



## Live Well Today Webinar Series

### Mood and Parkinson's

Davis Phinney Foundation

Polly Dawkins (MBA, Executive Director, Davis Phinney Foundation):

Hello and welcome everyone to the Davis Phinney Foundation's Live Well Today webinar series. I am Polly Dawkins, ED at the DPF. I'm very excited to be here today with someone who has been connected to the Foundation for a long time, Joanne Hamilton – Joanne, thank you for being here. I will do a proper introduction of Joanne in just a minute, but I'd like to go through a few housekeeping items now.

First, I'd like to thank our Peak Partners, Amneal, Kyowa Kirin, and Sunovion. We're so appreciative of your ongoing support and enabling us to provide these webinars and other resources to our community for free.

We've enabled live closed captioning. So, if you like to see the live transcript on your screen you have that option. If you would prefer not to see the words, you just click the little arrow near the icon that says CC, and it'll give you an option to hide subtitles.

We would love for you to click the little button that says chat and let us know where you're joining us from. You can also use the chat throughout the webinar to ask your questions and respond to others. If you'd like only the panelists to see the question, choose "Panelists," and if you'd like everyone to see, choose "Panelists and all attendees/everyone." As always, we will send you the recording of this webinar, along with the transcript, audio, show notes, and any links that are shared during the webinar by the end of next week.

Now, to introduce Dr. Joanne Hamilton. Dr. Hamilton earned her PhD from the SDSU/UCSD Joint Doctoral Program and specialized in neuropsychology. Her fellowship was completed at the Shiley-Marcos Alzheimer's Disease Research Center where Dr. Hamilton was the principal investigator of an R01 research award investigating cognitive changes in Parkinson's and Lewy Body Dementia. Dr. Hamilton currently works in clinical practice to translate scientific knowledge into practical tools to bring about meaningful advances in daily life for those living with Parkinson's. And you also work at Scribd, is that correct?

Joanne Hamilton (Director of neuropsychology at Advanced Neurobehavioral Health of Southern California, and resident neuropsychologist in the Department of Neurology at the Scripps Health in San Diego):  
That's right.

Polly Dawkins:

Yes, Super, so you are calling in from sunny California.

Joanne Hamilton:

I am calling in from hot and muggy at the moment California. Yes.

Polly Dawkins:

Well, in 6 months' time I would like to switch places with you. Super, alright. So today we're going to talk about some challenging topics that we are asked about so often in the community which have to do with some of the non-motor symptoms. You don't see in Parkinson's many of the nonlinear symptoms you don't see. But these are the ones that impact emotions and mood and are often overlooked because they are complicated.

Joanne Hamilton:

Yeah, so, they're harder to talk about and they're hard to talk about objectively than the physical symptoms, aren't they? And they're harder to measure than the physical symptoms. And market disease in a lot of ways. Unfortunately, not all physicians are comfortable or are feel trained, you know, prepared to ask these kinds of questions, and so sometimes you know, whereas they'll ask very, very quickly, you know, are you getting the same level of tremor control for your medicine? They won't necessarily ask you how's your mood? How's your anxiety level? And this becomes a real problem because then it feels almost like its taboo to even bring up and, you know, different folks have different comfort levels discussing these really intimate personal experiences.

And so not all people are going to just bring up without any kind of like a clue or any kind of queuing that their mood is poor. And you know, I'd be a little bit stereotypical, but oftentimes it's a very uncomfortable subject for men in particular, and certainly an uncomfortable subject for certain generations you know it. wasn't something that people talked about so I'm glad that I'm glad that this is our topic today.

Polly Dawkins

Yeah, and there's so much stigma associated with anything that has to do with mood or emotions or mental health. And you are just and our and our brains in that way.

Joanne Hamilton:

Yeah, absolutely. I'm trying, you know, we're trying generation to generation to start helping people understand that depression and anxiety are states like diabetes, you know, it's not something that you can control. You can't turn it on. You can't turn it off and the more we start thinking about these as illnesses as opposed to state of mind, or just not trying hard enough, the more likely we will start to get the resources that we need to actually treat this. These are really serious in some cases very, very severe illnesses and you know, they can be fatal.

Polly Dawkins:

Yeah. So, before we dive into strategies that our community and viewers here can employ to better handle mood issues, depression, anxiety, perhaps we could start and get everybody level set on sort of what are we talking about? So, to start, can you help us understand what people mean when they talk about mood? And what's the difference between having a bad mood or a good mood or an actual mood disorder?

