



The YOPD Council
Depression, Anxiety, and Coping with “Dark Days”

Recorded on November 18, 2021

Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Welcome everyone. Welcome to our Young Onset Council. Today's session, we are in the middle of November, 2021. I am Polly Dawkins. I am the executive director of the Davis Phinney Foundation, and we are thrilled that you are here with us again today. Without further ado, I'm going to turn the microphone over to our Young Onset Council members and welcome Kat Hill who's our moderator for today.

Kat Hill (Davis Phinney Foundation Ambassador, YOPD Council Leader, and YOPD Women's Council Leader):

Thanks, Polly. Hi everybody. Welcome to the Young Onset Council. We are, we had at the last council, a really interesting discussion about anxiety and depression, and we were kind of just getting into the weeds with it a little bit, if you know what I mean. And I'd kinda like to pick up our discussion there. Doesn't that sound like a lot of fun, everybody? But more than that, I want to spend some time today really talking about how each of us has our own strategies to get us out of those days when we're really having a dark day, everybody listening has had a dark day before they had Parkinson's, since they've had Parkinson's, they will have dark days again, for sure.

All of us will, no matter if you have Parkinson's or not. So these are tools that are sort of universal tools perhaps, but we'll tailor it, especially for those of you with Parkinson's. So we are super honored today to have a special guest here and we have also some new faces. And so I'm going to introduce our special guest and her focus is movement with a strong history in dance. Pamela Quinn is here with us today and she's very well known in these circles. She's done extraordinary work. A lot of us have followed her. We've seen her perform. We've seen her work. We share it with our support groups, and she's been a professional dancer for 20 years. She's also been living with Parkinson's disease for over 25 years. Her personal experience of Parkinson's along with her keen knowledge of the body and how it moves stems from her professional dance training.

And it allows her to analyze movement problems and create solutions for folks living with Parkinson's disease. She developed the PD movement lab, which is a functional dance class for people living with Parkinson's. She teaches regularly at Dance for PD in Brooklyn at Northwell's

PD program and at JCC Manhattan. She also presents and performs at conferences around the world. A lot of us were really honored to see her in Kyoto, Japan. So she's going to lend a really unique perspective today to us about the importance of movement and as it relates to getting us out of those dark days. So I also would like to welcome Robynn. I haven't met Robynn directly. I think she joined for another group, but I want to say hello to her. And she just, Robynn, tell me again how to say your last name. More eighties?

Robynn Moraites (Davis Phinney Foundation YOPD Council Leader):

Yeah, just think of the decade of the eighties and you want more of them. It's just pronounced more eighties.

Kat Hill:

More eighties. You're never going to forget Robynn. I know that I'm not going to. Welcome. The rest of you I've met. So when we left off last time, Sree was really kind to share a lot of kind of the inner workings of some of her, how it feels when you are having a bad mental health day with Parkinson's. And I'd love to kind of do a round Robin discussion like we did last time with our extraordinary leader, Heather. I have big shoes to fill today, so why don't I'm going to give you a minute to get settled, Sree, Karen, can you share with us a little bit about what it feels like when you're having a really down day and maybe what do you what's your go-to to help get you out of that?

Karen Frank (Davis Phinney Foundation Ambassador, YOPD Council Leader):

Okay. I had a really hard time with this the first couple of years after my diagnosis. And it really hasn't been until recently where I've been able to really like dip into a toolbox if you will, and pull the tool out to feel better because I have those days. One of the things I've done is really build a strong community of friends who have Parkinson's that I can tap into. And that has been some of the people here on this Council and other people in my life. You know, I started a young onset support group because there wasn't one in my community that was very strong, and I just took the reins and did that. And I think that that over the years has grown into something really positive. So I've done that. Day to day, I meditate, I do mindfulness every day. I try to keep something pleasant around myself, whether it's something I like to look at, like a piece of art or a nice cup of tea. And when I'm feeling down, I make it a simple small action to take a sip of my tea. I mean, this is my mindfulness practice. You know, I'm drinking cinnamon tea right now. I just like the smell and that helps me feel better.

Kat Hill:

Did you have a mindfulness practice before you were diagnosed with Parkinson's or has that developed since your diagnosis?

Karen Frank:

I've known about mindfulness, and I've used it time to time, but I really, I try to pick and practice a really what I call nervous system friendly lifestyle. You know, I do things I enjoy. I see things I enjoy. I spend time around people I enjoy and I try to just build a life around myself. I think it's a newer practice really. I mean, I think it's come out of necessity, and it's grown into joyful practice.

Kat Hill:

Kevin, are you up for sharing? I'd love first to hear about your hip hop dance moves since Heather put that in the text. And then Pamela, I'm going to have you up next on deck. So you can be getting your head around the question. What do you think, Kev? I think you're on mute babe.

Kevin Kwok (Davis Phinney Foundation Board of Directors Member, YOPD Council Leader):

For those of you see me on David Leventhal's Monday morning class Dance for PD, I am not a hip hop dancer. I guarantee it, no rhythm whatsoever. So I correct that rumor going around.

