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Speaker 1: Welcome to a recap of our latest third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at [Michaeljfox.org](http://Michaeljfox.org).

Allie Signorelli: Hi, everybody. Welcome to this Thursday webinar discussion on Parkinson's and mood. I'm Allie Signorelli. Thank you so much for joining us today, and happy to be moderating this important conversation. I was diagnosed with Young Onset Parkinson's in 2022. I was 47, and I'd had symptoms for four years at that point. I'm also a member of The Michael J. Fox Patient Council, and I'm happy to share that I am going to be the new host of Parkinson's IQ and You, which is a free educational series being held in cities across the country this year. For more information on that, you can go to the Michael J. Fox website.

Today we're talking about mood and motivation changes in Parkinson's, including depression, anxiety, and apathy. We'll cover how those symptoms overlap and differ, and how it affects your Parkinson's care, and how we best can manage them. And with that, we've got a lot to cover, so let's introduce our panelists. I'm going to start with my fellow patient council member, Israel Robledo. Welcome Israel. Israel was diagnosed with Parkinson's in 2007.

Israel Robledo: Fun to be here.

Allie Signorelli: Irene Richard is a movement disorder specialist and a professor of neurology and psychiatry, and the director of the Parkinson's Foundation Center of Excellence at the University of Rochester Medical Center. Thank you for joining us, Dr. Richard.

Irene Richard: Pleasure.

Allie Signorelli: And Andreea Seritan is a geriatric psychiatrist who specializes in treating patients with movement disorders and conducting research at the University of California in San Francisco. Thank you for being with us, Dr. Seritan.

Andreea Seritan: Good morning. Thank you.

Allie Signorelli: And before we start, due to your location, Dr. Seritan, and everything that's going on, we just want to extend a heartfelt thoughts and prayers to everybody in Southern California. I know you're a little north of that, but no doubt the entire state and the entire country is watching with heartache. So we send our thoughts to everyone out there and hope that you're dealing well with it, as best can.

Andreea Seritan: Thank you. Thank you so much, Allie. Really do appreciate it.

Allie Signorelli: Yeah, we're all with you. So depression, anxiety, and apathy in Parkinson's can show up in lots of different ways throughout the Parkinson's journey. I've personally experienced it, and we're going to talk about our journey. It can be treated either with Parkinson's or separately, and it can be very challenging for people. So I think Dr. Richard, we'll start with you. Can you tell us a little bit more about how mood and motivation changes in patients and what they're experiencing? Can they overlap? And how do they typically show up?

Irene Richard: So, yeah. I mean, basically, we said that we were going to talk about depression, anxiety, and apathy, and those will be defined. And there's overlaps in symptoms among all of them, and also people that have experienced more than one at a time. So with all of this, it can be quite difficult to be aware of it, and to diagnose it, and therefore, to treat it.

I think that the one we should probably focus on first is the distinction between depression and apathy. That's the one that I think is the most difficult to tease out sometimes and the one that I see most often in my own practice. So apathy is basically, it's the loss of motivation. And that can actually be in several realms. So it could be cognitive, or thinking, so that people maybe just aren't as curious about new things. It could be emotional. So for example, maybe they'll have less passion or just a decreased emotional reaction to something that they normally would have reacted to.

Or it can be behavioral. And in that sense, really, it means trouble initiating activities, and therefore requiring perhaps other people to do them, or try to get them to do them. And what I will say is that apathy can be seen as part of depression, and depression can happen without apathy. But what we've learned over the years is that apathy is also a syndrome in Parkinson's disease that can exist on its own. Okay?

And I would say that the two key features, I think, that distinguish these are that basically, in depression, patients have the mood itself is affected. And people consider mood all kinds of things, blue, down, hopeless, disconnected, whatever. But the point is that, emotionally, there's a negative sense. In apathy, let's just say for now, it's kind of neutral.

And then the other thing is, one of the other core features of depression is the ability to experience pleasure. So to derive pleasure in things that you usually wouldn't derive pleasure in. I'm going to just say this, that usually, if the situation is apathy, it's usually the care partner who brings it up, as this is actually quite a burden on the caregiver or care partner. And if they don't understand what it is, they may just think the person's being lazy or stubborn. So it's important, first of all, to explain what it is. But secondly, the patients themselves who are experiencing apathy rarely complain about it. But that's their apathy.

Allie Signorelli: They're apathetic to even being apathetic.

Irene Richard: Exactly. So what I do in these instances, if anybody mentions it, I will say to them... I would just ask the patient how they feel. I would literally just say, "How do you feel? Are you feeling distressed? In your mood, does this feel negative?"