Joanne Hamilton:

Absolutely. I think that's a really important first question because very often I'll even see it in people's medical records, you know depression. So, let's start off by just what is mood? I like to define it as kind of your emotional state of mind. It's where like when we say how is your mood? What we're talking about is where are you on the spectrum of emotions at this point in time and mood is very much state dependent.

Your mood could be kind of lousy in the morning, and moderate out by the afternoon, and by the evening time be really kind of a good mood. And it can also be very situational. Like, you know, if you get a traffic ticket on the way to work your mood's going to be kind of crummy. You're going to be a little irritable a little bit impatient frustrated. But perhaps by, you know, lunchtime, you've had a nice morning traffic ticket wasn't that bad Everything's going to be fine.

You get home, and everything's good again. it's really important to normalize a bad mood. Everybody is going to be in a bad mood from time to time. Is it a completely normal state of emotion when we start to talk about a mood disorder?

What we mean is that an individual is having a low mood, a bad mood, a sad mood day after day after day, for weeks at a time and that sad low mood is pervasive and is not fluctuating, depending on the situation. So, the person's mood is low and it's sad even though their favorite nephew just got into town and it's sad, even though they're about to do what would normally be a fantastic hike for that person. That pervasively slow, low, sad mood has begun to cause other symptoms.

Symptoms include loss of concentration, the inability to experience pleasure or interest in the things they used to love to do, fatigue, not just I'm tired and I'd like to go to sleep, but sort of like deep fatigue, where it feels difficult to move or even hurts to move. They may have problems with sleep, either sleeping too much or too little, or appetite eating too much, too little. They may start to feel really badly about themselves, you know, a lot of guilt. A lot of negative self-assessment, you know, I'm awful, I'm being punished, I might be hopeless.

And then you know very, very severe mindset. that is not uncommon. I want everyone to understand. It's not uncommon that some folks will start to think that maybe they're better off if they were not alive, or even more scary, maybe their families would be better off if they were not alive. So that's called suicidal ideation, and that's all part of this mood disorder. Not a bad mood, but a disorder. Okay? And it really is technically correct to say that mood is so significantly low, and it makes it difficult for a person to take care of their day-to-day activities. They may have a hard time just having the energy, the motivation to get out of bed and to get dressed. They may wear pajamas all day does not shower as much as they should, may not be able to take care of the kids, or, you know, have the energy, the motivation to take the dog out for a walk.

So that's when we really start talk about a mood disorder. and usually, we we're talking about major depressive disorder. But there's others as well, so depressive disorders fall under the umbrella of a mood disorder.

That's right. Yes, depressive disorders fall under the umbrella of a mood disorder. Today, we're talking a little bit more about depression but I'm sure people have heard this word bipolar disorder or manic-depressive disorder. That's when the mood fluctuates between a low mood and a very high elevated extreme mood. Bipolar disorders are a little bit easier to spot because of that high elevated extreme mood versus major depressive disorder, where a person will be not pretty fairly withdrawn, not able to be socially out there and may and may then not come to the attention of other people.

So then why are we talking about this in Parkinson's, well, mood disorders and Parkinson's disease are very common. And they're very common for a couple of reasons. First is Parkinson's is a chronic health condition that causes, in some folks, a level of disability that's difficult to manage. People with Parkinson's have to manage their physical changes. They may have to manage occupational changes, social changes, role reversals, and the demand in and of itself is challenging and can bring on a mood disorder.

But in addition, Parkinson's disrupts the transmitters that are the neurotransmitters that are extremely important for mood and thinking regulation, and it starts to just disrupt those transmitter systems very early on in the course, oftentimes even before the motor symptoms are obvious. And so, folks with Parkinson's are at a much higher risk somewhere between 40 to 60% of folks with Parkinson's experience early mood disorder and early anxiety disorder. And this could be the very first sign that Parkinson's is starting to emerge. It's just that we usually don't recognize it as such.

So, we talked about the umbrella of a sort of mood disorder, and under that falls depression, anxiety and apathy also fall under that same umbrella. So those are categorized differently. If we look at, you know, the criteria that we use to diagnose these emotional states or these emotional disorders.