Kat Hill:

It's on the record Kevin.

Kevin Kwok:

Thank you. Thank you. You got to clear the record. So, you know, I'm the last person that loves to hear someone say, rah, rah, go, you know, just bust through and you can do it because to me that, it sometimes rings hollow when you're sort of in the depths of your blackness. And that's the last thing you want to hear is, hey, you can do it. Just tough it out, man up, and just get through it. But I feel like I have had a pretty good grasp on my, I've always said that Parkinson's is dealing now with the highs, but with the lows and helping yourself get through the troughs and recognizing when you're about to get into a trough, what you can do, you know, proactively, you know, like Karen, I've tried mindfulness many times, I even enrolled in a mindfulness Parkinson's study, which did wonders.

And you would think based on the results, I would be practicing meditation every single morning, but I don't, as someone who professes strong discipline to workouts, mindfulness is not something I do every single day, even though I should, but I will tell you that what works for me the most is having a workout buddy that I meet with three or four times a week. Our wives and our girlfriends wonder how could you go to the gym for two to three hours? And I'll tell you what we, the first half an hour of our workouts is really spent stretching, doing a very eclectic mixture of tai chi, yoga and just general stretching but mostly the most useful part of it is really often sharing with you how difficult it was to stuff a pillow in a pillow case, or how I stumbled emptying the dishwasher and laughing is laughing and saying, you know, all right, well, that's why we're here to work out. And so I'm blessed with having great workout partners that share



that comradery in what we're doing. And to me, I can't stress the need for having a friend like that.

Kat Hill:

Yeah. Yeah. I think there's some really valuable points that I'm going to circle back to, to help those of you out there listening, wondering like, yeah, how do you get that? We're going to get into that in a bit, but I want to give everybody a chance to share here, Pamela, what are your thoughts? How, you know, you've had 25 years of dealing with this diagnosis, or more than that, you know, share with us some of your wisdom.

Pamela Quinn (Founder of PD Movement Lab, YOPD Council Guest Speaker):

Well, I would like to reiterate what Kevin said that the social aspect, the social connection is essential to maintaining our mental health and that if you, as far as exercise goes, I know I need a social part, a social component. To do it yourself it's just really hard and you shouldn't beat yourself up about it. You should just accept that it's difficult. And, you know, I'll honor an appointment I have with someone else in a way that I won't honor it for myself. And so the buddy system is just essential in developing a community. I mean, I swim I have someone that I play ping pong with. I have someone that I do a ballet bar with. I have someone else that I play tennis with. You know, I've developed a group of people to help me activate me because otherwise it just won't happen. And so I really encourage everyone to put energy into the social aspect of helping motivate you and doing anything is important. I mean, just do something if you're not feeling good, whether it's cooking or just anything that gets you up and gets you moving.

Kat Hill:

Yeah.

Pamela Quinn:

Even taking a walk. And there was, Karen was also talking about doing things that give you pleasure. I think that's really important to know in advance. What makes you happy? Because then if you know that you can go to that without having to think about it, and whether it's a phone call with someone that you cherish or whether it's playing a game of cards or whatever, you know, whether it's buying some flowers and having them at home, know what makes you happy and conversely, know what makes you unhappy so that you can focus more on the positive and take away the negative. So I think those things, activating yourself, using other people to help you do that. Movement is a wonderful way to get you out of your bad mood because the music is so transporting, and it can put you in a different state of mind. And it's also social.

Kat Hill:

Yeah, I agree. I think that there's so many components that we're talking about here. And I think the fact that all of us are here on this call today speaks to how much we all need each other. And just that action of showing up feels better. The action of seeing somebody else's face and knowing somebody else understands, we can't really undervalue that. I'm gonna put our last two panelists on hold for a second with sharing their stories. There's a really good question on the chat that I'd like to address and see if anybody has thoughts. I won't put anybody on the spot for it. How do you know if disease is progressing or something else is going on, is being tired a sign of disease progressing? How do you exercise when you can hardly breathe? That is a beautifully worded question. Does anyone want to take a stab or do you want...

Pamela Quinn:

I'll deal with the breathing part.

Kat Hill:

You want to talk to breathing? Perfect. And then Sree, you're on deck friend.

Pamela Quinn:

The breathing, shallow breathing is another symptom of PD that people don't often talk about. And it's hard because it makes us anxious and concerned about whether we can exercise. What I, my breathing changes according to where I am in my med cycle. And when my meds are functioning, I try to work my breath. I blow up balloons or I.

Kat Hill:

Pamela, your mic is giving us some static. I don't know if you want to pull it out a little bit and see if that helps. Forgive me for interrupting.

Pamela Quinn:

That's fine.

Kat Hill:

Better. That's better. Thank you. Yeah.

Pamela Quinn:

I try to work my breath by blowing up balloons or playing the recorder or swimming. I think you have to take your breath seriously because if you can't breathe, you can't move well. And moving is the only neuroprotective practice we have. So I think stretching your diaphragm forward and back in whatever way you can is really important too.

