## Introduction to mindfulness and Parkinsonu2019s

Welcome to the Parkinson's Solutions Summit. I'm Dr. Ken Sharlin and very, very pleased to welcome to this interview Dr. Barbara Pickut, who hails from the great state of Michigan.

Dr. Pickut has an esteemed background in research and clinical work in the arena of Parkinson's disease. And today we're going to talk about a passion of hers, or she has done quite a bit of work and publication, and that is mindfulness based meditation and Parkinson's disease.

Welcome to the Parkinson's Solutions Summit, Dr. Pickut. Thank you. Dr. Sharlin It's an honor to be here today to be able to speak about people with Parkinson's and their experiences with mindfulness based stress reduction.

It's excellent. There is a long history of utilizing this tool in general and understanding how it can help folks with chronic disease. Going back to some very classic studies that have been published looking at cardiovascular disease, prostate cancer.

You studied through the university in Massachusetts, which is sort of the Mecca of mindfulness based meditation. Tell me how you got interested in this in the first place as a neurologist.

Yeah. Well, we were performing we were performing the clinical studies back in the midnight knees and the dopamine agonists that were arriving on on the scene and important work.

We were very interested in being able to offer people with Parkinson's something beyond the cinema and carbidopa levodopa And so I was very encouraged and the clinical trials were a good way also as a young resident to, you know, learn the disease very well because we had to pin things down.

So we did that and worked very hard and I was left with a sense that despite the promise and the excitement that we were experiencing with having this opportunity, that there were facets of people's life experience, the lived experience of Parkinson's that weren't being addressed.

People would have traumatic stress events that they would come to us and tell us with very gripping stories. And many of these stories I still remember very vividly and would ask us, do you think that this event caused my Parkinson's?

And in the academic center that I was in at the time, I found it very difficult because if I were to speak with my the people who were there, full professors in the department, they would say no, these are anecdotes.

These. So I carry them with me.

## What mindfulness-based stress reduction means

And I started teaching mindfulness back in the early 2000, teaching mindfulness based stress reduction in a stress clinic in a hospital, and remembered that the folks that I had met earlier in these clinical studies were actually searching for something to help improve their quality of life.

So we started at that time, I think 2006 was the first cohort that we offered mindfulness based stress reduction to for people with Parkinson's. And then along the line, also for people with Parkinson's and their care partners, which is a very interesting dynamic so that people can realize and recognize and utilize mindfulness as a tool in daily life.

Well, why don't we step back just a little bit? We've used this term mindfulness based stress reduction several times and just help folks understand a little bit what exactly that is.

What are we talking about? Yeah, so mindfulness has become a buzz word. It's also appeared on TIME magazine covers and with largely folks that don't look like me and you.

So most of us. So these are it's kind of the hype and there are actually articles out now in mind the hype about about mindfulness. So mindfulness, when we talk about mindfulness, we're talking about an inherent human capacity, actually, and we all have this capacity for mindfulness, and some folks have more than others.

So it's this capacity that's expressed differently in different individuals. And the thing is, it can be trained. Mindfulness is, is a process, and it's defined as bringing attention, awareness to moment to moment experience on purpose without judgment and importantly, without cognitive elaboration. Hmm.

So it's seeing what's there. And, you know, we feel pain, we feel sorrow, we feel joy. Those things are there. But and it's about recognizing that fully and not ruminating about the negative and not going overly into the positive side as well. Yes.

My wife does a lot of this work, Valerie. She's an interviewee on the summit as well. And one of the things she talks about is sort of a perception that perhaps some people have that if they're practicing a mindfulness based meditation approach, they're supposed to clear their mind, not think of anything.

But you're actually saying quite the opposite. It's okay if these thoughts come in. It's how we sort of wrap our arms around those thoughts. Indeed. Very well put.

Yeah. It's not about clearing the mind. It's. It's about seeing what's there. And, you know, reality is they're running away from reality psychologically takes a lot of energy.

So it's this it's this process of realizing that in the first place. And the reason for classes such as mindfulness based stress reduction or mindfulness training is that through the training, one gains experience to learn to examine thoughts.

It's one idea. It's one thing to have the idea, it's the other thing to actually embody that in a non-judgmental way. And as I think about mindfulness based stress reduction and maybe associate the word meditation, sometimes it's easy to just sort of think of being in the lotus position, you know, and back straight and kind of breathwork.

And that's very, very powerful, effective, you know, thing to do.

## Stress, symptoms, and coping in Parkinsonu2019s

But it's my understanding that mindfulness can be applied in many situations, even if you're just at the sink washing your hands and letting the water run over your fingers, or if you're on a walk, for example.