So, anxiety is another extraordinarily common syndrome. For folks who are dealing with Parkinson's, anxiety is more of, not so much as state of mind, but I would almost call it like an internal sense of worry and apprehension. Whereas depression would be more characterized with sadness, anxiety is going to be more characterized by fear. And so, the anxiety that folks will experience can be sort of global where they're anxious about kind of everything, right? They're just kind of in a constant state of apprehension, or it can be more targeted and focused where the anxiety is really centered on a specific area of life. You know, is the family okay? Are our finances okay? Is my health okay? And for a lot of folks with Parkinson's, they'll tell me that they can feel it inside almost like an internal trimmer, and it causes them to feel very restless and agitated almost like they can never truly relax, like they're always waiting for the next shoe to drop and then apathy.

So, apathy is actually characterized even outside of that. Now, obviously all folks with mood disorders can feel apathetic. They can feel like they're not very motivated to do things they can feel like It's hard to get up and go. Apathy, in a neurological way, is more related to the brain itself. So apathy can be the loss of ability to initiate behavior, even when there are things around you that are interesting or that are that could be pleasurable.

So, a person who is apathetic due to a neurological condition may sit for hours at a time, may not even get up to go get something to eat on their own, but when they're prompted, when they're, you know, taken to the park for a walk. They will emotionally enjoy that walk, and once they sort of break through the inertia of the city, they will continue to act so. It's not a perfect distinction but the way. I think of it is a mood disorder is going to come with, and emotional experience attached to that indicates to motivate you know Oh, well, what's the point of it, anyway, like I'm not it's not going to make me any better. What's the point of exercise? You know? I just don't have the energy for a shower today. Who cares? I'm not going to see anyone, anyway.

The apathy lacks that emotional context, you know, and if you ask an individual who's very apathetic, well, would that be fun? They very often will tell me yeah, I love to do that, you know, or spouse says "Well, how come we don't do that," and they say, "I don't know you know." It's just the brain is not signaling that it would be good to do this or that they should do this and so they don't, and that's really the way I think about the differences between depression anxiety and apathy.

Polly Dawkins:

That's really helpful. I'm hopeful that our audience, who've asked some questions about the distinction, that's helpful for others before we jump into, well, I'll come back to one question that folks have asked about anger. Can somebody with Parkinson's have depression, anxiety, and apathy? Or are they overlapping or very different?

Joanne Hamilton:

You know, it's important to realize like we do these diagnoses based on these diagnostic criteria almost like decision trees. And that's wonderful in the lab, that's fantastic if we, you know, are drawing out a slide show or doing a PowerPoint. But in real life what we know is that all of these things intermingle and overlap, and so very often, if I'm going to diagnose a person who, with major depressive disorder, I'm aware that there's an anxious component but what I'm trying to do is kind of get through to the meat of what this syndrome mostly looks like.

For some people, they are mostly depressed with some anxiety on top, and then others are just mostly anxious, and they might have a sadness about their mood or numbness about their mood. That helps me know that there's a little bit of depression there and then. I'll have folks who are completely engaged and humorous and easy to test, and very fun to be around, and there's not a hint of depression and yet at home they sit all day long. Right? So those are the easy ones we know.

Polly Dawkins:

Okay, depression, anxiety, and apathy are different but, in most cases, it's going to overlap a little bit, and then what we have to try to decide is which treatment is going to get us the biggest bang for our buck and that's where we take it. So, as we're thinking about this, and somebody has just asked us this question just the 2 of us, but how do you distinguish between what is Parkinson's, and what is just normal like normal depression can? And what is the normal? Is there a normal level of sadness? And how do you distinguish between this is my Parkinson's or this is separate, I'm not sure. Does it always matter, you know, whether it's it my Parkinson's, or is it Major depressive disorder?

Joanne Hamilton:

Okay. Now, obviously, if you do a very good history, you can. There are people who have had pervasive or recurrent depression for much of their life, right? They may have had a very traumatic upbringing, a difficult home life, or they may have just developed depression at a very young age, you know, in their twenties. And now, as they go forward now, they're 60 and they now have Parkinson's disease, and that's for that person. This person probably has major depressive disorder primary and Parkinson's disease.

In addition, it's 2 separate things, but we have many patients who will tell me "I have never been anxious in my entire life. And then, 3 years ago, I started to become so anxious that I literally could barely get out of the house." And for those folks. that is most likely their Parkinson's disease, causing these symptoms. This is a non-motor symptom of Parkinson's disease, and the same, you know, with the depression, it's a non-motor symptom of Parkinson's disease. I suppose the only reason in my mind that we want to distinguish it is that if this is Parkinson's disease, causing this depression in this anxiety because of a

change in neurotransmitter then the neurologist and the with the help of the psychiatrist, as a team, need to really consider.

