestions for how to begin. It does take a little trial and error, which we've heard here, and I'm so glad that has come out. Start with a couple apps. There's a few apps because those are easy. You can download them if you have a smartphone. Those just happen to be the easiest, those you have in your pocket so that when you find that you either need it or you have a moment in your day, there's actually a great app from University of Wisconsin, Healthy Minds Innovation, Richard Davidson. Play a couple different of the tracks and just bring your attention inward. They're all going to ask you to go inside and start to pay attention to it. And I think that's really the first place to, and those are all guided meditations. A second exercise I encourage you to try is to go to YouTube and type in coherent breathing to bells, and you'll get a whole list of tracks that have a bell similar to what I played before, but they're timed to be every five seconds.

And the instruction is to inhale on one bell, exhale on the next bell, and you continue that for five, 10, up to 20 minutes. I would say start with five to 10 minutes. What this does, it helps you learn to regulate your breathing a little bit, but also I'm mentioning it because during my seven years teaching meditation to Parkinson's, but especially in the last three years, that has been the number one technique or practice that has gotten the best positive feedback. People find that they can get themselves in a relaxed state. And the third, if you want to try mindful walking, bringing your attention into your body while walking, I do have a video that I created, and it was specifically with Parkinson's in mind, and that's available on YouTube.

Rachel Dolhun, MD:

That's great. Those are all really helpful suggestions, and we'll put all of that in the show notes so people can find everything there. And on that note, I can't believe we are coming to the end of our conversation. We really just scratched the surface of this. Sarah, I'm going to ask you to close us with another short mindfulness exercise.

Sarah Mulukutla, MD: Sure. Well, why don't I just go ahead and do a coherent breathing if that's okay. And I know some people, this is to start to get comfortable, go ahead and breathing, but we'll do this for one minute. I'm going to hit the bell every five seconds for one minute, and let's see if you can stay focused on it. Inhale, two, three, four, five. Exhale, two, three, four, five. Inhale, two, three, four, five. Exhale, two, three, four, five on your own. Inhale, two, three, four, five. Has your mind wandered? Exhale, two, three, four, five. Just a few more on your own. Try again, stay focused, stay calm, relaxed. And last one. And go ahead and release your focus and come back to the podcast around you.

Rachel Dolhun, MD:

Thank you so much. And thank you to Ken and Sree. Thank you, Sarah, for all the information that you shared. I hope that our listeners feel more present, feel a little bit more relaxed, and are excited to try some of these new tools in the management of life and life with Parkinson's. For more on this topic, including the latest research, you can visit our website at michaelifox.org. And as mentioned, all of the resources and links are in the show notes. If you have a second, we'd appreciate if you rate and review this podcast. There will be links to do so in the show notes as well. Until next time, I'm Dr. Rachel Dolhun.

Speaker 2:

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