And most of the times, they'll say, "No. I mean, I feel bad she, or he, or they have to keep telling me to do things. But not really." Whereas in depression, you're going to get the sense that there is that negative mood. And in apathy, if you can get over the hurdle to actually get to something that usually is pleasurable, even as simple as a movie, usually people are able to enjoy it. Whereas in depression, that's not the case.

Allie Signorelli: Israel, we've talked a little bit about this, but you've experienced mood changes in your journey with Parkinson's. Would you categorize yours as depression, apathy, both? Tell us a little bit about your experience.

Israel Robledo: Interestingly, what doctor was saying is I didn't realize that anxiety for me was part of what I was doing with my depression. Because I did find out that I was not doing things that I enjoyed, not doing things that made a difference how I was working as a school teacher. But yes, for me, I've dealt with a depression since I was about 20. So it's been a long, drawn out battle. But it's interesting for me to think that Parkinson's saved my life because of my depression having been dealt with in a good way.

Allie Signorelli: That's such an interesting take. Yeah. And my experience is slightly different, which is I had not dealt for long periods of time. I had some postpartum depression and some other isolated incidents. But for me, it didn't really come on with consistency until this past summer. And it was something that my MDS, my neurologist, warned us was a potential side effect or symptom of Parkinson's, which I'm very grateful that he did because we were on the watch, if you will. And we'll talk a little bit about that later on. But interesting, Israel, that you say that Parkinson's saved your life in the sense that your depression existed before Parkinson's, and having Parkinson's helped you work through that.

Israel Robledo: And it took my movement disorder specialist to realize this treatment isn't working for you, let's try something else. And that's where everything changed into positive. It was a life saver.

Allie Signorelli: That's great. Dr. Seritan, when do you normally see, or is there some typical progression of mood and motivation changes in Parkinson's that you've seen with your patients?

Andreea Seritan: Thank you so much. First of all, Allie, and Israel, and everyone who's listening, thank you so much for your courage for discussing, sharing your experiences. It's still pretty hard for people to talk about their own mood changes and their own emotional journey in Parkinson's disease, so I want to applaud you for being here, for sharing, for your blog, Allie, and for everything the foundation is doing also to help people with Parkinson's.

I don't think there is any determined time when the mood, anxiety... And I'm going to differentiate just a little bit, adding to what Dr. Richard said. In psychiatry, we think of mood as depression, or elevated mood, the opposite mood, and anxiety is a little bit different. They're a little bit different brain circuits, if you want. So we treat them similarly.

But to go back to your question, moods as in depression and anxiety can actually show up decades before the onset, before the motor symptoms, before the tremor and maybe stiffness come up. And I think the two of you are perfect examples, if you want, of Israel having had depression decades before, since your 20s, and then Allie maybe newer with the diagnosis of Parkinson's.

So the first point I wanted to make is that of the prodrome that we're actually studying and learning more and more about that the mood changes can be part of this prodrome, before people have any movement symptoms, any movement manifestations. And then, of course it's very important for us to educate psychiatrists because psychiatrists may be the ones to see people with Parkinson's disease way before they had the tremor or the stiffness. Or maybe some people in the audience had this experience, starting an antidepressant and, antidepressants actually unmask, or I shouldn't say cause, but unmask the tremor. So it's very complex, a bidirectional relationship and quite complex. And I see Dr. Richard wants to add there.

Irene Richard: The only thing I just wanted to say was just that a lot of times now, that psychiatrists and primary care doctors are using medications that can block dopamine for specifically mood and anxiety because they can help. And those in particular are the ones that can actually really worsen Parkinson's symptoms, or unmask them, or even cause something that looks like Parkinson's. So I 100% agree with that. I just think it might be more common in that class of medications that seem to be used more liberally now for anxiety and depression. We've seen that a lot.

Allie Signorelli: A question actually came in from the audience, which I think ties back to that really well, which is that when people are expressing their anxiety, especially Parkinson's patients, and they're sort of told, "Well, anxiety is just part of life, or anxiety comes with aging." It's not necessarily to say that everyone gets anxiety in their lifetime. And that looking out for it and knowing what to be aware of with your own care team, with your own MDS, with your own psychiatrist is really important. Because as you said, Parkinson's may not even be on some people's radars, and it's unmasked, and then... So just very important to have open and honest conversations about it.

Andreea Seritan: Yeah. Yeah, you're absolutely right, Allie. And I would add to that, that, no, anxiety is not part of life. I mean, stress responses are part of life. Think of what's happening all around us. But anxiety as in clinical anxiety is not necessarily something that the entire general population is experiencing. Neither is depression. And if we look at the rates, the prevalence in the general population is certainly not 100%.

Allie Signorelli: I think one of the things that people feel some amount of comfort in when they're dealing with mood changes, and Israel, feel free to jump in on this too, but I think what I have felt some sort of comfort in is that I wasn't alone and that this is, for lack of a better word, common among Parkinson's patients. Maybe Dr. Richard, you could share with us, how common is it? Is there a statistic that we know of around patients dealing with other changes?

