



## **YOPD Council Series: Mental Health and Parkinson's**

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Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello, everybody, and welcome to the YOPD Council. My name is Melani Dizon. I'm the Director of Education and Research at the Davis Phinney Foundation. And I am here with all of our fabulous YOPD Council members. Hello, Erin and Kat, Gaynor, Kevin, Steve, Tom, and Heather. We're super happy to have you. If you haven't been with us before, we are a lively bunch. We like a lot of interaction. We love for you to put your comments and your questions—hi, Amy—in the in the chat box. So you can just click the little chat icon at the bottom of your screen. It'll pop up to the right, and if you want to send us a question, you can do so.

We're going to be talking about mental wellness and emotional health, and our leader for today is Kat. So Kat, I'm going to let you take it away.

Kat Hill (Davis Phinney Foundation Ambassador and YOPD Council Leader):

Awesome. So welcome, everybody. I'm glad you could come join us today, or if you're seeing this later, that you tuned in at all. So I just want to say that I have had the privilege of helping a lot of people who have struggled with anxiety and depression over the years as it relates to women and in big transitions in life. I was a clinician for many years, delivering babies, as a nurse, midwife, and part of—as a nurse practitioner, part of my training is to look at human beings as whole beings. We are not just a combination of parts. We're more than just a combination of parts. And when somebody has a diagnosis or an illness, it's not just that one part of them that's affected. The whole person is affected. And so I'd like us to think about mental health not just as it relates to Parkinson's disease or diabetes or pregnancy, but more as it relates to the human experience.

And so I challenge you to think about that as an integral part of your health. Feeling good is an integral part of your health. We know that with Parkinson's disease, though, we are more—those of us with the diagnosis—more risk of developing mental health challenges. There is anxiety, there's depression, and there's apathy. And apathy is that state where you really don't care, and apathy can sometimes be the toughest one to deal with because you don't really care that you don't care. It was brought up earlier when we were chatting before we started, how important it is that we allow and encourage our care partners to give us feedback as people with Parkinson's, but also be involved in our appointments when we go in and talk to providers, because they may notice first changes in how we are behaving.

And I think it's very important that we're able to have candid discussions with the people that care for us and live with us about how they're doing, about how we're doing. And we need to be in a

place to be able to hear that. I will tell you I'm not the best patient. I'm a much better care provider than I am patient. And so my husband's really careful about when he chooses to say. "Hi, I've noticed something sort of different." And if my hair doesn't stand up on end, he's like, "Okay, this probably was a good time." If the hair starts to stand up, he goes, "Or maybe we'll talk about it later." So it's not always easy to hear, as a person.

So why do people with Parkinson's have more mental illness? Well, the place in our brain that makes those chemicals that make us feel good is right where all of our neurotransmitters are made—where dopamine is made, where serotonin's made, where oxytocin is made. So we think it's because it's that same part of the brain that's affected that we may have a higher incidence of it, and it can affect us in different ways. People have described anxiety as like that internal tremor, like this tremor that is inside, and that can really make you feel anxious. Many of us—yeah, like Heather—Heather right there. Do that again. Awesome. If you start looking like that, you need to go talk to somebody.

But for many of us, it may have been our first symptom too. I know for me personally, I had a lot of anxiety for many years before I had the diagnosis. And I just didn't—I felt off, I felt anxious. I felt edgy. Sometimes it would come out. I would be more angry, especially with my teenagers. Although that can happen, too. Heather's thinking yes. So it may manifest different ways. It may manifest depression, may manifest by you sleeping all the time, not caring about food or caring too much about food, not getting any sleep, getting too much sleep. So I just, I can't stress enough—it's gotta be an integral part of what you talk about with your provider. If you're uncomfortable talking with your movement disorder specialist about it, talk to your primary care doctor about it.

What do we do about it? The best treatments are showing up, being social, watching Heather do fun things with her computer. What does it say?

Heather Kennedy (YOPD Council Leader):  
There's someone at my door.

Kat Hill:

Oh, got it. Sorry. Heather's just going to check out for a minute and go check her door. See, this is live guys. Isn't this the best?

So you can take medicines to treat depression. Your provider can talk to you about those. I'm not going to talk a lot about medicines, but things that we're lacking, if we're lacking certain chemicals, there's ways to get those medicines. We know though that exercise and counseling and staying social are also integral parts of treating anxiety and depression. Certainly if you cannot get out of bed, if you're experiencing severe symptoms, you need help more acutely and need to call a provider right away. We're going to talk more about that gray zone of "Am I feeling good? Am I not

feeling good?” So I know for me personally, exercise, medicine, and regular counseling has been the best formula for me. I've seen a counselor for many, many years. I believe everybody deserves a special person to sit and talk with. And for that—for you, that might be your partner. It might be your somebody in your church. It might be a professional therapist. It might be a psychiatrist, but give yourself permission to have somebody to talk to about how you're feeling. Having a major life blow like a diagnosis is a time when people can have a real spike in symptoms. Having a baby is also one of those times.

Kevin Kwok (YOPD Council Leader):

Hey, Kat. One of the questions that comes up is that medications can actually cause some of the issues of mental health, like obsessive compulsive disorder. I, you know, I mean, I felt probably my best when I had DBS and was able to wean myself off a lot of medications.