Are their biological treatments that are going to be most beneficial in this case? It's a very complicated system. And so, if you're increasing the amount of dopamine available for the brain through medication, you have to acknowledge the therapeutics. It's also that you're kind of disrupting the amount of dopamine for the other symptoms. The other systems modulate mood and thinking, and sometimes what you can see is too much dopamine on board, too much anxiety and problems with thinking. But we also don't want the psychiatrist prescribing medications that are for that could have the potential of sort of changing the way the domain agonists are working. And so, in that case, there is a very closely link between psychiatry and neurology.

Neurology is going to be important for some folks who have Parkinson's. A big part of their disease is going to be their mood disorders. They are going to be situational; you know this: it's a change in rule. It's a loss of occupation it's a loss of individual concept, you know, self-concept in that case, psychotherapy may be a very important component of treatment because in psychotherapy you're going to actually work through what your self-expectations are, what your roles are, how you're interacting with your spouse, and all of these pieces can actually alleviate the depression and anxiety. Some, and it may be in addition to, or instead of medication.

So, if you are living with Parkinson's or living with somebody who has Parkinson's, how do you know if someone is sad or I am depressed, and how do you know when to seek therapy or help the trigger in your mind. These needs some addressing externally, you know, is this an individual who has a down couple days, because maybe they've just taken a fall. And it's you know really kind of hit him up the head like, you know, a ton of bricks that there are some physical limitations, you know. And it just lasts a couple days, and then then, you know, they move through, and they keep going. Or is this something that in my mind a trigger would be?

It's pervasive, it seems to be day in day out of sadness. You're starting to hear a lot more talk of death and dying. You're starting to hear a lot more you know suggestions well, maybe you know just be better if I were just around at all right now. Red flag. Other red flags are, you know, inability to sleep, so anxious that they're just up all the time, not ever able to rest, not eating very well. And you know definitely, and spouses are usually the ones that notice this first just extreme irritability, right? Just biting off the heads of anyone around them all the time, because irritability is going to be one of those symptoms of anxiety and mood disorder.

It does not add enough frustration tolerance to even, you know. Deal with the Costco line like you know just by the way, no one has enough patience. But if you're hawking at people



more than you really do, you know, maybe that irritability is too much. A few people who have asked about sudden bouts of anger. Is that sort of this irritability, or is there something else that you see that might be going on? Probably it can be very much that you're in apathy if out of the blue you know there is nothing you could even label to explain this sudden bout of anger. It may be that this person is just constantly on the threat of not of not being in control, because they're so irritable, or they're so frustrated.

Many people will tell me "I lose my temper because I can't do things that I used to do. You know I used to be able to fix the faucet in the sink, and I used to be able to do it in 5 min. And now I'm all of a sudden calling a handy man because I can't figure out how to do that you know, and that causes this burst of anger." This first irritability, but with Parkinson's, there's also some changes in executive functions right the ability to monitor behavior to have insight into the fact that the behaviors are maybe over the top to be able to get out responses you know to be able to inhibit that anger and so sometimes those sudden bursts of anger actually more akin to executive dysfunction which is caused by the cognitive or the changes associated with Parkinson's then it is depression or anxiety.

Polly Dawkins:

Got it, so we talked a little bit about identifying wins the right time. What are the triggers that say we really need to get help? We meaning somebody living with Parkinson's or a care partner identifying this one of these triggers? Where? What's seen? Where do you go? Who do you go to? Who do you talk to first?

Joanne Hamilton:

Well, if so, everybody's, you know, has a little bit different care team. You know, if you are fortunate enough to live in a place that has a movement, disorders care, team- Sorry my light went out, and I didn't realize it- then the very first place you go is your neurologist because the neurologists in a movement or sport disorders care team is going to understand these non-motor symptoms. And we'll have hopefully the resources kind of put together to know where the next step is.

In a complicated situation, sometimes the next step is going to be geriatric psychiatry, or psychiatry. And geriatric psychiatrists are those that specialize in conditions for folks, you know, 65 and older, who may have multiple comorbidities, not just major depressive disorder, not just anxiety, but a bunch of different things. And if they feel like that, the situation is a little bit more complicated, sometimes the neurologist feels more comfortable having a psychiatrist, who specializes in these kinds of medicines, managing them.