Irene Richard: So that's a great question and one that we're still trying to figure out. Because as you might imagine, to figure out exactly how common it is when there's a lot of overlap is a bit of a moving target. But I think it's safe to say that roughly in the area of 40 to 50% of people with Parkinson's disease will experience depression, anxiety, apathy, or one or the other, or even all three. So very common.

And absolutely it's common, but it is not universal. So you can see two people who one person may be more disabled or be in a worse situation than others, but is not experiencing depression. Another person may have very mild symptoms and for the life of them doesn't know why. And so it's important to realize that there's an influence always of environment and our brains and bodies, but it is neurobiologically wired, and the neurochemicals that cause Parkinson's disease in many people, almost half of them, also cause these things.

Allie Signorelli: So 60% of you on this webinar, more than 60% of you have experienced some depression, which is amazing. I mean, I guess amazing is not the right word. But holds up to exactly what you were just saying, Dr. Richard, that so many of us have suffered through this. That alone is really astounding. And Israel, you had dealt with depression before you were diagnosed with Parkinson's. Did you experience it as a different iteration of it when you were diagnosed? Why don't you share, Israel, a little bit about how your depression manifested itself?

Israel Robledo: Absolutely. What was happening with me was I didn't get any relief from medications that I was given. And as a matter of fact, I was on two antidepressants for several years, but I always have said I wanted them to work. I was willing them to work, but they weren't doing anything. So with my diagnosis and my movement disorder specialist says, he says, "Why are you on two antidepressants?" I said, "Because they're trying to make them work."

And he says, "No, let's not do that. There's one that I will prescribe to you that will help you with the symptoms of depression and will help you sleep." And that changed my whole life. So yeah, it was a process where I was dealing with something that I could not come to grips with. I was suffering daily, mentally. I would say I'm so tired mentally because I can't deal with it. It can be daunting, but let me tell you, it can be fixed to a right degree.

Allie Signorelli: Yeah. And that is the experience that I had. Like I said, my MDS had warned me, and somewhere around last summer, I started feeling just generalized sadness that I couldn't escape. I, like many working moms, had been very, very busy and was just ignoring it and thinking I could outrun it, or work it out, or get enough sleep, or all of the things that they tell you to do for your own mental health wellbeing. I thought if I just keep leaning into these, I'll get past this. But I couldn't.

And at some point, I had said to my husband, who was extremely sympathetic, and again, had been warned about this potential that I couldn't get out of it. And I'm grateful that my neurologist had set that up for us. Because in that moment, I was able to very quickly message him. We had a subsequent virtual meeting where I described what I was going through, and we set forth a plan.

He was very clear with me that there was no quick fix, that it was going to... If I chose to do a pharmacological intervention, which I did. But it was also going to take all of the other things that I had already tried doing, to continue doing those. And then as well as that layering in consistent talk therapy, which my therapist is amazing and I've had for years. But I think knowing all of that in advance helped me to be able to take those actions quickly and then also just recognizing that it was going to take a few months for me to get back to my baseline.

Dr. Seritan, how do you encourage your patients or the people that you work with to discuss it with their family members? Because to Dr. Richard's points earlier, sometimes if you're apathetic, you don't actually feel like you want to fix it versus the more significant sadness and depression state that I felt, if I had been apathetic, I probably would've just kept going.

Andreea Seritan:

Yeah. No, this is a great question and thank you so much for sharing your experience again. Just quickly before I move off to actually answering your question, I wanted to make the point that you just reinforced, that medications take time to act. So if people are going to decide to take medications, know please that every person is different, and you might not find the exact perfect fit from the beginning. But it could take three to four weeks for medications to work, and then maybe even six to eight weeks in some cases for people who have never taken medications.

And then of course, there are side effects and things like this that we have to talk about. But I think going back, Allie, to your experience and what you mentioned, being prepared that knowing that Parkinson's disease is a neuropsychiatric disease, and knowing this from the beginning, and expecting that mood changes might come up, depression might come up, anxiety, and knowing how they will manifest and how to differentiate them, bringing them up to the movement disorder specialist, I would say.

Neurologists, I would say, movement disorder specialists in particular, are very good at treating these symptoms. We were talking about this in preparation for this call with Dr. Richard. You treat probably a lot more people with Parkinson's disease and depression, anxiety, and/or apathy than I do. I tend to... My practice is more for people with Parkinson's disease who've already tried two, three antidepressants and need a little bit more help.

And also, before we move from the point of how to address this, I want to make sure we're going to spend some time on non-pharmacological management approaches. Because I don't think people should start with medications always. Medications were good for you Allie, but you are already doing a lot of the other things that I would recommend to my patients.