Kat Hill:

That's an excellent point, Kevin. And I think because many of us are already taking medicines for our Parkinson's or any other issue, that can happen. There's side effects and potential risks with anything we do. And that goes for treating or not treating. So if you choose to take medicine or if that's a part of your treatment plan, I think it's critical, really critical that there's really good follow-up and checking in. And I think any patient that might be considering starting medicines needs to ask three questions, think “bar,” B-A-R. Not “let's go to the bar,” but bar—what are the benefits of taking this medicine? What are the alternatives to taking this medicine, and what are the risks of taking this medicine?

It works with everything, actually, when you're thinking about it—“Do I want to go to the market today?” Well, what are the benefits? What are the alternatives and what are the risks right now? There's more risks than there used to be. So that helps, cause it's not that medicines are for everybody.

And some people manage their mild depression and anxiety with exercise. That's enough. That really helps. Some people can manage with just doing some talk therapy. So it's kind of a dance and a formula. And if you don't feel good, keep going back, keep asking the questions. And remember, it's part of your overall health. It's part of your overall health. It's not separate from your Parkinson's. It's not separate from the rest of you. So there's my soap box. I'm done now. I want everybody to chime in and share what their experiences have been and what y'all think of it.

Tom Palizzi (Davis Phinney Foundation Ambassador and YOPD Council Leader):

First thing I experienced was anxiety. Even before I was diagnosed, I started to get anxiety. Riding my motorcycle became suddenly very, very tenuous for me and quite scary. So I didn't know what was going on. Of course, after I was diagnosed, you start adding it up and the pieces kind of fall into place. And so my doctor put me on Citalopram at that time. And to this day, that is the pill I always make sure I take on time because that has helped me regulate for the last 11 years.

Kat Hill:

For some people, it can be scary to start a medicine because it's one more thing to take. And I know for me personally, it's like, "Ugh, I don't want to. I want to do this by myself. I want to try it by myself." And I could have lived a fine life managing, but I would have been anxious. And so it really was about a choice about *how* I wanted to live. And I, like you, Tom, had taken a low dose of Citalopram, and I've stayed at that same dose the whole time, even through the diagnosis. And I've tried over the years going off of it and it just, I just don't feel good. So it's a choice. Yes, I would still live. No, I didn't think I was at risk of harming myself, but *how* did I want to live? And I will tell you my family much prefers when I take it.

Melani Dizon:

I think one of the things about the medication is that the media and articles and people on social, they will have you think that if you can't figure this out through exercise or just making sure that you sleep, that there's something wrong. And it's not that case at all. So some of these situations, it's not going to be exercise. I know plenty of people who exercise hours and hours a day and it's, they still have that feeling. And so definitely be open to the other possibility that it *is* another thing, but it's just one little thing, and it can have a really big impact. And one of the best benefits of it is that if you're not taking it, you might not be as inclined to exercise. You might not be as inclined to have social connections. So really what we're trying to do is give you that. So then you do exercise more, you do want to connect more with people, and then that is going to have a bigger impact. That will help your Parkinson's symptoms. Okay. Kevin and Gaynor both have something. Go ahead, Kevin.

Kevin Kwok:

Yeah. You know, the pharmacist side of me now comes out. One thing that you have to be very cautious of when you're taking medications for depression and anxiety, is that if I often see people say, "Hey, I feel great." And they stop cold turkey, right? Taper. It really requires a taper because your receptors have to catch up with the medication that you have.

Kat Hill:

That's an excellent point. And I actually really would stress that with any medicine that you're considering stopping, that you don't do it without collaboration of your physician, because it also, it can, some of it can be actually life-threatening, right? Kev, we both know that. So stopping cold turkey can cause something that can be life-threatening. Now, not everybody's at risk of doing that. So it's just like with anything—being intentional about it and doing it in partnership with your provider, whether that's an email communication, whether that's, you know, a telephone call or whatever. It doesn't always have to be a face-to-face conversation, but it's serious. And Mel made a good point. I, when I was depressed and anxious, when I stopped, I will withdraw. I don't do things socially. I don't—like, Tom, you probably stopped riding your motorcycle, stopped going out

as much.

And that then becomes isolation. And loss of social interaction puts us at risk for a whole lot of other things. And it isn't good for our Parkinson's. Gaynor, you wanted to add something.

Gaynor Edwards (YOPD Council Leader):

Yeah, sure. Well, a couple of things there. Of course, the keeping social at the moment is a trick in itself, isn't it? It's a whole new level of pressure that we're all kind of dealing with. But I was just wondering—and by the way, in the next one, in the December webinar, I think we're doing the medication topic currently, and we'll be touching on a lot of that stuff: how to gradually wean yourself off of certain drugs or whatever—but I was just wondering, is the presenting symptom, I think, depression for a lot of people? It was for me. I'm just wondering if the group generally found that. I mean, I'll just put—before they diagnosed me with Parkinson's I was depressed for years.

Heather Kennedy:

Well actually, Gaynor, you might just be a hysterical woman and you might just need some drugs because it's all in your head. Right. That's what they told me. Yeah. They told me I was just like this hysterical woman and that it was all in my head. And it turns out they were absolutely right. That is where it's. So, yeah.