Kat Hill:



Yeah. Thank you. I think that helps just even starting with breath, right, Sree, what do you have?

Sree Sripathy (Davis Phinney Foundation Ambassador, YOPD Council Leader):

My voice is a little hoarse, so let me know if you can't hear me. First of all, I have to say, I think chocolate should be a great neuro protector. I'm just going to throw that out there. So the more I eat chocolate, the more I feel I'm getting better, actually, not true, but I'm sticking with that.

Kat Hill:

It's knowing what you love Sree, right? Chocolate is something you love and brings you happiness. So perhaps you're not all wrong there.

Sree Sripathy:

Yeah. So if anybody is listening from Canada, please send me Godiva truffles. The speculoos kind specifically thank you very much because they are no longer available in America. In terms of how the disease is progressing. I asked my my old neurologist and my new neurologist, that question, and my old neurologist said, you're doing really well. And I said, well, how do you know? I mean, how do I know how I'm progressing? And depending, like, if you are a young female and I'm saying young, maybe 55 and younger we'll say, not that anything is older, but you know, diagnosed with YOPD, there aren't a lot of studies or markers to see, to base how you're progressing against. So she couldn't really tell me how I'm progressing in comparison to other people, because there isn't really enough data that. When I asked my new neurologist, how I'm doing, he said, you're doing great.

I said, okay, but what does that mean? Because for me, when I think of how I would have been at 46 without Parkinson's, I don't feel that I'm doing so great. So in terms of how do you know you're progressing that is a very difficult question. I think it's a combination of asking your doctor, figuring out what your own symptoms are, and also realizing not everything is Parkinson's disease, right? You know, if you get a cold that isn't Parkinson's disease, that's getting a cold, if you are not sleeping well, part of that is Parkinson's disease but part of that is a repercussion of not sleeping well, the fatigue, the tiredness, but it also could be Parkinson's disease. So these are all like systemic integrated systems that change the way we feel. So I don't think there's an easy answer. What I like to do is I like to document how I'm doing every day when I remember to, when I can write, and I'm not tremoring, and note down my symptoms and do like a little audio check-in sometimes I'll take my iPhone or smartphone out, put out the audio recording pad and say, this is how I'm feeling today. If I'm eating unhealthy, I definitely feel worse, never with chocolate, but all the other stuff. So like last night or the night before, it's 12:00 AM in the morning, I could not sleep at all. Hadn't slept for about 24 hours. I

went to the kitchen; I got a bag of Sun Chips, Harvest Cheddar Sun Chips. It was such a great day.

Kat Hill:

So Sree's answer is kitchen related.

Sree Sripathy:

So I'll tell you the next morning I felt terrible. I felt absolutely terrible. So diet makes a huge difference. So how do you know that you're progressing? How do you know what it is? You don't really know. And sometimes what the doctor tells you isn't always the right answer. So you have to work with your doctor, work with the physical therapist, work with your friends, figure it out together. I think it's a team effort to figure out how you're doing.

Kat Hill:

Yeah, I would concur, Robynn "more eighties", I'm going to have to say your whole name every time. I'm sorry. It just makes me smile. Do you have something to add to that? And, if so, and or, I'd love to hear how you kind of dig out of a tough day.

Robynn Moraites:

Sure. So I ascribe to the belief that the practice of bring the body and the mind will follow. And I started putting practices into place years before it was ever diagnosed with Parkinson's. And I just translated them into applying them to Parkinson's. And I'm extremely social, all of this was before Parkinson's, before Parkinson's was even a blip on the radar screen for me, I knew that I wouldn't go on a bike ride unless I was with friends. I wasn't going to do it alone. And so for me the social aspect is imperative and having an accountability partner and someone put in the chat, you know, does it have to be people with PD or can it be other folks? Whoever's your people, whatever you're comfortable with. I have some things I like to do with friends who have PD because they get me and they understand me.

And then I have other times, frankly, I want to be away from them because I don't want my whole life to be about PD. And so there's a couple of things I do, one is exercise with bring the body and the mind will follow and meet with an accountability partner, meet with people. If people are expecting me to show up, I'm not going to have an excuse why, and it's kind of a habit that formed years ago. But the other thing for me is that I do stained glass and mosaic work, and I'm able to still do that work. I know I won't always be able to still do it. I had to get away from it for a little while, until I had the deep brain stimulation. And I'm back to it now. I like the mosaic work because it's less skilled.

You can, there's more room for error than with stained glass, but COVID was very difficult because all of that group stuff went away and I'm happy to report I went to a mosaic class on

Friday. I took a vacation day and went to a class. And that recharges me being around other people who are doing similar creative pursuits. And then I can do the creative work when I'm alone. I get recharged being with people, but when I'm having a down day, I just go up to my art studio and I fiddle around. I look at things that make me happy, brightly colored glass, and tiles and things like that. I also want to pick up on something that Pam and Sree said about the question that came in. I think it's imperative that we talk to our doctors, but Parkinson's, everyone, a lot of my friends who don't have Parkinson's thought that I was overdoing it when I was researching so much stuff in the beginning of my diagnosis.