Indeed, yes. Most of us don't have the opportunity to go sit in a cave and to Tim to exclusively meditate. We have life and one of the things that comes from the training and one of the discussion points during the training is how to apply mindfulness in daily life, how to be mindful more than just the jargon word suggests, but to apply it and there are tools that people are given.

There's there's apps actually that you get a text message from, you know, go from one room to the next and realize the space, feel the space, sense the space, see what thoughts that are brought to you and emotions.

So there are ways to apply this to daily life. And it's and it's it's a work in progress. Dr. Sharlin And we are a work in progress. So as human beings, we all are.

Yeah. We talk about in our brain to the program at Sharlin Health, we talk about folks where we talk, we share, you know, folk stories. We listen to a lot of listening, but we hear a lot of I just wish I could get back to the way it was before I got sick.

And I'm like, oh, this is the former journey. You know, we want you to be the best version of yourself. And sometimes we have to say, look, you know, the the version of yourself before you got sick is sort of how you got here.

So we have to continue to grow and evolve. But how how does stress play a role as a risk factor in the development of Parkinson's in the first place and the symptoms expression of Parkinson's disease?

Yeah. So stress is ubiquitous. Stress is everywhere. It's a part it's a natural part of life. And in relation to mindfulness, this psychological stress that we have, it's a matter of using mindfulness in that is how we perceive the stress and the ruminations and the the, the cognitive load that that brings us to ruminate.

So this is a highly individual quality. Some people worry less than others, but worry is a source of stress and so the idea that actually stress is a that risk factor in Parkinson's has been debated.

It's been hotly debated. In fact, you know, we when I told you earlier about people that I was concerned with, people with Parkinson's who were serving, that, you know, they they had difficulties with anxiety and stress.

You know, leading forth from from their experience with Parkinson's in life. I was the general feeling at the time was no, stress is not a risk factor.

But the idea that stress is a risk factor is not new. In fact, 100 years ago, Sir William Richard Gowers, who is considered by some to be the father of clinical neurology, said that emotional shock and anxiety often precede PD. Hmm.

So in the years following that, a lot of discussion about is that true? But I think importantly for us here today, that we now we're coming to see that stress is maybe a modifiable risk factor in Parkinson's, both in the acute stage and the chronic stage and even in the prodromal stage.

Right. So we learn from our patients, of course, who have chronic stress that there is an exacerbation or aggravation of symptoms. I mean, we hear this in the clinic all the time when people say, you know, I am in it, I'm in a store and I have my change purse, and there's a super line behind me at the cash register at the end.

The person at the cash register isn't particularly friendly, and I have to get or my card or my change or whatever out of my wallet and my tremor just goes.

And you know, what do I do? Right. Right. It's in those moments that mindfulness can be applied more, that people can connect with their own capacity for mindfulness and bring the nervous system back to some rest.

I had a gentleman seven years ago who, for example, was someone I followed in a clinic and his daughter was getting married and he was to have a father daughter dance with her.

This gentleman with Parkinson's had freezing of gait. Oh. So you can imagine a huge dance floor and everyone looking at him. So he the marriage plans were in the next year or so.

So it wasn't immediate. Well, he enrolled in one of the mindfulness stress reduction programs that we had and completed the program, did a great job, was showed up and and did his practices.

And he came back to tell me that he was able to stand up and was able to monitor his inner voice and his. In your feelings and the heart pounding recognize those things are natural, normal.

And to get beyond that, he was able to get to the dance floor without music because you would think, oh, it's cueing. He's getting there. Now he was able to get there.

And then an upbeat song came on and he was able to have that dance with his daughter. So.

## Research findings and brain imaging studies

Yeah, I'm just curious and this may be a slight digression, but have you noticed if certain types of rhythms or tempos are better for people with Parkinson's at all when it comes to dance?

Because there is actually some data on dance just from a movement therapy perspective. Yeah, certainly the my experience with cueing stress, you know, that falls within the realm of cueing strategies, right?

And there are a lot of publications about cueing strategies and the work of Beth Bloom and his team are are very knowledgeable and helpful in that area.

I'm not aware of any particular type of music, but I would just assume that it might be music that, you know, has has it has a rhythm to it that is like, let's say, freezing of gait.

You know, there used to be device is that people would wear that would that would tap they would give them a tap. But the problem is it has to be the cadence is something that is biologically consistent with the person.

Right. So if we were to play Mozart, it might not, you know, sync well with with someone, one of the young parakeets, I don't know. But it's what I'm trying to say is that it's highly individual.