Kat Hill:

And if so—so I want to bring that, that is an excellent point, Heather, though, that if—here's the deal. We are consumers. Each and every one of you out there is a consumer of healthcare. You have the option to shop around. If you're not getting an answer that you like, if you don't feel heard, go find somebody who will listen to you. You don't have to feel condescended to or judged. If you don't feel good, you can seek help.

Gaynor Edwards:

You'll bang on, Kat, but it's really hard to do if you're depressed.

Kat Hill:

It's really hard to do. And that's it. You're right. It's hard to. It's even hard to exercise, right? So everyone says, what about exercise? I couldn't exercise well, or keep up a schedule. And then I felt even worse. "I'm doing it wrong. If I could just get out and start and do this, I'd feel better." So I think that those care partners that are listening, and support folks—we need, you need to be aware of that part. And also, even reaching out through a support group leader, somebody online, fellow friend. It is hard, though, Gaynor, it's hard. And somewhere we have to dig deep. And how did, what took you in, finally, Gaynor when you went? When you finally decided to go and get some help?

Gaynor Edwards:

Well, the depression was one of the early symptoms, because I didn't realize it was Parkinson's. They just treated me for depression, and actually Citalopram didn't work for me anyway. And I wondered if that was because it wasn't addressing the dopamine. I'm not entirely sure. Frozen shoulder, stress, tremor. Yeah. That was it. Frozen shoulder is everyone's favorite.

Kat Hill:  
Erin?

Erin Michael (Davis Phinney Foundation Ambassador and YOPD Council Leader):

Yeah, Kat, I was going to say, so one of my first symptoms outside of anxiety, which Tom had mentioned—which was completely through the roof—was I had, I felt like a pendulum. I had these really extreme mood swings. So I was either super happy-go-lucky or bottom of the barrel, everything in the world just was unbearable. My life was horrendous. And it got to the point where people started telling me that. They're like, "Look, your moods are either like, you're so happy or you're so depressed." They're like, "What is going on?"

And you kind of—so then I started taking offense 'cause I felt like people were judging me or having an opinion. And you feel kind of normal as it's going on. You kind of don't, but you kind of do, because you're still yourself. It's hard to explain. So then you start, you know, feeling like people are judging you and making decisions about you. Starting to talk about what's going on, and that creates more anxiety. If you get stuck in the circle, especially in the workplace, which a lot of us still work. And it's, you know, it gets brought up and people are like, "Oh, you know, it's been, it's been brought up," but they don't know what they expect out of you anymore. And you're like, "Well, that's troublesome because then how will that relate to job performance and everything else?" And you're not really sure what's going on. You're trying to figure it all out internally. And it's a real challenge and struggle until you find that right path forward to direct you where you need to go, because you really don't know what's happening because there're so many symptoms at the same time.

Kat Hill:

And I think for me, the year I was diagnosed, I had started, was just starting menopause. Perimenopausal. So I was so—and of course, as a women's healthcare provider, I'm like, that must be it. That explains everything. My mom was dying. We were caring for her. She was in hospice. I was the director of a busy practice. I was doing lots of calls. So I wrote off all of those symptoms for a long time. And in retrospect, what was going on is, I was being treated for anxiety and depression, but not the Parkinson's piece of it. And I had life circumstances that were challenging. And you know, those of us with young onset are often in that kind of, that sandwich generation, right? I had kids at home. I had a type-one diabetic teenager at home that I was managing. A dying parent and a busy practice. And those that are diagnosed later in life have a little bit, perhaps different life circumstances that may afford them the ability to look at symptoms



differently. But we're in that mixed, you know, that in-between stage, and that makes it challenging. It's more demanding. Anybody else have any bits to share any experiences that they feel comfortable sharing? Gaynor? Yeah. And then Amy and Heather. We'll do a circle.

Gaynor Edwards:

I think the first thing I did was get talking therapy. Absolutely. Absolutely the biggest improvements for me. I remember going in and basically saying to him, "I've lost the joy," which is exactly how it felt.

Kat Hill:

Yeah. "Deflated balloon" is what I said that I felt like, yeah. Amy, you have something.

Amy Montemarano (Davis Phinney Foundation Ambassador and YOPD Council Leader):

I'm going to speak from a different perspective, and that is that for those members of the audience who might be newly diagnosed or their caregivers, this is not necessarily inevitable, too. Right? Just because it is a big facet for many people doesn't mean that it's definitely gonna happen. And one of the things that I learned really early on when I went to the World Parkinson's Congress in Portland, this research by this Penn professor was, if you expect it to happen, it will. And that's a big effect of your dopamine. And so I want to remind everybody that it's not necessarily going to happen to you. And if it does, okay, then there's lots of support. And also my mantra: Not everything is Parkinson's, right? So there are many, many, many people right now with anxiety, depression, and other mental illness, especially in this time of COVID. And so it doesn't necessarily mean that it's because of PD, but it can. So I just want to make those points.

Kat Hill:

Yeah. And we're going to go there, and we were going to talk about shifting our mindset. Yeah. Kevin?.