Allie Signorelli:

And we did discuss that at length, my neurologist and I, because he wanted to make sure I had tried all of those approaches first before we jumped into another medicine, which we'll talk about in a little bit. But as someone who was taking many, many pills every day already to manage my Parkinson's, the idea of another one can seem daunting to a patient. Maybe Dr. Richards, you can talk a little bit about that. And also, does the medication that you take for a depressive

state or an anxious state have to be regulated, if you will, or at least considered when you're taking Parkinson's medicines as well?

Irene Richard:

Yeah, so a lot of this is not black and white. I think that, as you said, everybody's different and everybody has different symptoms. Everybody comes to this from different places. I think it's been shown that actually, the ideal thing would be a combination for most people, of medication and... You mentioned talk therapy, which I think that we should also just make the distinction there is talk therapy, for example. I'm not going to get into the specifics of the different kinds of talk therapy.

But another thing just to keep in mind is the term cognitive behavioral therapy. Because that is not widely available because not a lot of mental health professionals are necessarily trained in it, but there is definitely evidence that cognitive behavioral therapy, if you have the motivation to engage in it, can be very helpful, actually, for anxiety and depression. But on the other hand, I think that I personally think that it depends how severe somebody's depression is as well. And if somebody's really suffering from depression, I think that actually I would start a medication.

And at the same time, I would encourage them to do all of the other things, including, you say, talk therapy. And that's an important point. Because as a movement disorder specialist, we generally see people twice a year, maybe every three months, or maybe there'd be a call after we start a medication. So while I happen to know a lot about depression, and anxiety, apathy, I'm not in a situation where I can monitor somebody in the same way, let's say, that a mental health professional could after they start medication, and that can be very important.

Obviously I can deal with side effects and things like that. But I do think that it is best to have, first of all, a twofold approach, at least. I mean, there's general well-being that will just help everything. I mean, exercise helps everything, let's just be real, if we can get motivated to do it. But I think that I personally actually... If somebody seems to have a depression that is from which they're really suffering, that's severe, I usually do start a medication. But at the same time, I try to get them set up with a mental health professional of some kind.

And this may be a social worker who is licensed in therapy. But just somebody else, as you say, for talk therapy. And honestly, though, I would say that cognitive behavioral therapy, if you can get it, could be as effective as medication. They've shown studies where the combination is better than either. I think that when you do start a medication for depression, you definitely have to be careful about which medication you pick.

And I don't want to go into specifics of medication, but this is something that Andreea and I were hopefully not just having our own discussion. But basically, the typical antidepressants that are used and that have been around, I think they'll mention them, selective serotonin reuptake inhibitors, then the serotonin norepinephrine reuptake inhibitors. Some people call SSRIs, SNRIs, or the tricyclic antidepressants or bupropion, even, the well-futured.

The thing that you want to avoid are what they call the atypical antipsychotic medications. And I say this because it really is an important point. Because I can't tell you how many patients I see who have been started by the primary care doctor or even psychiatrist on one of these medications. And as a result of that, have... And to Andreea's point, now that we're realizing anxiety and depression can happen before the motor symptoms, it may unmask or even mimic Parkinsonian motor symptoms.

So the first thing we do, literally the first thing we do is we look at the list of medications, and we see what's on it, and if there's one of those particular types of medications, there is no way to distinguish, actually, on clinical grounds, we've looked at this, between what we call idiopathic Parkinson's disease and drug-induced Parkinsonism. And this is an important point, because it's exactly what happens. People develop anxiety or depression premotor, they see a psychiatrist, and if they happen to get treated with that... Which there's nothing wrong with that. If you are a psychiatrist or a primary care doctor prescribing that, you just have to be aware of the potential side effects.

Allie Signorelli: I think I erroneously a little bit here, jumped right into treatment and drugs, but I don't want to lose the point, because I know so many of the people joining us today are patients and care partners. I just want to circle back really quickly to the point about how we communicate, either as patients or as care partners, about this to each other. I think, Israel, maybe you could just share briefly how you shared with your loved ones or what, if anything, they brought to you about your experience being depressed. And I'm happy to share some of the feedback I got from my own family, but I don't want to miss that point before we go too deep down into the discussion on actual treatments.

Israel Robledo: Yeah. Interestingly, my twelve-year-old daughter who, at the time when I was diagnosed, she mentioned one time, she said, "Dad, Mr. Ferguson next door, he's always busy. You don't do a lot of things." And I thought, "That's interesting." I mean, I thought I was active. But after I was diagnosed, I thought maybe that was apathy. Maybe that was something that she saw in me that was different. So she was twelve at the time. And my wife as well, she'd been very supportive, and sometimes she lets me deal with certain things and then she'll say, "Was that the best way to do it?" Because let's say sometimes our care partners like to give us, "This is how you need to do it." But she's been very good about saying, "You've got to deal with this, and let's see how we can make you better."