They will also, like me, refer for either social work or psychology for psychotherapy. And sometimes it's combination of both. I think most studies will show you that folks do best when they have both psychotherapy and medication management for some forms of anxiety and depression. Sometimes it's family therapy that's going to be the most



important treatment because it may be that the depressions largely due to family stressors associated with changing roles.

You know it's the case that it's very rarely just a patient that's struggling. It's usually the whole family system that's struggling so first step is position. If the physician cannot be terribly helpful for whatever reason, either they don't have that knowledge base or they don't have the resources, there are a number of places where you can start to look for help. This is not an advertisement or anything, but I found a website called [psychologytoday.com](http://psychologytoday.com) to be a very helpful website. It's national, and when you go to that website you can put your specific location and you can indicate your insurance, and then it will give you a number of options of people who treat that condition, and you can specify with you want a psychiatrist. So, the difference between a psychiatrist and a psychologist is that a psychiatrist is a medical doctor who can prescribe drugs and in most states a psychologist or a PHD does not prescribe drugs and that psychologists do but for the most part psychologists don't prescribe medicine. And so, this is this is the next step if your physician can't help. Then, you can take this one on and see if you can find some resources yourself.

Polly Dawkins:

There are some questions about meds. Can Parkinson's meds contribute to any of these disorders or can side effects of those meds contribute?

Joanne Hamilton:

Yes, so you know, obviously, I'm not an MD. So, you know, I'm not given any medication advice or anything like that. But what I will say? Okay, really, you're not moving enough, Joanne. So that might down room knows that I'm still literally sitting here. Sorry about that, everybody. So, what were we just saying before my lights went out?

Polly Dawkins:

We were talking about Meds. The Parkinson's meds contribute to any of these disorders.

Joanne Hamilton:

Yes, okay. So, sometimes, we'll see elevated levels of anxiety in some folks who may be taking too much medication dopamine, is quote unquote your pleasure drug, your pleasure neurotransmitter. And so, the brain loves dopamine, and there can be cases, it's called, it's basically a domain overuse syndrome where folks who are taking a dopamine agonist, or even or like levodopa, we'll get a little bit of a like a little bit of a jolt of energy, a jolt of positive emotion, a jolt of good feeling and well-being when they take their medicine, and so sometimes they'll start taking it more often than they need to take it, because their brain starts to like it to help them.

And so too much dopamine can cause some increased levels of anxiety and can cloud thinking. It can kind of make you feel a little confused and kind of a little bit not as clear. It's a sweet spot, because too little can also make you feel that way. And so, your neurologist is constantly trying to keep you in this little, small box of not too much, not too little. But that's why, when I say, "where's the first stop," the neurologist should be the first stop because it's important for them to try to think through, "Okay, do we have you on something that's not helping us?" Let's put it that way and it could even be contributing.

Polly Dawkins:

That's a really great point. So, reinforcement of why your neurologist needs to be a going to. To go back to another question that somebody has asked, I'm going to go back to apathy since there's so many questions. Somebody has asked about apathy. Is apathy also not feeling emotions when most people would?

Joanne Hamilton:

Yeah, no, like, you know, you've just learned that your sisters passed, and you know you should feel sad, you know. You know you should be crying. But there's just there's no emotion. It's not there's no happy there's no sad. There's just sort of a blank slate almost for emotion.

Polly Dawkins:

And is apathy is treated similarly, that you would speak with your neurologist and talk therapy and treatments? Or is it a different course of action for apathy?

Joanne Hamilton:

So, apathy is not well treated by medications. Apathy is really better treated by behavioral changes to the environment. Routine helps a lot with apathy because the idea is that the brain just isn't saying, hey, you know you, you need to be doing things right now. It's not giving that signal that gosh have been sitting here for 6 hours, you know, and I haven't really gotten up and done anything. And so, a routine becomes really helpful with that respect and a very set routine, you know. Every day at 9, we go out for a walk. We go to rock steady. We do some boxing, we bicycle, whatever that is. At 10, you know, we sit down, and we have our coffee, and at 11, we do some chores around the house, and at 12 we have lunch, and at one we take a quick nap, and at 2 we do, you know, whatever, because that routine helps overcome the nothingness the lack of signal.