And I don't because I eat on an auto immune diet, and I try to rigorously maintain what functionality I have and it's hard cause I don't know if I would have progressed at the same level if I hadn't of done that. I don't know because I can't have a parallel universe like sliding doors. But I know for a fact, I have weird rosacea breakouts and I know certain things that make me make that happen, it's inflammation based. And I know like dairy products and egg products. And so I steer clear of those because if inflammation is showing up on my skin, inflammation is going on inside of my body as well. But I have things that show up that I, when I have a flare up and I don't know what it is that I've eaten. So I've just decided that I'm going to start working with an inflammation specialist that specializes in kind of dietary intervention. And this isn't anything other than minimizing the amount of inflammation I'm putting my body through. So that's what I've got.

Kat Hill:

I think it's, yeah, I'm going to comment. And then Pamela, the floor is yours. I think it's, Parkinson's, we've all heard this at everything we've gone to, you've seen one person with Parkinson's you've seen one person with Parkinson's, it's confusing for us, partly because it's confusing for everybody about what symptoms we're having, what's gonna work best. How is it going to progress? I would just like to throw out that you get to be your own expert on your body. I'm hearing things, different things from different people, different kind of exercises, right? We all know the best exercise is the one you're going to do again. Right? No matter what, whether you're meeting friends, whether you're going to crank the tunes, whether you're going to listen to Pamela's videos, whether you're meeting your friend at the gym. So, I think you have to start start to learn how your own expert, and I just want to get back to when you can hardly breathe starting with the breath is important and build from there. And also to know you're not alone. You know, if you're tuning into this, I don't want you to feel alone. If you don't have a group, we can be your group. We can help hook you up with a group. So I think, I just wanted to be sure we touched and answered that question. Pamela, what do you have?

Pamela Quinn:

Yeah. I just wanted to add it's an issue of self-analysis can be furthered by if you go to a website of Sarah Rigarre, it's R I G A R R E she does a lot of analysis of how one is doing and has forms

for tracking or progress and for discerning what issues you're dealing with and et cetera. So that just might be useful.

Kat Hill:

Thank you Leigh. Yeah, she popped it up in our chat. That's great. Pamela, Heather, my friend. How you doing?

Heather Kennedy:

I'm good. I'm good.

Kat Hill:

I'll tell you. I couldn't do it without this lady. So.

Heather Kennedy:

So about peripheral nervous system, the autonomic nervous system with breath, there are so many programs. Hey Tom, what's going down?

Kat Hill:

Tom, welcome.

Heather Kennedy:

Programs for breath. Like the LSVT Loud. What is it?

Kat Hill:

L S the LSVT

Heather Kennedy:

LSBTQ? QRS? Sorry, I'll stop. But you know, this breath thing, we can take the breath in for kind of three, let it out for three and build on up to 15 like many people have suggested in like all kinds of programs. Pamela has done this, and Pamela knows, well, that music gives us a little boost. I was perusing your site. And I noticed you have everything from like swing dancing to classical, to like pop music, to disco. I mean, we have to switch it up, you have to have something to look forward to. If you do the same workout every time, you're in the same place every time, you go to the same drab gym, you're not going to keep doing it. If you have to schlep to the gym, you're not going to do it, make it easy on yourself, set up something that you have at home for the nasty weather or the days when you can't get out, set up something online, which you can see, there's a plethora to choose from. Surely you'll see some links pop

up there in the chat and then set up another thing where you are accountable where you go out and you meet people like even just for a hike, you know, were it not for the hikes that the women take in the morning, the world would blow up because we get to unload there together, you know, so let's do it, you know, let's do it together.

Kat Hill:

Start small. And I think there's real value to getting outside too, do you all feel that way? Even on like the rainiest of days, I live in Portland, Oregon, right? It rains a lot here, but we, if we didn't get up, if I didn't get outside some, I think I would kind of implode, especially during COVID, just a walk in my neighborhood will shift my mood. So, hey, Tom. Welcome. Welcome. We're chatting about how you get yourself out of a dark hole when you're having a rough day, maybe having trouble logging in to a webinar kind of thing.

Tom Palizzi:

I wasn't going to be able to make it cause I was trying to run an urgent errand this afternoon, but I just got that done, so Polly asked me if I could jump on, so I thought well, I'll just pull over and jump on. So here I am.

Kat Hill:

Love it. How do you get yourself out of, you know, kind of the mental hole sometimes that we can get in? Do you have tips for our listeners?

Tom Palizzi:

That's one way to get out of it, pull over.

Kat Hill:

Pull over and stop driving.

Tom Palizzi:

Yeah. You know, really you know, the easiest way for me to do something like that is just to start doing the things that I just have to get done. I keep a list of things that I need to do and maybe not so much need to do but want to do stuff like that. So I don't get into a deep hole very often, but it happens from time to time. And so I just try to stay focused on and get refocused on some of the things I need to do and getting caught up with things really helps me feel better about, you know, just doing what I do. So, you know, I get behind a lot cause I, you know, the short term or the short I can't focus on stuff very long, the attention span. Thank you, doi. That always makes life tough. So I have a million little projects going on all over the place. And so I just pick something up and start working on it. And again, that kind of gives me some self-fulfillment on that end. And of course the exercise is always helpful. So.