Kevin Kwok:

Yeah. I want to go back to your bar analogy. It's not tequila that I'm talking about, right? But look at alternatives. To dovetail into what Amy says, is that, you know, sometimes there are alternative things you can do other than medication. It's not always medication. It's not always something that you can't handle. First of all, you have to admit that you're having issues and then try to deal with them. I mean, I just—not make this about me, but I just feel like I've come off, like, the month from hell, right? I mean, my brother passed away. I lost my job. A friend of mine died of Parkinson's symptoms. It all happened like in a three-week period of time, you know? For me, it was sort of this, "What can I do," right? I mean, you know, you may be in the doldrums and you may think that, you know, the world is really dark and you've got a cloud over you, but there are things you can do to try to, I mean, I think the first thing is admission, right?

That you're having problems. Reaching out to other people. I mean, there are a number of you on this call here, this panel, that were the first people that I spoke with. And you guys gave me very supportive help. So knowing that you're not alone really does make a difference.

Kat Hill:

And as a clinician, I also want to say, I didn't start with medicine with patients, because I think it's important to explore things and not just take a pill for everything. So I'm not here to say that's the answer. And really what the data shows is that the most effective treatments are those that have multiple approaches to them, not just this one thing, not just this one thing, but things in tandem with each other. Those help the most for the longest period of time. So Kevin's is an excellent point. And Amy, I want you to know we're going to shift gears here pretty quick and start talking about how you take ownership. But Heather, I want to hear what you have to say first.

Heather Kennedy:

You guys are so awesome. You're on point with everything. We were talking about integral, you know, and whole-body medicine. We were talking about that. Before, we were talking about the importance of interconnectedness. That would be number one on my list for priorities, because we do start to feel like maybe we're crazy. We believe our thoughts are real. Thoughts are not real. If you can find a way to observe your thoughts, whether it's prayer, meditation, whatever works for you. Yeah. Right. Do a little dance, sing a little song. That's why I do karaoke because I'm playing a role. I'm getting rid of some of that angst and anger. But I think what's more important here is what someone last name McAuliffe brought up. I think it was Garrett McAuliffe. He asked us if it's chemical or if it's a thought we have, a thinking, or whether it's—so that's the old chicken or the egg. Is it causal or chemical?

Once you know that, working with a professional—don't ask your friends—once you know that, then you know how to hit the depression. And it does usually present for me as anger. A lot of people get hit with apathy, but you really need to know that. You really need to answer that question first, because nothing happens in a vacuum. You know, we've been talking about death, grief, and you know, COVID quarantine and all this jazz. By the way, I'm extremely dyskinetic today. I apologize. I'm jumping all over your screen. But this is the one place where that's okay, probably. Usually people just think, you know. But I just want to end by saying that that's a great question, Garrett McAuliffe. And I think once you know that, it's good, and then you can use your reflectors and your touchstones.

Then you can check in with your friends and say, “Hey, am I acting or behaving strangely? Do you feel like I'm being maybe a little suspicious?” Ask them pointed questions if you can, because otherwise your friends are gonna be put on the spotlight. “No, that dress doesn't make you look fat. What do you mean?” You know, so let's—because not everybody has the language like we do either. So we have to learn the language. Know which one it is, causal/chemical primarily, and then work with it. So thank you for letting me say all that.



Kat Hill:

Some of the things though that we do can up our chemical intrinsic production—I think that, Garrett, I'm sorry, whoever was on the thread, is right on. But can we affect it enough with some of these other tools, or do we need exogenous or taking medicine outside? And we're not going to know that. It's not like there's a blood test. Oh, you're a little, you know, “we do do the oil change. Right? Okay. Where's your dopamine today? Okay. Oh, okay. We need a little of that.” Oh, don't we wish, right? Someday that'll be, you know, we'll go in and get scanned and we'll know what all that is, but yeah. So go ahead, somebody here.

Melani Dizon:

The other thing is—what we were saying was, you don't just take a pill. You just don't just take your carbidopa/levodopa and just be like, “Okay, I'm, I'm all up. Set it and forget it.” You have a whole lot of stuff, right, that you do throughout the day that is complimentary to that pill and is going to make that pill work better, whether it's drink a glass of water or exercise or eat better. So the depression and anxiety is similar. You're not also going to just take a pill and then “Whoop dee doo dah, life is grand again.” There are a lot of things that you can do, and that's just everything in life. And so if it ends up that you're like, “Well, I'm doing a lot of things. And this thing might just put me over the edge, take the edge off and make me feel better,” great. But it's important to do all the things we can. There is no magic pill, unfortunately.

Kat Hill:

Yeah. I told my patients all the time. I wish I had the magic wand that worked, you know. Steve, do you have anything you want to add? I don't want to leave you out of the discussion.

Steve Hovey (Davis Phinney Foundation Ambassador and YOPD Council Leader):

Yeah, I think you also have to be honest with yourself because I think there is a stigma with mental illness, mental health, and people don't want to admit that. “Hey, listen, I have a problem.” And I definitely fall in that category. You know, as I look back, I can see things—the apathy; certainly my ability to handle stress. I became—that was the key driver with—I know I've shared this story with with you folks before, why I sold my business. When I did it was five years after my diagnosis and everything was just compounded by 10. You know, problems that I dealt with easily became, I couldn't sleep at night, you know? So that's when I realized that I needed to make a change.