Allie Signorelli: Yeah. For me, it too, in part, came from my kids. I was being very sensitive and reactive to things that, in the past, would never have bothered me. Comments I was getting, or gentle criticisms, or even not even criticisms that I was taking deeply personally to the point where my daughter and my husband both said something to the effect of, "You seem so sensitive." And maybe not... She's 20, so maybe not quite in those gentle terms.

But for outside people to witness changes to their loved ones I think is really hard. And I think when you are depressed or struggling, those criticisms, if you take them that way, as I did, only compound the problem. And so maybe, Dr. Seritan, you could share with everybody just a little bit about, are there best

practices or are there suggestions that you can make to the care partners who are watching today to say how they can approach gently their loved ones who maybe aren't getting off the couch or taking everything personally? Is there a simple way to say to them, "I love you, but you're driving me nuts," or something to that effect?

Andreea Seritan:

That's a great question. And thank you again, Israel and Allie, for sharing your experiences, and thank you to your loved ones for being there for you in this way. I don't think there's a best way. Every person is different. The loved ones will notice changes from baseline, if you want. So like you said, maybe not being as active or busy as you used to be, Israel, or maybe being a little bit more sensitive, less equanimity for you, Allie. And for other people, it will depend on the person.

I don't think there's a good way to say, "I love you, but..." Maybe it's, "I love you, and I have noticed this thing." So try to bring some objective information into the discussion here as, "We used to go, I don't know, to the park once a month, and I noticed we haven't been in six months. Every time I invite you to go or I say let's go, you find the reason not to."

And granted, the world of people with Parkinson's disease is so complex. As you know, it's an obstacle road. It's so hard to plan things, and I know so many of patients, or all of my patients, universally, can't plan things because they're afraid they're going to be off. You go to lunch with friends, or maybe you're at work, and you're going to be off, or the tremor will show up in the middle of a conversation or a meeting.

So your loved ones knowing you so well and knowing your tolerance level are going to be like a great barometer for, "This is something new, what I'm observing," or, "Something has changed, and let's talk to your doctors." And I will encourage all the care partners to talk to the doctors. As Dr. Richard said early on, we hear a lot from the care partners and maybe not directly from the person with PD, and all of that is grist for the mill, as we say in psychiatry. All of that is something to follow up, and ask more questions, and try to see how we can best help. I hope this answers the question.

Allie Signorelli:

Yeah. No, it does, very much so. I wanted to answer one of the questions we got, which is to share a little bit about what talk therapy is. I use that term broadly. I don't actually know if that's the right term. But for me, talk therapy is that I meet with my therapist, I generally meet twice a month with her on regular days. We check in. It's been very helpful to me on many fronts well before I was diagnosed with Parkinson's.

And it is exactly, to me, what it says, which is we talk and we go through any issues that I've faced or roadblocks that I find myself up against. She explains to me why I might be experiencing those and how best to move past them. I wonder, Israel, have you ever done talk therapy? Are you of the generation, like some of us, who are resistant to it? Or have you used it successfully?

Israel Robledo: I have tried it. But for me, it wasn't successful because it wasn't impacting how I was feeling. And each therapist is different, and I'm so glad to hear that you have that positive relationship. Because I would love to have that, but it didn't work for me. And for me, we realized it was organic, more, just like people say, shake it off, or think positive, or do exercise, things like that. It didn't work for me and that's what I share with people. Try it, but if it doesn't work, then go do something else. Have that discussion with your doctor.

Allie Signorelli: It's hard to find, one, a therapist at all, that isn't completely swamped. Two, that you connect with and that is successful relationship with. And I think it does take time. Although I had a couple that I knew right away it wasn't a good fit, and then you feel like, "Oh, gosh. I have to break up with them. That makes me a terrible person." And so, maybe, Dr. Seritan, you can talk about, are there, besides you, specific people who treat Parkinson's patients specifically, or just aging patients in general? And is there an easier process to finding them than the hit or miss way that many of us just Google?

Andreea Seritan: Yeah, it's a great question Allie. And thank you so much again. I'm so glad we have both of you here with different experiences about psychotherapy, because that is the reality. The reality is that we might not find a perfect fit with a therapist right away. Actually, I've heard this once from someone else who's more experienced than me, that it takes three trials. So you have to interview three people until you actually find the right fit for you.

But it's the right fit for you. So it's a diet. You are adding one other healthcare professional to your team, right? So it is a process of trial and error, if you want, interviewing people. There are also some questions you can ask when you are, let's say, being given a list from your neurologist's office. Many of us, the neurologists keep lists, or they have someone in their office that can give you a list of therapists.