Kat Hill:

Yeah. I find having a list is really helpful. I'm the queen of post-its on my desk and if I'm having a crummy day I'll have something on my list, like journal or gratitude. Yeah. Walk the dog, right. Take, even taking out the garbage or making my bed makes me feel better, you know, the tidy bed thing. So for what it's worth, you're laughing at me, Sree. Sree's cracking up.

Heather Kennedy:

Just using your voice and yelling at somebody else to take out the garbage too.

Kat Hill:

There's something, I know Heather has teenagers. Yeah. Kevin, yours, and then Sree.

Kevin Kwok:

I know this sounds a little bit cheerleaderish, but one of the things that really helps me out is helping someone else out.

Kat Hill:

Service.

Kevin Kwok:

I feel like if I take someone's call, who's in need, and then I hear their story and I listen and then I respond and they feel better. I somehow get uplifted as well.

Kat Hill:

Kevin, being of service, you know, there there's a lot written about gratitude and doing for others, that it really is probably really physiologically good for us to do that. So that doesn't surprise me. And don't you think too, that even though you're in a crummy place, you put the words out that you really believe, even at the very moment, you're struggling to believe, saying them out loud and saying them to somebody else somehow makes your brain, that neural pathway gets activated. Right. Okay. I'm back on the, I'm going to be, you know, grateful highway or I'm going to not stay down highway.

Kevin Kwok:

It's all a matter of imaging and sort of in your mind, seeing success by helping someone else and you start believing what you're telling them.

Kat Hill:

Exactly:

Pamela Quinn:

It's the best anti-depressant I know. Helping others.

Kat Hill:

Helping others. Yeah. Sree, you had a comment, then Robynn and then Tom, yeah.

Sree Sripathy:

Remind me what I'm supposed to be talking.

Kat Hill:

I didn't know if you wanted to comment on anything about being of service. Sorry.

Sree Sripathy:

No, I think in terms of how you make yourself feel better, first, I'll say Kat, if you want to fly down and make my bed, please feel free anytime. Anytime. Okay. I will say the smell of fresh laundry is beautiful, especially when I don't do my laundry. So that's great. If somebody else could do it for me that's great.

Kat Hill:

You're a real friend Sree.

Sree Sripathy:

Thank you. Thank you. So I actually like to feel depressed sometimes, and I'm not talking clinical depression. I'm not going to say like, let me rephrase. I don't like to be pulled out of a dark spot all the time. And there are a few, I will say, if you feel that you are going clinically dark or it's really getting to the extreme, you would need to seek medical help. Do not, you know, do what I'm doing. This is just me feeling like blue or depressed, you know, like rainy days on Mondays, like the Carpenters song. Although I don't know if they originally were the people who sang it, but you know, sometimes I just want to be down. I don't want anyone to lift me up. I just want to be what I'm being. I want to feel sad about Parkinson's. I think we need to let out those emotions.

It's like that movie where you have the little people with the different emotions, you know, that little animated movie and no one paid attention to the little blue person with who was sadness because you need sadness. You need some of those emotions in your life to balance it out. So every time I'm feeling sad, if someone's like, cheer up, or exercise, I just want to say basically, something really terrible, not safe for this webinar. And they leave me alone. But on the days where I do need to be cheered up, I actually have a list. Ah, there we go. It's not that song,

Heather. I decided to bring myself a list of things to make a list of things that will cheer me up because oftentimes you won't have a friend to call, you know, everyone is busy with their lives. So there are days where I'm feeling just so desperate to talk to somebody. I'll call seven people. Nobody picks up the phone. Nobody is free, 1:00 am 2:00 am in the afternoon. So I have a list. You know, I read a romance novel. I'll watch an old, funny Cary Grant movie. I will watch videos of my nieces and nephews. I will look at old baby photos of kids that I love. I will read a funny book. I'll watch a comedy. I will listen to a podcast. I will eat chocolate. I will look around the house.

Kat Hill:

I knew the kitchen was coming.

Sree Sripathy:

Yeah, exactly. I look around the house. I might buy something. You know, I might buy something that I actually already have, which if anyone wants to help me avoid that, that's great. But it gives me a little zing of pleasure. I suddenly might get an idea to do something creative, or I just might force myself to get out of bed and just move and go out and smell the earth. You know, if I've been stuck inside for days, cause sometimes that can happen. It's not apathy. It's just sometimes you just wake up and you're like, how many days went by five, six? And I've never been out of the house.

Kat Hill:

Sree, I think you have a really valid point. It's like, we need to grieve, but it's the after the grief, when we need to turn things around and we're going to have, life has ups and downs. So we're not trying to say you're supposed to be happy all the time. It's more that if you're feeling lost in that dark place, we're trying to, you know, give some tools and I like the tools that you shared because everybody's going to need different tools. Robynn, how about you? And then Tom, sure.