And I know I shared this with you guys, too, but I'll say it again because there may be people out there that haven't heard it, but when I did move up here, I walked away from everything. You know, things that I was involved with, my business work, everything. I just basically really started kind of feeling sorry for myself. And I realized I needed, like, my fix right now—so far, I don't need medicine—is I need to be with people. I need to be involved, engaged. And I also need to get outside and go for a walk or a bike ride. And I don't care if it's raining or snowing or whatever, I need to get outside. So those are the ways that I manage it more holistically. I so far, I haven't

needed medicine as long as I stay around people and I can get outside and, you know, enjoy the outdoors. I seem to be handling it pretty well right now. So it's not always medicine. You can still feel anxious and still feel apathetic. And there are ways that you can cope with it that are not, you know, pharmaceutical.

Kat Hill:

And there's times where, you know, grief—you know, we were all talking about those things that happen. So grief is really an important part of moving on with things. To experience grief doesn't mean that you're going to be depressed forever. If you've got a situation, you know, you lose a parent, you lose a job in big transition, Kevin, right? That's huge. You've got to feel it. So getting beyond it is the important part in it and not letting it control everything that you're doing. All right. Kev.

Kevin Kwok:

There was a great speaker on a webinar a few weeks ago, Laurie Santos. Somebody who hasn't seen it, who's experiencing some of these issues, I highly encourage you to go back and watch it. One of the things that she did said, to me which was an “aha,” is that if something is creating depression or stress in your life, don't ignore it, accept it. Because by ignoring it, you actually compound it. Right? And so many of us would like to do this. You know, “I'm a macho man. I'm just going to not let it bother me.” But in fact, I think accepting it and then take it in and then kind of handling it is really beneficial.

Kat Hill:

So I want to pose a little bit. You know, we all get in down parts. We're human, right? We have emotion and that's normal. And when we experience a hard thing, it's normal to feel grief. And Kevin, that's a good point—not to ignore it, but to be there, sit with it. If you get stuck in what I call the rabbit hole—the rabbit hole is this thinking of a disease, despair, dysfunction “nothing's ever going to get better.” And you can't get out of that space—that's where it can really start to impact your living and other things.

So now I want to shift a little bit, and I want to talk about how all of us get *out* of our rabbit holes. And I want to pose because there's good evidence now to support it, that we have the ability with our minds to shift how we think.

And the more we shift *how* we think, the easier it is. We train ourselves to shift how we think. So being in the moment. Or mindfulness, we've heard a lot about that. That takes huge practice to be here right in the moment and not thinking about, “Okay, what am I going to say next?” And, “Oh my gosh, what happened this morning with my neighbor?” or whatever. To be here right now takes focus. And mindfulness practices, gratitude practices, wellness practices—how we define ourselves matters. And the more we stay in the positive highway. So there's only so many lanes of

traffic going in your mind at any one place. If we can flood those highways with messages like, "I am happy. I am healthy. I am strong." There's fewer lanes of traffic for the, "Oh my God. I've got Parkinson's. Oh my gosh, what's my life gonna look like in 10 years? Oh my gosh." You know, all of those things. And the evidence shows that the more we stay in those lanes of traffic that are positive, the better we feel, the less medicine we need, the less depressed we are. I mean, there's now evidence about it. So how does everybody do that? Even in the hard times? Gaynor?

Gaynor Edwards:

Just to quickly chip in on that. I spoke to Matt Eagles the other day. Matt's had Parkinson's since I think he was seven.

Kat Hill:

He's had it for 45 years.

Gaynor Edwards:

Exactly. Taking to him, I was chatting to him and he was so sweet. He was saying, "Do you know what it is, Gaynor? I'm quite positive because if I'm positive then people around me become positive and that reflects back on me and buoys me up." And you know, that's his knack. He is. He is the most positive Parkie out there. Bless him.

Kat Hill:

Bless his heart. And he says—in *The Book of Joy* that was written on the occasion of the Dalai Lama's 80th birthday, there's a whole book about joy. And there's this concept called the virtuous circle. And the virtuous circle is if you are free from your suffering in your own mind and what you're doing, you are more able to attend to others who might be suffering. And that's that principle, right? So Matt stays positive and he exudes the positiveness. He's available to people in his world for them to perhaps have aid in their suffering, and they are more positive. And therefore there's more positivity in the world. And, you know, humor has to be in the mix as well. I think. I get joy just hearing your accent, Gaynor.

Gaynor:

Yours too, love.

Kat Hill:

Kevin, I know you have something to add about this and you're involved in an interesting study.

Kevin Kwok:

Yeah. You know years ago I took a mindfulness training program by Jonathan Kabat-Zinn. He has a textbook out called *Full Catastrophe Living*, which is highly recommended. And anyway, I took the class and then proceeded not to practice, you know, mindfulness, even though it was so good for me at the time. And so recently, you know, as I was going through this navigation of all the

things going on in my life, one of the things that popped up on his screen was this opportunity to volunteer for a clinical trial, looking at mindfulness 90 minutes a week for eight weeks, plus everyday homework. And so for me, you know, I think, you know, I work out, you know, I'm incredibly disciplined, but when it comes to mindfulness, I'm really not good at that. And I think what we tend to do is we tend to train to our strengths and not to our weaknesses, but the mindfulness thing of this clinical trial, if anyone's interested in, it's being being conducted out of UCLA. So that's, I just signed up for it in LA three days ago.

Kat Hill:

Yeah. Heather?