If they're to get up and do stuff and truthfully, most of my patients will tell me they just really enjoyed, you know, the walk that they took on the beach. It was fantastic and they wish they would do it more often. They don't have that brain signal to say, "Okay, well, let's hop into the car and let's go do that." They need help. They need help from their care partners, from their loved ones, from their friends to say, "you know what, it's 4 o'clock, today's the day we golf. Let's go." You know, and they'll tell me, like, "Oh, man, I great time

out there,” but they don't quite do it on their own. So routine behavioral activation, that's a big part of apathy treatment.

Polly Dawkins:

Yeah. And somebody mentions that the last couple of years has that exacerbated, the last couple of years of social isolation has that exacerbated it?

Joanne Hamilton:

Absolutely. And, other than apathy and depression, and I'm sure that all of you know all of the folks are listening right now can say, or maybe the majority can say, that they've noticed a really dramatic shift in many aspects of their Parkinson's during this last 2 years, social withdrawal, not even withdrawals, just absence of social opportunities was really bad for everyone with Parkinson's, you know. You get out of the habit of doing it. And then the depression starts to sink in a little bit more and there's more isolation gives more depression. You don't exercise as much. You know, a lot of my patients, they weren't able to go to the rock steady because their gyms closed. I mean, we were really fortunate in San Diego, because most everything we can do is outside and so people were still out at the beach, and such. But those classes that are really important to overcome the apathy stopped at, because that those classes you know they're social. There's a little bit of competition there. You're beholden to someone else. You know it starts at 9. It ends at 10 and you have to be there, and people notice if you're not. When we lost our classes, folks had a harder time finding that internal drive to go out and do the exercise on their own, and we all know exercise is medicine for Parkinson's. If you don't do it, your condition gets worse.

Polly Dawkins:

You've touched on a topic that we love to chat about here at the founding at the Davis Phinney Foundation, which is physical activity and exercise. Does exercise help as a treatment for mood, disorders, for depression, for anxiety, for apathy?

Joanne Hamilton:

100%. So, there are studies that show that exercise is actually as beneficial for many people to relieve anxiety and disband mood disorder as antidepressants and longer lasting. Now, you know, obviously, Yeah, it may be that those were exercise folks doing those studies and lots of people you know it hurts and it's hard to do. But I will tell you that there is a plethora of empirical evidence that exercise matters for improving mood and improving anxiety, that if you can get 30 minutes of exercise where, you know, I don't need you to run in a marathon, but where it's a little bit tough to talk to your partner, if you can do that, I prefer 7 days a week, but if you can go 5 days a week, it will matter for your mood. It will improve your mood.

It's hard to get started, I you know, for those who are not used to exercising and who exercise isn't its part of their lifestyle you know the first 2, 3, 4 days, and I can't believe I'm doing this and now I'm tired, and now my legs hurt, and whatever but if you can push through, it might actually save you, you know, another med. And that meant that matters.

Polly Dawkins

Yeah, if you had the choice between more medicine and less medicine, seems like I would choose less medicine if I had that choice. But if I had that choice, I would choose less medicine. Because if you think about like, what other treatment do we offer that literally has no side effects? You know, the only side effect is well-being and endorphins, and we have no other treatment that can do that, you know and it, and it's not just for your mood and it's not just for your anxiety and it's not for your Parkinson's, but it's for you for your brain, you know, your memory, your attention, your heart, you know your immune system, all of it. So, I know it sounds like, you know, just beating a drum to death. But we don't have anything else as good as exercise we just don't do it enough.

So, it sounds like maybe a combination of talk therapy exercise. Maybe medicines might be used as guided by somebody who knows what they're doing is a good might be a good combination. A 100%, you know, and for some folks for some phone.

Joanne Hamilton:

I would say. one size is not going to fit all in this case, you know, some folks are going to get a lot of benefit from their spiritual communities. Some folks get a lot of benefit from meditation and from mindfulness. You know I mindfulness sounds like What kind of sounds like a psychobabble sort of a thing. But mindfulness is also empirically valid it's a method to help focus your brain and activate the side of your systems. That allows for restoration of you of your fighter flight So there's 2 sides right there's the fighter flight. The sympathetic nervous system that's on hyper alert for most of us in our chaotic world. System releases stress hormones and it releases adrenaline, and it does a great job if you're going to be eating by a bear. Day in, day out, day in, day out, it will start to break your systems down, and its sister system, which is the parasympathetic nervous system, rarely gets turned on in our world.