The Cuban video, it really throw them off if we did Beethoven's Fifth because it just goes, Oh, wow. Right. Yeah. I wonder if some of this you know, first of all, we do have to emphasize, we talked about this a lot on the summit, that there is a biological stress response system in the body.

That's just part of how we're wired. It's connected to our limbic system. There are hormonal and and neurotransmitter dimensions to this. And then it spills down into the effects on the immune system, on mitochondrial function.

And so stepping back from a disease centered perspective to more of one to why we get sick in general, that this is something that is within our power to an extent, to a large extent, to affect.

And as we improve overall function because we know that this has again, it has effects on the immune system, mitochondria, you know, gut health, which has been connected very much to Parkinson's disease.

It sort of stands to reason, perhaps without even the the clinical trial to back it up that this can have a very positive effect. And then, if you will, there is also the dimension.

It's a little bit of a chicken and an egg, but we know that there are non-motor symptoms of Parkinson's that are part of that disease. So whether we are sort of of that personality type, that's the worrier in general kind of coming in to that experience.

So Parkinson's, there's also the recognition that sometimes the neurodegenerative changes that are in fact Parkinson's change, the wiring of that part of the system.

So it warrants attention beyond sort of just giving someone leave a dopa. Would you would you agree with that? Oh, indeed, indeed, yeah. In fact, interestingly, people with Parkinson's who do not engage in task oriented coping strategies may be at a greater risk for developing depression and anxiety and have poorer quality of health measures.

So in in with chronic stress in PD with this, we see that there is more of a risk of depression and anxiety that those publications exist. So coping strategies are very important in mindfulness as a coping strategy.

So there are others, but we have evidence that these coping strategies can be very helpful, in fact, for depression and anxiety outside of Parkinson's.

There was a recent head to head study with mindfulness and escitalopram that's given as a treatment for anxiety. And there was a clinical study and the conclusion was that mindfulness was not inferior to escitalopram in the treatment of anxiety.

This reminds me of some of the studies that were published. I think going back to the nineties again, looking at, you know, prostate cancer or looking at cardiovascular disease and folks who might be randomized into a group that had more traditional medical therapy versus those that practiced a mindful risk based approach and integrated granted other lifestyle factors such as diet and exercise.

But they were dramatically able to modify their disease trajectory without some of the traditional interventions. And what has been tell me a little bit about what's been kind of coming out of the of the research literature that you've done in terms of mindfulness based stress reduction and some of the metrics that you've used.

Yeah. So it's important to to understand that this perception of stressful events and the processing thereof has an impact as you as you just said, psychologically and physiologically to, to tee off the the, the fight or flight mechanisms.

So it's the perception and the ensuing processing of the stressful events where mindfulness can be useful. So we have seen actually we've conducted a number of studies in Parkinson's and mindfulness.

And back in 2013 we did an imaging study. It's actually to this day, to the best of my knowledge, the only one that's been done in Parkinson's and mindfulness.

The what got us thinking in this way is that Sarah Lazar, published back in I believe was 2005, a study that she had done on long term meditators that showed a difference in cortical thickness in long term meditators, as opposed to controls which were age matched, education matched socioeconomically matched in the Boston Cambridge area.

So there was an increase in cortical thickness. But of course, as we know, there are other deep structures, subcortical structures in the brain that play a role in Parkinson's.

So it was an interesting study and the outcome of that was that the meditators who were in the 40, 40 and 50 year olds had the same cortical thickness frontal areas, which is where we often lose cortical thickness in aging, that their frontal cortices were equal to the 20 and 30 year olds.

In this study and the and the controls of the young age of the 20 to 30 year olds. So that showed that there was less loss of cortex in these individuals in this study.

And that was a tagline for the popular press right. Is oh, meditation makes the brain grow. Well, of course it's not that simple. So that kind of simmered for a while.

And then the technique came out to be able to look at whole brain and subcortical structures, and that's using a technique called voxel based morphometric.

So using that technique, images of people, long term meditators started to be studied and we could identify areas of the brain that were impacted by mindfulness and showed less release.

Also the amygdala, for example, in long term meditators as compared to controls. So that was very interesting. And then researchers, Britta, who also published a study on mindfulness in a population of people seeking stress reduction at a stress reduction clinic.

So we're not talking Parkinson's here and using this VBM or voxel based or photometry, they could show that after eight weeks time there were measurable brain changes.

So I said, Just as you. Hmm. So what did we do? We set up a study to look at people with Parkinson's. We used a control group who, you know, treatment is usual, which in retrospect should have been in active control.