Heather Kennedy:

That sounds great. Kevin, I'll join you there. I was thinking about how well, Shakti Gawain wrote a book called *Creative Visualization*. I think it was written in the late seventies or eighties. And that's, that thinking has been around for a long time, to the secret and all that, all of this—and I don't want to oversimplify this process, by the way, this takes a lot of time—there's a meditation technique that I use that's helpful to me. Sometimes. Sometimes it works. Sometimes it doesn't. But I sit quietly and I observe my mind and I'll say, "Oh, there you are, anger. Hello." And I kind of watch it go by like a cloud. It's just sort of passing. I throw it up on the screen and I become as much as possible, just a breathing witness. Just kind of non-judgmental. "Oh, there you are. Wow. That's a lot of anger. Oh, here comes more anger." Or "here comes a sadness, grief, pain, anxiety." And then I can meet those emotions and those thoughts and those feelings from a place of a little bit of distance. So there's a pause, hopefully, next time. So I'm not so reactive and I can respond rather than react to whatever the stress, the stimulus would be. So that's one thing that I would highly recommend everyone try. Sometimes it even works.

Kat Hill:

Okay. And the idea, I think, around meditation—now, others chime in, I'm not an expert—but is to quiet what we're doing and try to learn how to be in the moment. And I do something similar, Heather. I recognize like even a sound, right? So somebody's leaf blower's blowing and it may be bugging me, but instead of reacting to that, I go, "Oh, a leaf blower." And then suddenly it's not so annoying. It's like, Oh, you know, nobody's going to die. If the leaf blower goes off for 10 minutes, you know, I would say, "What's the worst thing that can happen. Oh, leaves float around."

Heather Kennedy:

Have you ever noticed how we get so angry with people? But if it's an inanimate object? Pema Chödrön tells this story about how during meditation, some rock had fallen on someone from the ceiling, from the place they were in. And they were like, "Those kids, we're going to get them. How dare they shoot rocks at us?" And then they realized that it was just falling. And then another meditation, there was something clicking. And somebody said, "That lady next to me is making terrible noises, kick her out." And they realized it was the radiator. And then they could calm down

and go, okay, radiator. We're going with the sound. And then you watch your agitation, you watch your ego come up, and then you work with that. So we can work with whatever. You bring up a great point, Kat. 'Cause we have to do improv all the time, right? Life's not easy.

Kat Hill:

Yes. And we we had a trainings, and there are Ambassadors here, we learned a little improv from there. It was fabulous. And the idea of "Okay, we have Parkinson's. Yes. *And* I get to participate in this great panel. Yes. *And* I am writing a book. Yes. *And* I've learned how to do a podcast. Yes. *And* my family still loves me. Yes. *And* I couldn't get my earrings on." Hmm. Okay, Gaynor? Isn't it one of the, probably most rewarding things you've ever done when someone newly diagnosed reaches out to you and you—"Just, don't panic, don't panic. It's not as bleak as it looks." And you start chatting and actually, you know, *you* feel better. They feel better. There's no bad thing happening there.

Being of service is a great way to get you out of your own mind. And that can mean a million different things. Being of service might be, you might rake your leaves for your elderly neighbor. You might help a friend out with their go-fund-me campaign. You might bring your partner, a cup of tea. It's beautiful to get out of your own self, even for short periods of time. And it's a great way to add to good feelings and feeling well. And even though we have a diagnosis, I always, on the forms, check "very good health." I'm eating better, exercising better. I dare them to challenge me. My hands don't work. Right. I can't get my earrings on, yeah, no one's going to die because I didn't wear earrings today. Yes. Sometimes it's painful, but even pain, right, even pain is something that you can say, "Oh, I'm having pain. Oh, my hands are cramping. Oh." And observe it from further away. I don't know, we're getting kind of off topic, I know, but it's powerful. Our minds have the ability to do it.

Kevin Kwok:

Yeah. You know, I mean, we're in a stage right now in this country, in this world where there's so much unhappiness, so much tension. And the one thing that you can control is a random act of kindness to someone that does not look like you, someone who's different than you. It doesn't have to be a Parkinson's patient, although that tends to be my pet project. Anyone who calls with Parkinson's, I take their call. But if you do this random act of kindness, just to people in the streets, waving at people, just acknowledging them, it's amazing how good you feel, right? It comes right back to you. It's all part of that karma, right?

Gaynor Edwards:

When you were doing your random act of kindness, Kat, say when you help a neighbor rake their leaves. *Raking* the leaves. This time, don't get too, too dicey to bring the leaf blower back out.

Kat Hill:

I've got to confess, I do not own a leaf blower.

Heather Kennedy:

Well some people think you can avoid forest fires by raking your leaves, too, but we won't say who said that.

Mel Dizon:

I want to take a couple of questions that have come in through the chat. So just going back a little bit—somebody asked about shopping around and does anybody have an advice for those living in rural areas who don't have providers in close proximity? What advice would you give to people who feel like they don't have a lot?

So one of the very best silver linings of COVID is telemedicine. And a lot of, you know, a lot of offices are doing that now, and you have access like you've never had access before. So my recommendation: there are, we actually have a link on our site somewhere; I don't have it off the top of my head, about finding a movement disorder specialist. You can also find a physical therapist. You can find lots of different people that specialize in working with people with Parkinson's.