Robynn Moraites:

To me, what we're talking about is not really clinical depression, it's more apathy. And I'm sure that there's people out there before I was ever diagnosed with Parkinson's. I, my whole life, I never had depression. I was never a depressed person. And I had a period, an episode of major depressive, a major depressive episode as one of my first earliest indicators. But I didn't know that's what it was. And it knocked me out for about three months, and I sought medical treatment. I work in the mental health field. So I had a lot of strategies, and a lot of staff support to do what I needed to do to take care of myself. I thought it was situationally driven because my ex-husband had moved to another state. He had a business opportunity. I had started going back and forth. I thought it was circumstantially driven, but I believe today it was, it predated my diagnosis by about a year to a year and a half. And it was severe and there was no pep talking myself. There was no, you know, it required serious medical intervention and

time off and a lot of TLC. And so if folks out there are dealing with that level of depression, ask for help, ask your doctors, you know, get a game plan with your healthcare practitioners in place. I did know that exercise helped. I mean, exercise helps everything, but it's very hard to motivate when you're in that place.

Kat Hill:

Yeah. I agree with that. And we're not here to take the place of your mental health system. I believe that everybody deserves a counselor and a touch point, whether you have that in a friend, whether you have that in clergy, whether you have that in a support group. So that is an excellent point, Robynn. I appreciate that. Tom? And then I want to shift gears a little bit.

Tom Palizzi:

Yeah. Okay. I'll be real quick on that. I wanted to go on about helping others. Some of that time you're helping others you're actually helping yourself as if you made the phone call to yourself and talking yourself into things that you would normally use the Parkinson's as an excuse for not doing, like snow skiing for example, I'll say what I can, blah, blah, blah. And then I'll make it a point to talk myself back into doing stuff like that. But the other thing that somebody mentioned was calling or you know, going back and calling friends or taking a call from somebody, that's always really uplifting to me. And I love going back and calling people that I've talked to in the past and just following up to see how they're doing that. Usually just it brightens their day, which really brightens mine. And I genuinely care about what's happening. So, and I often find that if I don't call, I don't hear back from a lot of people. So that's important to me to keep those connections.

Kat Hill:

Yeah. Connectivity. I love, Heather. Yeah. Heather, I love what you're saying in the chat.

Heather Kennedy:

Can I give a shout out too to VR? If anyone uses virtual reality, Pamela, I don't know if you do the ping pong with others online or in person?

Pamela Quinn:

In person.

Heather Kennedy:

Okay, great. And then Karen Frank was nodding about the VR. It's more generational. Everybody can do the ping pong in person, but then the VR, we have an extra opportunity if we're shut-in to connect even that way. So we could play games with people, enjoy music, even dancing, which we can do by checking in on your videos. I mean, there's so much there. There's

no reason to just sit around and be like, Hmm. You know, there's so much, there so there's always something to snap us out of our little stinking thinking, you know, with the music.

Kat Hill:

I was just going to say music. I wanted to get back to Pamela's comment. And Pamela how do you select your music for your workouts? Because I think even just hearing the music, we heard some of Pamela's music before this and boy, it shifted my headspace. So how do you select it for your...?

Pamela Quinn:

Well, that's a really good question. I have to like it and I try to find music that takes me to a different place. Either mood wise or energy wise or that creates a specific way to move like melting ice cream or something that's very upbeat. And I also try to when I may hit my movement, it's symptom driven, I'm trying to deal with Parkinson's symptoms. So if rigidity, I might be working with the image of being seaweed and water, and I might find some jazz piece or some blues or something to go with that. I, you know, Spotify has this system where they list different musical pieces that you might like according to what your playlist is, so that can help me find new pieces of music. I'm always searching for them.

And I like to find as many different kinds of music as possible. Of course for Parkinson's music, there has a really clear beat is really important to help us move whether it's a march or whether it's Kodo Taiko drumming, or David Byrne or Rolling Stones or whatever. And those of us who grew up in the sixties and seventies too, grew up in an era of such fabulous music. There's so much that we know that we don't realize that we have to draw on as well. So I have a piece of music today, which people might be interested to move to. It's Brazilian and it's very energetic.

Kat Hill:

Yeah. I love that. And I love, do you, does anybody have a playlist for different moods or different...? Heather, I'm guessing you do.

Heather Kennedy:

Sorry, I was answering someone in the chat. Yeah. I have five hundred playlists on Spotify for every possible mood. The only thing I'm not into is death metal. Not so much, but Pamela, I was impressed with yours. What's that?

Kat Hill:

It's got good beat, just too much of it.

Heather Kennedy:

Yeah and we do have a couple of rappers here. Sree what do you think?

Sree Sripathy:

I like death metal. I pretty much like everything.

Heather Kennedy:

I knew it!

Sree Sripathy:

Yeah, Norwegian death metal. I just wanted to quickly touch on what I think Polly had put a comment in the chat about someone transitioning in YOPD groups. And we actually recently with the YOPD group that I'm a part of went through almost the exact same scenario...