But active controls are tricky because, you know, what did they learn doing the active control. So that's being worked on.

## Social support, group practice, and quality of life

But in any case, back in that time and talking 2013, we used a waitlist control for this population. So we enrolled people and before and consented them of course, and they started.

So we did a number of clinical measures ahead of time. We did the updraft unified Parkinson's rating scale in all its parts. We did the pre Q 39 and all its parts and a number of other metric measures.

And we found that after eight weeks time that the order of magnitude of change in the brains of people with Parkinson's were equal to those found in the general population.

Also changes in the amygdala, the amygdala also changes and these people were more right handed changes in the left cerebellum, which are accounts for, you know, compensation, motor compensation.

So it was an interesting work. However, that being said, I was again left with the feeling that we're not doing enough, that there are things that we're missing, that these this training, this mindfulness training that that people had had and were telling us after the fact, you know, in conversations in the hallway or at the follow up conversations in the clinic, that there were reflections that they had, that we were not capturing the positive reflections, that we were not capturing, that the routine clinical scales weren't capturing.

So we decided to do a new study using qualitative measures in the form of a focus group. And some very interesting things came out of that study. We found that people had body four.

What we did is we analyzed the data and we did the routine measures and we also had the focus group results and we found that there were things that people were saying in the focus group that weren't picked up by the routine clinical measures.

For example, there were some statements in the focus group suggesting that there was an improvement in body sensations and pain reduction in mobility, but that wasn't picked up on the Epidaurus motor Part three We had people talk about coordination and coping and those weren't picked up in the PD.

Q 39 Coping and well-being. So we did have some very interesting findings here, and this is found also in other the work of other people that social support, in fact the group effect came out as a very robust finding.

But people said for the group effect was they expressed gratitude to the group that yeah, that eight out of ten of them mentioned the importance of social support as a positive outcome of their participation in this group.

Training of mindfulness. They pulled strength from each other. I can read you some of the comments that the folks said. This has been published in abstract, so I'm sort of sitting on it right now.

But the participants often described gratitude to the group and overwhelmingly expressed positive experiences with their shared understanding. Eight of the ten of the people in the group mentioned social support as a positive outcome on their family and their future lives.

People also found that it was intrinsically tied to this feeling of transcendence or spirituality that they had within the group. They talk about, you know, this is a quote.

You know, the teacher kind of brought us all together and we kind of just know by certain things people say about how to communicate. We all had the same disease, so we all communicate.

It's kind of like whales. Well. And then they continued saying it was nice because we drew on honesty and the people. You could tell when something was wrong without speaking.

And then an example of research reciprocity that was empowering. And we pulled from each other. We pulled strings. And I think everyone wants the other person to succeed and not quit.

Another participant described the impact of the of the MBA training and a group setting and says this group has been wonderful and I've been able to take things from all of them, the other people.

It's also given me courage and we see this to we have the opportunity to provide monthly meetups online for people who have studied Parkinson's. So in the monthly meetups, which are Zoom meetings, we do breakout groups and people can meet up with each other for for some time during during the meeting.

And they really express a joy and gratitude and connecting with others in that way. So this desire of people with Parkinson's to connect with others and find emotional support has also been reported in the literature.

In the study that Kwok did. She performed a study of people with Parkinson's and compared mindfulness yoga to physical therapy. And they note the importance of mindfulness therapies specifically as they assist people with Parkinson's in their symptoms, such as connection to others.

And they talk about transcendence as well, and they conclude that this points to a need for interventions that may help people with Parkinson's effectively manage their disease.

So there's also two short things that I want to mention in connection with that. There have been surveys published using the multi dimensional scale of perceived stress and social support.

And in these surveys we see that the social support reported in in this scale and also the particular 39, that it was a predictor for to all the domains of quality of life.

So that single factor social support was predictive of all domains of quality of life. And another survey that last one was I think they had 238 participants, people with Parkinson's.

Another survey of 124 people found, and these were from three different online support groups that this revealed that the perceived emotional support increased the psychological quality of life for these people.

And on these measures. That's so interesting. So interesting, because, you know, one of the dialogs that often comes up in an I work with folks not just with Parkinson's, Alzheimer's, ALS, multiple sclerosis, but I think especially with the Alzheimer's and Parkinson's patients, is even if historic, you know, as a personality trait, they tended to be very social individuals with the onset of these illnesses, very often there's a withdrawal.

There is, you know, I don't want people to judge me. I don't want to be seen like this. I don't want people to remember me like this. And what I'm hearing from you is even outside of the mindfulness based meditation, that that human connection is so critical for thriving with these conclusions.