And if they are in your state, it doesn't matter where they are, how far away they are. You can call them up and say, "Is anybody taking a new client via telehealth? What can you do?" And the really great thing about now going forward is if, you know, once you are able to go and have your sort of initial visit—if you don't have a movement disorder specialist or somebody else who you really need to see—you can go to that one appointment, and then in the future, a lot of people are going to keep telehealth. They're just going to make it, because now that we know we can do it, and it's working for people. They're going to have those followup appointments via telehealth. So I highly recommend calling any clinics and cities near you and talking to them about lack of access, and is there any way that you could see somebody via telehealth?

Kat Hill:

Heather Kennedy.

Heather Kennedy:

You asked a question right before that, and then we're going to return to this. You said, how do we beat the blues? Or how do we get away from the depression? When we see it coming, I'm going to go with song, dance, theater, play roles. You can fake it till you make it. Go ahead. And just like when I say I do karaoke—I don't sing karaoke because I'm a good singer. I sing because I have something to come out. So I'll sing the angry song, like "Mother" by Danzig, when I'm angry, you know, "Mother," and then you let it all out and then you're like, "Huh, okay. It's just life, you know." A little skip in your step. Even if you can't sing, it's not about the performative. None of this is about the performative. It's about how we feel inside. That's really what matters. Right. So anyway,



back to Kevin.

Speaker 3 (46:26):

Kevin Kwok:

No, I, you know, I put on headphones and I've put on "Talking Heads" with David Byrne. I cleaned the house. It's something that I can do, you know, if I'm not quite feeling up to, you know, going out and doing a major bike ride or something. I'll just put that on something like that. But Heather's exactly right. It just brings joy to you. Right. And you're doing something constructive.

Kat Hill:

I just do a FaceTime with Heather and watch her and I just get a huge chuckle and it totally works for me. But you know, use your lifeline, you know. Call a friend. Reach out to somebody.

Kevin Kwok:

Yeah. The buddy system. Someone asked a question, "Do we have a buddy system?" You know, I think it's someone that you trust who has Parkinson's, because that's the one thing that I gather—is that you all understand. You get me, I get you. We're in the same thing. And I'm just very lucky to have you all.

Melani Dizon:

Yes. Yeah. Everybody's lucky to have you as well. And our buddy system is our Ambassadors. I mean, these are—most of the people on this call are Ambassadors. And if they're not, they're still ambassadors for Parkinson's. And you know, look on our site. Contact them. You can email them and they are more than happy and happy to talk to you.

Kat Hill:

And I wanted to touch on something, too, about telehealth. Also a lot of support groups have gone online. And so there are great resources. I'm involved with doing a "young onset happy hour" support group, which is online now. We don't meet at a pub anymore. My husband runs a care partner support group. It's online. So those things have opened up. It doesn't have to just be here in Portland, Oregon, which is where our home is. People can join from all over. And I think, so folks in rural areas who have historically not had as much access, even just because there's not the sheer numbers, they're there. There's going to be more access going forward. I think our world will be—we'll get back to more in person, but I think we will continue to have more of an online option for people.

So anybody else want to add how they keep the joy? How do they find the spark? How do you get back to it on a tough day? How do you make your lemonade?

Kevin Kwok:

I think it's important to note that you're allowed to feel really bad. And sometimes talking to a cheerleader kind of is annoying, right? You know, you get the “rah rah, you gotta get out there.” And I think there's this feeling that we have as Ambassadors and resources to say, “You shake it off, you can do it.” Sometimes you have to go through the different stages.

Kat Hill:

It's critical, because it's back to you. You don't want to stuff it. And I think, Amy, you brought up a good point. You know, when somebody's newly diagnosed, it feels—the burden feels enormous. And just because some people might have depression or some people have anxiety—some people have tremors; some people don't have tremors. Some people it's, it's very different for each individual. It's hard to know where you're going. It can feel overwhelming, but after you grieve the initial blow of a diagnosis, it's what you do after that. That's going to be critical, but you can't skip the grief part. It's not good for you to skip the grief part. You've got to *feel* it because it's real. But then it becomes part of the last chapter, right? So now we're moving to chapter two. Post-Diagnosis now. Now you can start opening up your world a little bit to how are you going to be? Yes, you have Parkinson's. And that's the start of your chapter two. And we're here as Ambassadors, as resources, to help you know what your resources are. But ultimately the choice is really yours about how you're going to navigate that. And you'll have choices. You'll get there. Heather?

Heather Kennedy:

You both said what I was going to say. One is that, the shaming part of “just don't worry, be happy. Stay away from negativity” is awful because when you're in chronic pain, you are sort of self-absorbed. I mean, let's be real here. When you're in pain and you want to help people, you then flagellate yourself for not being helpful if you're a helper, because you're so much in pain. And then, you know, Kat, you also said this great thing. Well, you've said a lot of things today. They're spot on. Thank you. You make us feel like everything's going to be okay. There's something really nice about that. How do we be that person for ourselves, too? How do we remember that? All the resources we need are right here. We just have to sort of work with that so that we never really feel alone. And we do need touchstones to remind us all we do for each other, through each other. Tell us while we're in the ringer, you know, put a light on the pathway. We don't really have a lot of agency to reach out, you know, in person now with all this COVID stuff. So just staying in touch. And I cannot tell you, I do not know what I would do without WPC, without DPF, without all these organizations, this in particular, this group of people. You guys, some of you have saved my life. So thank you.