And what we do, honestly, at our center, we keep a list of people who are recommended by patients, actually. So that's the best vote of confidence. And then also we talk to them. I have to refer a lot. So just to be clear, what psychiatrists do, we are trained in psychotherapy, which is the same way of saying talk therapy. We call it psychotherapy. Multiple, multiple ways. Talk therapy is the perfect term for a lay audience. So you nailed it there, as in everything else you're doing.

So we're trained in multiple modalities. We will use those. But because we don't have the capacity for the frequent appointments that are needed, we usually refer to a cadre of other people, either in our own clinic or in the community. Always check to make sure they take the insurance that the patients have. A lot of my patients, obviously older adults, are on Medicare. But a lot of younger people with PD, they can't work. As you know, you can't work. So financial aspects are a big consideration. So we always try to make sure that the therapies are either affordable, or on a sliding scale, or take the insurance.

There's Psychologytoday.com that we use liberally. And there are a few other resources that I can send you maybe after the webinar is over, and maybe we can

attach them somehow to the recording. And I'm going to add just one other thing. With the pandemic, telehealth, so in virtual meetings like this, whereas perhaps we thought they weren't as good as in person, actually there's quite a bit of research emerging showing that they're as good as in person. I wouldn't recommend that for your neurologist. Your neurologist has to examine you and do these new PDRS scales from time to time. But for psychotherapy, for talk therapy, it might work.

Allie Signorelli:

I actually transitioned to virtual with my therapist in the pandemic and I love it because I can sit on my own couch and just chat with her. And one question that's come up a bit is about the anxiety as it relates directly to having Parkinson's and the knowledge that it's progressive and currently incurable disease, though we're working on that. And I have a theory or a therapist strategy, which is this, and I'm interested, both of doctors, and also Israel, to see what your experience has been about anxiety specific to Parkinson's. But here's my take.

I tend to not think too far in the future about what could happen to me. My layman's term for this is remaining a happy dummy, although I know that's not probably the best way to say it. But if you're doing all of the things, if you are exercising, trying to eat right, getting sleep, doing therapy, taking meds as needed, to me, it feels as though the more I worry about the future and what could happen, the more stressed I am about today. Now, compartmentalizing is very challenging for me, but I work on it daily. And I wonder, Israel, maybe we'll go with you first, do you have anxiety about having Parkinson's and what's happening to you physically as you move through it?

Israel Robledo:

Yes. But to the extent that I had it before, no. This is what I mean. I often tell people you need to come to terms with having the diagnosis that you have Parkinson's. But it doesn't mean it's the end of the world or the end of your life. Every day is going to be something that you're going to deal with. And the changes are not overnight, to be very clear. They're not overnight. So you can deal with those changes as they come about.

But at the same time, if there are some issues, as far as depression-wise, for me, what happened was it changed me. It changed me from worrying about the disease that has moved in, and it's not leaving until we find a cure for all of us, and it changed my way of thinking. So coming to terms and realizing for me to say I needed the medication and I need it. And so, I'm 18 years post-diagnosis. And the reason I'm able to continue working as a school teacher full time and staying active is because of that optimism that I was able to get as a result of being triggered from my depression.

Allie Signorelli:

That's so smart. I want to make sure I leave time for questions that are coming in. There's lots and lots and lots of them. But one thing I wanted to just touch on before we shift to those is, Dr. Richard, if you could tell us just very high level what we know and what research... I know you're heavily involved in research on this particular issue. What is the research showing us about mood changes, anxiety, depression, apathy in PD? Is there emerging research that shares hopeful paths forward with this? Do we know it? Obviously we don't know enough about it yet. But are we on the right path in terms of research?

Irene Richard:

Yeah, I think we're on the right path. I think that it is a path and it is a process, but I think that one of the first things is I started this 30 years ago and the concept of non-motor symptoms was not even a thing that I was interested in, but it wasn't a thing. But now we're coming to recognizing that it's part of it is the first step, and then trying to understand it. And once we understand it, that's helpful, just to understand that it is a thing and it is part of Parkinson's.

And I think from a research perspective, there's multiple different problems happening at all times. People are trying to understand the underlying neurological basis for it, so the chemicals, the circuits, what causes what. And then also just how does it progress, what does it relate to, and how can we better treat it. I think we've made strides on how to treat depression. I think that we are still... I'd say that anxiety, we are making strides, and apathy is a bit of the final frontier there in this triad.

I do want to interject one thing, because I think it's a really... I just think it's an important thing. It was on our... And I know that because things... This is how conversations go. We go off script every once in a while. But I want to get back to one important thing. So first of all, I can't help seeing a lot of the questions come up is how do you know if it's a reaction to the situation or if it's biology. And what I'm going to say about that is it doesn't have to be an either/or, okay? But I can guarantee you that the underlying networking in the brain, chemicals in the brain are set up, and very often even before the diagnosis.