Kat Hill:

Sree, I'm going to put it out there for our list. There were some questions about starting a young onset support group. And then as people aged, is there succession planning and how do you plan for that when you end up being a young onset group now suddenly in your sixties? So, okay. Sree take it.

Sree Sripathy:

Right. So in my young onset group, we were all like thirties and forties when we first started and now we're kind of older and Kevin knows, Kevin was part of that group originally when I first joined it in San Francisco, and then a question came up that said, well, there are some younger people who've joined the group that feel that the name is a little bit misleading. You know, these are people who are maybe in their mid to late twenties and very early thirties. And we're all, you know, forties is so much older and it can definitely seem that way. So there was a discussion that was had as to whether we should split up the group or, you know, what was decided. And it was actually quite an interesting discussion. And in the end we decided not to do that because we figured there's not enough people that are in their twenties to early thirties, that, you know, you would need a young onset support group like that.

You know, we thought we can learn from them and they can learn from us. So there's a group of people out there, or people as part of your group who are younger, who are worried about dating or money or jobs, you know what? We can create a little subgroup. We can give them advice. We can work on those things together, but splitting up groups, does it make sense? Cause we are community. At what point do we start splitting things up that it's too split up, but at the same time, you have to make the best decision for your group. So in the end we decided to keep it together and just counsel people individually as they needed.

Kat Hill:

Yeah. Karen, you have something to add to that?

Karen Frank:

Yeah. I have a little different perspective. I actually think it's okay to split it up if that works for the group. I mean, I think both are necessary and have a wonderful place in support group communities. But I know when I went to my first young onset group, it was in person before the pandemic, and I walked in and everybody was older. They were young onset, but they had had it for 18 years and I think it has a lot more to do with progression. I find, I get a lot of people call me and they don't want to come to a support group if there are people in the group that are advanced when they're young. And I think I don't want to leave anyone out, but they have a hard time seeing that and I don't want them to feel that they can't have a place to come. So I think there's a possibility. I mean maybe if the group's big enough and it has both, you could have breakout sessions too to address certain needs of the group, but that's still, I think there in my experience it's been good to split groups up.

Kat Hill:

I think if the group's big enough. Yeah. I think what I'm hearing, Tom, you have something to add though. Go ahead, Tom.

Tom Palizzi:

Just real quick, Kat. I think it's good for like, I just turned 60. I'm a little over 61, I think. Yeah. 61. And I think it's good to have the kind of background available to people that are newly diagnosed that someone like myself or the rest of us in this Council have, because we've kind of been there, done that or this aint our first rodeo kind of thing. And that's where I've been probably the most helpful or I've seen the most attention is from people that are newly diagnosed that are just looking for some answers and some guidance and some things like that. So I think if anything, if groups get split up at that's a good thing too. Cause they're, you know, we all have different needs and we're at different stages, but you know, you can always count on someone like myself or Kevin or someone else that can offer that kind of a guidance and opinions on questions that you might have. So maybe once a once a quarter, we come in and help with the YOPD group, whatever, something like that.

Kat Hill:

Robynn?

Robynn Moraites:

As a practical matter, one of the questions in the chat about this was are we misleading people? I've been leading the group for a long time. We all started out young onset, but now technically we're not young anymore. And it's easier to just change the group name than worry about succession planning. Like if you have an established group that's cohesive and meeting regularly, maybe you could be the formerly young onset group and then someone can start a new young onset group. But I think succession planning is difficult for these types of groups and

better to just change the name if you decide that you are misleading young people, you know who and technically young onset diagnosis doesn't mean you're 20 or 30. It's like under, I dunno what it is under 50, under 55.

Kat Hill:

It depends on who you ask. There's not a universally agreed upon age. Kevin, you had something.

Kevin Kwok:

Yeah, I think this young onset age is really not a chronologic age, but a state of mind age or issue. I mean, I learned so much from one of my best buddies in San Francisco who I box with, he's 74 and he will kick ass on anyone on this group right now, you know, he has so much youthfulness in him. I think just looking at the spirit of where you are, when you have your diagnosis, are you trying to raise a family? Are you dealing with personal relationship issues? Are you trying to maintain a job? These are all things that transcend age when you're 20, all the way up till, you know, the end of our journey. And I think to be segmenting and denying that. I mean, I fully appreciate that different subgroups will have some issues, but as a whole, we gain so much when we talk to other people.

Kat Hill:

Yeah. I think I want to circle back a little bit and kind of, because we're talking about the need for support groups, we talked all of us in our sharing about how we get out of holes, talked about the importance of community and support groups can really be the entrance into a lot of that. I know that's how I met some of my folks. I know that some people look at this for me showing up here as somewhat a support group. So I think that it's really important that people not feel included. And at the same time, I think that as groups grow naturally, sometimes they can segment off. And I liked sort of what Sree said that giving them the opportunity, if they want sort of a separate section, maybe that will be more meaningful to them.