Kat Hill:

So community, right. And right back at you, Heather, and all of you. It's a gift, and it's also hard, you know, you feeling exposed a little bit. Wait, somebody touched on there. You know, there's a lot of stigma associated with mental health. And I think slowly as a world, we're becoming more

aware of how prevalent it is and how important it is that we can talk about it. Because talking about it allows us to feel like we can reach out and get some help. And even just talking about sometimes just getting it out, singing a song and getting angry and saying, “Oh, I'm really down right now.” Suddenly that feels better. Gaynor?

Gaynor Edwards:

Yeah. I was pretty much on the same point. So much of this is about, you need your safe, trusted people, whether they're Parkies or not Parkies, but so that, you know, people who know, I think Erin was saying, sometimes it takes other people to first flag up if you are having a dip, but you also need those other people to kind of realize that maybe you just need to have a rant. Or maybe what's coming out as anger isn't really anger. Maybe it's just, it's grief. It's sadness. It's hurt. Could be anything, you know. If you know that person well, you can read them better, can't you?

Amy Montemarano:

And so I just wanted to add to that there—aside from therapy, which is, I agree with Kat, is, we all deserve our own special person to talk things out with—there's this other area called coaching, which I have been interested in lately and getting some training in lately. And that's different. I'm fascinated by the discipline of coaching. And just very briefly—it just asks questions of you. It doesn't focus on your past. It focuses on your future. And by answering the questions, you uncover a lot about yourself and all of those things that Kat's talking about. So that's something in addition to therapy. It's very different from therapy, but it's also something out there that helps.

Kat Hill:

It says that we all have the inherent wisdom to solve our own challenges. Yeah. Every single one of us here today has a hundred percent success in getting through the last hard thing. Right. We're still here, we're still showing up. And I was, I, once I started thinking about things that way, I was like, “Wow, that's a pretty good percentage, you know, managed to survive a hundred percent of those things.” And so it's interesting. It's a subtle shift, but it helps, right?

Amy Montemarano:

It's a little bit of magic, yeah.

Kat Hill:

It's a little bit of magic. It's a little bit of magic wand. Right. I'm still seeking the magic wand. I'll let y'all know first here if I find it.

Tom Palizzi:

Can I borrow it?

Kat Hill:

Yes. When I find it, I'm bringing it here first.

Gaynor Edwards:  
Make sure it's not the leaf blower.

Kat Hill:  
I hope it's not the leaf blower. Maybe it *is* the leaf blower.

Heather Kennedy:  
Teachers come in strange places, shapes, sizes.

Kat Hill:  
Yeah. I also want—somebody was starting, I think it was Steve, talking about how important it is to get outside. That's important. Sunlight and the way that we make vitamin D, I just want to touch on that. In many parts of the world, and we're part of that up here in the Pacific Northwest, we don't get enough vitamin D and we're so quick to put sunscreen on and not get exposed because of the skin cancer risk. But what we're learning is we're not making enough vitamin D. And not enough Vitamin D can really add to mood stuff. So again, we're these, this whole being, right? The whole being. No, we don't want skin cancer. Yes, we want to make vitamin D. So either think about that. Get some sun, take a vitamin D supplement. You know, look at yourself as a whole bring, be of service, find a hobby that you love.

Heather Kennedy:  
And a pet and a dog.

Amy Montemarano:  
And a dog. Bring the dog outside.

Kat Hill:  
You are not alone. There are people that you can reach out to, even if you're in your home and feeling really isolated.

Steve Hovey:  
All right, Amy, I'm going to, I'm going to let my wife, Nancy, know that you've told me to do that, all right? You'll be getting a phone call really quick.

Amy Montemarano:  
Yeah, we all get one.

Steve Hovey:  
I would love to get a dog.

Kat Hill:  
You all have permission. Permission granted to go find your joy.

Amy Montemarano:

And for those of you who aren't allowed to get a dog or can't get a dog—actually volunteering at shelters right now is one thing you can still do in COVID, and it's amazing. Yeah. Little doses of not only dog therapy, but also service, you know, that whole thing that Kat was talking about. It's amazing.

Gaynor Edwards:

Like dopamine.

Kat Hill:

Yes. Art. What do you have there, Heather?

Heather Kennedy:

Number two, that during these isolating times when we can't see each other and we don't know what people are thinking, there are people who smile and their eyes still look kind of like this. So here's what we're seeing of the rest of society. I mean, it's kind of an isolating time. It's a lonely time. "Lonely." The word comes up a lot.

Melani Dizon:

You're supposed to put a smiley face on your forehead.

Heather Kennedy:

Exactly. Oh, no, those are just lines.

Melani Dizon:

No, no. Like, you really can put a smiley face on your forehead. Like we can, it's a cute thing to do. And people are like, "Oh, Hey!" It's great.

Well, we are out of time. This was a fast one. I really appreciate all of you that came today to listen in. I'm gonna put my email there. If you have a question, if you're one of those people that wants a buddy and wants to connect with our Ambassadors, you know, let me know or check on our site and we'll hook you up. Kevin, did you have something to say? We will send the recording as soon as it's ready and the audio and the video. And we'll see you all in December for medication.

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