So there's a natural reaction to getting the diagnosis. People can get... It is hardwired. People can get depression, anxiety, apathy. Having said that, obviously there is always that influence. That's why psychotherapy can even work. The things around us, what we do, how we think, how we behave, those can have an impact as well. So I don't think that it is an either/or, but I think it's very important to understand you cannot just will yourself. It's not a lack of willpower. It's not, "I'm tougher than this. I can fight it." It's not like that. If you're going to take something for your tremor, you can take something for your depression. It's all part of it.

The other point that I want to make, because I think this is very important, is we talk about apathy, anxiety, and depression in, I think what we're referring to are the symptoms and the syndromes, which are more pervasive and then maybe treated. As patients become a bit more advanced in their disease, many patients, first off, have just a steady response to their Parkinson's motor medicines, but then start to develop what we call fluctuations. I think you referred before to where the medicine may wear off before its next dose. People can get excessive involuntary movements.

What I'm going to say here is that that's a very important thing to be aware of. Because some people have extreme anxiety and a feeling of depression only during times, for example, when their medicine is wearing off, and that's treated differently. So I think that you can have both, right? And you want to treat the underlying pervasive depression, but some people don't have that. And really what it comes down to is leveling out the dopamine the same way that we're trying to do that, for example, with motor symptoms. So there are two types.

There's the more pervasive type, and then there's the episodic type that is distinctly related to fluctuations.

Allie Signorelli: So interesting. Okay. We're going to try and power through some questions because I feel like we could talk about this for days. But okay, Dr. Seritan, what other options are there besides talk therapy and pharmacological interventions for managing symptoms?

Andreea Seritan: That's a great question. So you've definitely touched upon exercise. So I would say that that's how I start the conversation with my patients. We've talked about psychotherapies, and I do want, before moving off this point, to put a plug in for mindfulness-based interventions. Mindfulness-based interventions are a little bit more emerging right now. We're still researching their efficacy for treating anxiety and depression in people with Parkinson's disease.

But I think, Allie, you said something earlier. Focusing on the future that is quite unpredictable and it may change from one day to the next is not always that helpful. But being aware in the present and being kind to ourselves. It's a manualized intervention, something you can learn, something people can learn. So more research, I would say, in the non-pharmacological approaches.

And then, a little bit at the opposite end of the spectrum, if you want, more and more biological interventions, deep brain stimulation, people usually go for deep brain stimulation for motor symptoms. It should not be for non-motor symptoms. Do they help the mood in addition to helping the motor symptoms? Yes, they can. But that's an entire discussion. We should do another entire webinar about the DDS. Yes, a separate one. And then, I don't know, maybe we'll move on to the next questions and some other ideas will come. Yeah.

Allie Signorelli: Yeah. I think this one is for Israel. You've talked about having depression and dealing with it for a long period of time. What advice do you have with people for... Are there any other techniques that you've learned or tricks that you've employed in your journey with depression that have helped you?

Israel Robledo: The best way I can describe it, and please understand, it's not medical advice of any type. I think what happened with me being long-term depression state was that, like I said, I tried counseling, therapy, everything having to do with not taking medication. But when I was taking the medication, I wasn't realizing that they weren't working, because I've often said I'm trying to will them to work.

But let me be honest with you, if you're on a medication, you will tell the difference. It's life-changing. So don't give up on making your life the best quality that it can have. So that's just my opinion. Don't hesitate. There's nothing wrong with medication. Because if it helps you deal with life, deal with Parkinson's, and have a productive life, that's what I want for everybody who has to deal with this.

Allie Signorelli: Yeah. And I'll put in a plug for this, which is that I think there is... When I was growing up, there was not a lot of acceptance or talk. Or putting it another way,

there was a lot of stigma around therapy, about antidepressants. I feel like this next generation is the complete opposite. They have embraced it, they talk openly about it. I learned from my kids and their openness to changing the stigma around mental health, whether it relates to Parkinson's or not. They've really opened the portal to not being embarrassed about it and considering it as, as both of our doctors have shared today, a true biological issue, rather than something you can will to go away.

And so, I know that it may not have completely floated up to my parents. And well, my parents are very open about it too. But I think there's still a bit of a generational stigma about therapy at the older generations that I hope will continue to change. Dr. Richard, maybe is there anything that you can, as we start to wrap up here, encouraging loved ones who are of the mindset that therapy or pharmacological interventions are not okay, or that they still harbor some concern about?