So I think before we head out of here, I can't in good conscience the week before Thanksgiving holiday not talk about gratitude a little bit. And since I have the honor of being the facilitator, I just want to say how grateful I am for each and every one of you who showed up today, I'm deeply grateful for the insights that our esteemed speaker came and shared with us and her taking time out to come and share with all of you. I want to give her some applause, but I'd also like to hear if there's anything in particular that you all are grateful for since I stole the obvious ones, sorry, who wants to share some gratitude or what you have coming up next week?
Heather.

Heather Kennedy:



I have tremendous gratitude for people that take the time to try to understand a little bit about Parkinson's and they love me when I'm not very lovable, they love me if I'm OFF or if I'm ON and manic or if I'm ON and sort of okay, I went to trivia night the other night with some friends who I hadn't seen in a long time and I don't want to drink anymore at all. So I just don't see anyone since brain surgery, especially. And they were like, what's wrong? Like what happened? So I was sort of shuffling along and then pretty soon they just went along with me. I said, I'm a little stiff. And I was pretending that I was sort of like doing the robot and stuff and it just ended up being kind of funny. Like it was all good. So I want to give a good shout out to our caregivers, friends, relatives, coworkers, who just go with the flow. Thank you.

Kat Hill:

Yeah. Yeah. Anybody else? Kevin.

Kevin Kwok:

I'm thankful for chocolate, but even more than that dark chocolate and a good Cabernet. I love that. But in more seriousness. I really want, I'm very grateful to the Davis Phinney Foundation for giving us this vehicle for chatting. To me, this has been my savior more than anything.

Kat Hill:

Indeed, indeed. Yeah. Robynn.

Robynn Moraites:

I'm grateful to be invited to this group. Many of you know, I've been stalking you. I've been watching these webinars for, you know, the last year or so, emailing you and it's nice to be part of this.

Kat Hill:

Well, we really appreciate what you brought today, Robynn. Really. Yeah. Glad you're here. Anybody else. Tom's gonna be grateful to get out of his car I think.

Tom Palizzi:

Ah yes. It's getting hot in here.

Heather Kennedy:

It's getting hot in here.

Kat Hill:

Did you have something? I'm sorry. I interrupted.

Pamela Quinn:



Just I'm grateful for your interest in my movement and my music choices. And I'm very happy to hear that they give you a lift because that gives me a lift.

Heather Kennedy:

They really do. Thank you so much.

Karen Frank:

I can't wait to try it, I haven't check it out.

Heather Kennedy:

Her website's beautiful.

Kat Hill:

Pamela, can you chat the, can somebody put Pamela's website in the chat? It probably is already there.

Pamela Quinn:

PDMovementLab.com

Robynn Moraites:

They put it there.

Kat Hill:

Perfect. It's there. Fabulous. So we've given, if you're out there feeling a little lost, feeling like you don't, like you're in a hole and you can't get out. At a minimum, you can type a few things into your computer and some of it you're going to have to pick and choose. Not one of us here is the same, not one of us here has the same Parkinson's symptoms. Not one of us is going to need the same tools to kind of get out of our space, headspace. So I think Pamela, do you want to send us off with a little movement break?

Pamela Quinn:

Yes, I'd love to do that.

Kat Hill:

If we run out of time, she's just going to send us off.

Pamela Quinn:



It's under three minutes.

Kat Hill:

That's all right. So we're going to hear some great new movement and some music, and I'm wishing you all a wonderful holiday next week at whatever you celebrate. Thank you for joining us. The floor is yours Pamela.

Pamela Quinn:

Ok so you'll need to stand up if you can. And I'm going to shift my camera.

Alright, here we go. Start by shaking the wrist and include the elbows and shoulders. Shake it all up, whole spine. And just have arms go front and back, include the hips. And take a big circle, and reverse direction. And big circle and reverse and stretch all the way up, big stretch. Way up. And back. Up. Back. Up. Back. Up. Side to side. And take the weight. Shift the weight back and forth in your feet in take it into moving. Move any which way. And two feet, balance, balance, balance, balance and back to wrists. Elbows. Shoulders. Include the spine. And arms go front and back. Include the hips. And circle again. And hula hoop circle and raise up, way up stretch up, back, up, back, up, back, up, and shift side to side, and stop.

That's it.

Heather Kennedy:

And if you couldn't see, you could do your interpretive dance.

Karen Frank:

Yeah, I couldn't quite see. I just did whatever.

Robynn Moraites:

Heather, when I saw you, I started cracking up when I saw you do the...

Kat Hill:

Thanks so much everybody. I hope everybody that joined into that dance feels a little bit better. I know I feel a little bit looser and Pamela, your choice of music is fabulous.

Heather Kennedy:

With Kevin bacon called I love Dick. That's the name of the series. That song.

Kat Hill:



Okay. You can write that into the chat, Heather.

Thank you all for coming today, Leigh, thank you so much for your help in the chat. Everybody at the Davis Phinney Foundation we appreciate you and we appreciate your time. Happy Thanksgiving, everybody.

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