Because, you know, Costco lines and late for the next appointment and Parkinson's, and everything else under the sun. You know, Covid, and you name it take priority, because your body is always trying to protect itself and trying to stay alive. So, it's constantly on alert mindfulness turns on this other system that will help restore your blood pressure. Your heart rate your immune system. It gets your gut. Working again helps clear your mind, improves your sleep, and so especially for anxiety, I always recommend a mindfulness, base stress reduction program.

And you can Google it, there's websites that will help with it. Universities have programs that do it and it's pretty simple, really, but it helps train your brain to allow it to be aware of things like breathing deeply where your pain is where how your muscles are relaxing. And it can help overcome some of the anxiety that what most of us will feel.

Polly Dawkins:

So, I'm glad you brought that up, because we had neglected to really talk about the other strategies that are within the power of our own bodies and our own tools, and right now you could start it right now you know if you're feeling a little bit of a little bit of anxiety.

Joanne Hamilton:

You know, there's multiple apps. You can download them right now. Again, not an advertisement, but I've really found one app. It's called Balance. I like it a lot. I use it myself. I will tell you, I cannot meditate to save my life, because my brain just goes- And the second someone says, "oh, meditate," I'm like, "Okay, Okay, I've got to stop, I've got to do this useless but guiding thing." So, these apps are guided so you have a person's voice. It's helping you, that's training you, that's bringing you along on what you're focusing on, and it makes a difference, and you can do it right now. You can get up, and you can decide for the next 5 min you're just going to go for a walk around the block right now.

Well, when we're done, we're done right. Now, you can do these things and these things matter, and they make a difference. And you know, even right now, you can reach out to a close friend, or someone who you haven't spoken with, and some time, and we kindle a social relationship because isolation is depressing, and withdrawal is depressing so right now you can make that change. So, there's things that we can do for ourselves, too. I mean, you know, like you are effective people. You've managed a lot of stuff, and this is one more thing which you know all of us are like, okay enough things, but it's one more thing, and it has some, you know, there are strategies that can make it better.

Polly Dawkins:

There are quite a few comments in the chat about specific medications and recommendations, and I think, given your expertise, it might be better to leave those for another expert, is that-? Or do you feel comfortable talking about?

Joanne Hamilton:

Well, what I will say is, you know, there are classes of drugs. that have been around a long time, and some of them are better at treating both anxiety and depression simultaneously than others. Specific drug questions, I would totally talk to your neurologist about those. But what I would say is that so to the extent possible, you want to minimize drugs like Benzodiazepines for anxiety. Those are Ativan, Xanax, Valium, and the reason you're trying to minimize those is those that class of drugs tends to cause more confusion and

risk of falls, as people get older. So, if you're taking those, it doesn't mean stop doing it right now without any, you know, your physicians help, but it means that would be a great topic of conversation at your next doctor's appointment, you know. Is there something more? Is there something else that we might be able to do here?

I find that, you know, I'm using this Ativan a little bit more often than I probably wants too likewise. There are older classes of antidepressants like Triptoline that absolutely have their place in this world and so they're not drugs that you would stop taking right now. But they may be drugs that you want to have a talk with your doctor and just say, well, what do you think, you know? Is this a safe drug for me? Because those classes and drugs because what's called an anti-cholinergic effect that can impact a person's memory as, you know, they get older. So again, none of these drugs are in anything that you would stop taking right now.

You would talk to your doctor about it, but you absolutely, you know these are topics of conversation at your next appointment. Gosh! You know, I've really been feeling pretty low lately. I'm already taking this. Do you think there might be something else I should use instead. Or do you think that, you know, maybe it's something that we want to add to those? These are very vital conversations that you're going to have with your physician. You know, if your physician isn't asking you at every appointment about your mood, and how you've been feeling with respect to your emotions, put it on the very top of your list of the things you want to discuss at your next appointment, and just say, you know, "I want you to know that more often than not, I feel like I'm going to jump out of my skin because I'm kind of anxious and worried."

These are topics that, even if they're not real comfortable, you know, to bring up as they are just as important to talk about with your doctor as, you know, I'm not getting quite as much tremor control, as I did the same level of importance, maybe more important, and I think, probably more important, I think, 100% more important. And as a caregiver, care partner, you know, if someone who's managing Parkinson's, as hard as it is, to ask this question. It is very important that you ask, are you feeling low? Are you? Are you feeling sad? And if yes, you know, do you sometimes feel so sad that you would even think of killing yourself, because you'd be surprised how many people will say, yes, I think of these things, and it's okay.