Yes, yes. And so to get the word out that, you know, oftentimes one of the issues that people with Parkinson's have in going to group is that indeed they're afraid of being seen.

And sometimes being with your peers is comforting and sharing and can open doors. Yeah. You know, doing there was a study, I believe, in 2017, Shapira, who did a review of patient patient blogs and found that social support was a big factor in their wellness.

So often that even think of mindfulness work as being, you know, an inherently sort of isolationist. I'm not sure if that's really the right word, but something that we do in our quiet time by ourselves.

Privately. And privately. But in fact, we're hearing is, you know, and this may not just exclusively apply to mindfulness based stress reduction. It could be, you know, rock steady boxing class or an other a dancing group or a group cycling, all of which have, you know, good, good scientific data behind them.

But connection, go to a class, connect with other people, find community. And that is yet another tool in the toolbox when it comes to thriving. Indeed indeed.

So you pointed to an aspect of the the the private. So yes. And in addition, you know, when when during these mindfulness classes, people meditate together, people do the mindfulness yoga together, people do the body scan together.

## How to start mindfulness practice and resources

So you can do these practices together in a park. It's a matter of training, right? Getting people the training. This trait mindfulness, which is a trait, it's something that we ambulate to be a lasting trade.

But like learning to play an instrument, one has to practice. One has to practice so that as we are getting toward the end of our interview that this is a great segway.

If I want to learn how to practice mindfulness, how can I do that? What what are your recommendations? Yeah, I think that choosing a place to work and a teacher is is of importance.

I would recommend that people with Parkinson's discuss this with their health care provider from I'm thinking of doing this. And what do you think particularly people who have a on offs that may be troublesome to maybe bring they get the medication as stable as possible.

The you know, currently there's no regulations on who can teach mindfulness and I would gently advise people to look into the qualifications of the person who will be teaching them.

General speaking teachers that are certified in the big schools is that UMass has that brown is that you see San Diego. I mean there are a number out there, but these training programs are rigorous and one is required to have a practice, a self practice of hundreds and hundreds of hours before teaching.

So people would be advised to look into the credentials of a teacher, speak with the health care provider and get their okay on it. In preparing for the sessions, it'd be good that people could be medication on.

Not always easy to plan, I realize that, but perhaps some refinement of the of the medication schedule ahead of time so there's likelihood to be in on there are rescue medications for Parkinson's and some people use them and they could have them close at hand during the sessions.

People should show up and be fully present to participate. But that doesn't mean you need to talk. You know, you can be a silent observer. And most of those people, they do their practices, but they come loose as time goes by.

It's interactive with the teacher and with the participants. And between the participants, if it's an online course, people should prepare a quiet place where they will be undisturbed and maybe have something to take notes with.

That would be my advice. We currently teach online. I'm bringing this material also to the International Movement Disorder Society Task Force on Wellness that I'm a member.

We have a program that we're teaching now for actually two one with per people with Parkinson's exclusively and one with people with Parkinson's and their caregivers together and are planning on in the fall teaching a class for caregivers of or care partners that are said of people with Parkinson's exclusively because sometimes things want to be said in a group of care partners. Yes.

So if someone wants to participate in one of the classes you're talking about online, how would they find that? There is a website, it's called Parkinson's Mindfulness, spelled out dot com (parkinsonsmindfulness.com) and they can email me at barbara@Parkinsonsmindfulness.com So long typing but complete.

Yeah. Wonderful. Well, now we have voice recognition and, all kinds of adaptive things. So folks can do this and I

certainly encourage this. You come from a long tradition of really esteem and tradition started by people like Jon Kabat-Zinn from University of Massachusetts at Amherst.

And we really appreciate the work that you're doing in bringing this important skill, this important information to folks who are suffering from Parkinson's disease.

You know, I often say because we focus on sort of a multimodal approach where we're, you know, sleep and nutrition and movement and mindfulness based stress reduction as well.

And folks often want to just sort of pigeonhole and say, well, I can really work on my nutrition. And of that's valuable. But if we're not paying attention to to sort of the other muscles that we need to kind of tone up and strengthen, it'd be like, I'm just going to work on my right arm, but not my left arm and just going to get one leg strong, but not the other leg strong.

This is a critical part of wellness and is a powerful tool when we think about healing and transformation in Parkinson's disease. Well, Dr. Barbara Pickut, thank you so much for participating in the Parkinson's Solutions Summit today.

I encourage folks to check out your website, participate in your class, and really just become a student in general. This long standing tradition in America that has helped many people with a variety of complex chronic diseases.

Thank you. It's been an honor. Thank you.