Irene Richard:

Yeah. I mean, I think that basically you just have to... I think that I'll tell people, we know that this is not, again, to make the point, this is part of an underlying illness that could be aggravated by other factors. But if you had diabetes, would you hesitate to take insulin? If you have strep throat, would you not take an antibiotic? The brain is tissue. I mean, obviously there's more to it. Our brain and mind, there's a lot of different ways in which we can impact them.

But I think that I just tell people it's literally just another symptom of Parkinson's disease, and it's another medication to treat one of those symptoms. And to be opposed to it on the basis that it's somehow taboo, I mean, certainly I do feel, and I've been doing this 30 years, so I have definitely seen the fortunate evolution, and like you said, like us being much more open to that. And I think that's becoming... Fortunately, I think people are starting to realize that this is not a thing of will. It's not going to make you a different person. Literally, if it works, it's going to take away that cloud and make it be yourself again.

Allie Signorelli:

Yeah. And I just want to put in the plug one more time for a combined approach. And my neurologist was very, very supportive and clear about this, that there's no one step that will... None of these are magic pills. If there was such a thing, we'd all be on it. That there's a combined approach to a holistic, if you will, mental health, good mental health hygiene, which could be pharmacological. And everybody has to decide that with their own care team.

But also getting yourself active, even if it's the most minor walking activity, whatever it is. There's a lot of questions. I know we're not going to get to them. But how do I motivate my partner to be more active? And that goes back to the apathy thing. But even just small steps every single day made a difference for me when I was in the throes of depression. I'm sure, Israel, you can relate to that a little bit, that sometimes it's just the most minor change in behavior or pattern of habit that helps get you out of it.

Israel Robledo:

Yes. Making strides daily, I think. I'm in total agreement. Look at the positive. And sometimes it's not easy, but know that every day is doable and we're all in it together.

Allie Signorelli: Yeah, for sure. A couple of other things I just want to put plugs in for here, if you haven't already joined the Parkinson's Progression Markers Initiative study or PPMI at the Michael J. Fox Foundation, I will tell you, I joined it when I was first diagnosed. You can either be a clinical participant or a data participant, is how I describe it for myself.

I do, I think quarterly, maybe more often, check-ins. I provide a lot of information to the study. The study is vital, vital, vital to finding a cure for Parkinson's or modifications to the disease. So if you're not already a part of it, I would suggest joining it. It's easy. There's information on The Michael J. Fox website, on all their social channels.

But also one other thing we didn't really talk about, and I think it's important to cover, is that your community makes such a difference in your mental health. And so, not all of us are fortunate to have care partners with us all the time. I'm sure my husband would love a break once in a while. But not all of us have somebody by our side every second of the day to complain to. And so, creating your own community and source of support is vital.

And again, the foundation has tons of resources available to you for that. I joined the Parkinson's Buddy Network shortly after I was diagnosed. I met tons of great people. I was able to ask questions that you can't always check in with your neurologist. They're also not on speed dial for you every five minutes. And so, there's a lot of crowdsourcing of information of sort of, "Well, is this normal? And is this okay?" And it's great to hear from fellow patients and for care partners to be able to connect with each other. So definitely suggest checking those out. And before we go, any last pieces of wisdom, advice for the group? Maybe each person could just give a little bit of wrap up.

Israel Robledo: If you don't mind, what I'd like to say. Don't give up. Don't give up.

Irene Richard: And I think just try to be aware, try to understand it, and feel free to share it, because there's definitely help for this. And honestly, if you help these things, it's going to make a huge impact in your quality of life.

Andreea Seritan: Yeah, agreed. Yeah. And thank you again for the opportunity. I would echo what everyone else has said. Information. Information from the right sources. So education is very important to have the correct information. And you made an excellent point, Allie, I was going to make about support networks. Local support groups, young onset support groups are very important. And then national and international opportunities forums like this. And hopefully we'll see some of you in person at the upcoming World Parkinson's Congress and other conferences, if we can all travel.

Allie Signorelli: Yes. Yeah. I think there's lots of different ways to view our resources for mental health wellness and mood changes for Parkinson's, whether it's pharmacological, or talk therapy, or community, or support groups. I will say the most effective thing for me was to have a plan in place before I was dealing with the symptoms of it. And I highly encourage everybody to have the conversation with your

neurologist, with your care team, with your care partner in advance of when you may, even if you're not feeling it now, so that when and if the time should come...

I'm sorry. That's my reminder to take my medicine. And when the time comes, you can easily put the resources in place. And with that, I'll just say thank you for joining us today. Thank you for being part of this community. Thank you to the Fox Foundation and all the work they do for all of us. There will be a link to the webinars. You can watch it on demand. And lots of resources available to you afterwards. And we hope to see you at a future webinar. Thanks guys. Thank you, panelists.

Andreea Seritan: Thank you. And thank you for hosting. Thank you, Allie, Israel, Dr. Richard.

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