I want to reassure everybody it's not uncommon to have these thoughts. Parkinson's can be difficult to manage sometimes. It becomes an emergency if you're starting to think about it all the time, if you're thinking about it so much that it's distressing to you, or if you've actually started to think about how you're going to plan to do this, then you know that's an emergency situation, the same type of emergency is if you're suddenly having a heart attack, you know. Hey, chest pain, or you have shorter breath. We need to start thinking about all of these symptoms as just as important as a physical symptom. You know, we



wouldn't allow you to walk around with the blood sugar level? you know, in the extreme diabetic range, you know, if your A1C is 80, we're going to do something about it. We tend to, you know, always say, "I'm just feeling that, you know, sad today, yeah."

Polly Dawkins:

So, we have so limited time, and these topics are so important, people are asking great questions here. You talk about going, you know, putting this on the priority. When you go see your clinician or your physician, do you have a suggestion of, like, to work, like, write it down, or how can you ensure that you're going to be compliant, that you're actually going to bring up this hard topic? Give a suggestion for folks to what to say.

Joanne Hamilton:

So, I, if your health system uses like a like an electronic medical record, where you're able to message your physician today, right now, if you're experiencing these symptoms, and you're fine or your loved one is and you're finding day after day progress like pervasive sadness, right now, log into your electronic medical record and message your doctor, and just say, "at our next appointment, I would like to discuss my anxiety with you. I would like to discuss my mood with you," and send it.

If you don't you know, if you don't have that kind of a system, you can, you know write it down in your phone and take it along with you. You want to talk about the fact that, you know, your gait seems to be a little bit less steady, or maybe you've had a fall. Write it down at the same time. If a care partner is noticing it, have, you know, call a nurse right now. Go to your doctor's appointment and say, "hey, listen!"

At your doctor's office, say, "listen, the next time we come in, we want to discuss this." But if the mood is so low that it's day in, day out, the irritability is so high, the agitation is so high, you know you're starting to not be able to control your temper, you're lashing out at people, make an appointment about that specifically. That's okay, you know, that can be the primary reason that you're coming in to talk to your doctor.

Polly Dawkins:

One question, and I think this might have to be the last one given our time, Joanne. Did somebody ask that I honestly haven't considered is when you're talking about xylotherapy or talk therapy as a part of the strategy overall strategy? What if you can't speak very well anymore or your person with Parkinson's has a really hard time communicating? Do you have any suggestions for that? Knowing that voice and communication is so challenging?

Joanne Hamilton:

Yeah, and that's that is a very hard piece of this puzzle because once the hypophonia the soft voice gets to be so extreme sometimes it's not really possible. So, a couple of things: is it possible for that individual to write, you know, are they able to get out, even if it's just

pieces of thought, onto a piece of paper? If no, you know, if the motor symptoms have gotten past that, is it possible to do something along the lines of touch therapy, massage to try to get at it in a different in a different way?

And sometimes you just have to find a patient clinician and even if you're only going to get through one sentence, you know, in your 30 minutes, at least, to get out that sentence, so that so that someone with Parkinson's is being heard, and sometimes you, even for me, we get to the point where, even for me, and this is all I've done for decades, even I can't quite get it. So, sometimes, it's just a matter of, you know, putting my hands on their shoulder, and being right there and looking at their eyes, you know even in just letting them express through their eyes what they're experiencing because that becomes that becomes a real issue. So sometimes we have to go around it right? We have to. We have to just do it through touch, through eye contact, waiting until the person can get out a couple of sentences, listening for it, and then just responding with as much compassion as we can, you know, and that's what we need.

Polly Dawkins:

Well, you are getting me choked up because that's one of the reasons I think you are so terrific at your job, Joanne, because you care so much, and that comes across getting choked up its yeah, I haven't Yeah, you're one of a kind. For those of you who are watching, Joanne, thank you so much for being here today and shedding light on these very important topics. And audience members, we are so glad you were able to join us today. Here are a few reminders. The recordings will be coming next week and will be posted on our blog and on YouTube. If you have any further questions, please email [blog@dpf.org](mailto:blog@dpf.org). We're going to be having a conversation with Dr. Anna Lembke about her book, *Dopamine Nation*, on August 29 at 1 pm MDT. Our next Victory Summit is on sleep and Parkinson's and that will be on Friday, September 9, 2022. Thanks for joining us today!

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