

Dr. Karen Jaffe: Hi everyone, and thanks for joining us. I'm Dr. Karen Jaffe, a member of The Michael J. Fox Foundation Patient Council. I'm also a founder of InMotion, an amazing wellness center for people with Parkinson's Disease located in Cleveland and your moderator for today's very timely webinar. While we won't have time to discuss how world events are causing many of us to have mood changes, today we will be discussing how and why mood changes such as depression and anxiety happen in Parkinson's, how you and your loved ones can talk about these symptoms with each other and with your providers, and what treatment options are available. You can type any questions in the Q and A box near the middle of your screen. We'll get to as many as we can. And if you want the slides for download or for other helpful information, please check the resource list on your screen.

There's our list of what we're going to try to talk about. We'll see what we can get to. Go to the next slide, please. We do have a lot to discuss, so let's get started. First, let me introduce our panelists. Sebastian Krys is an 18 times Grammy award winner and CEO of Rebeleon Entertainment. He was diagnosed with Parkinson's disease in 2019. Thanks for joining us, Sebastian.

Sebastian Krys: It's good to be here.

Dr. Karen Jaffe: Thanks. Roseanne Dobkin as an associate professor of psychiatry at Robert Wood Johnson Medical School at Rutgers University. Welcome, Dr. Roseanne Dobkin.

Dr. Roseanne Dobkin: Hello. Very happy to be here as well.

Dr. Karen Jaffe: And Irene Richard is professor of neurology and psychiatry at University of Rochester's School of Medicine and Dentistry. Hi, Dr. Richard.

Dr. Irene Richard: Hello. I'm happy to be here as well.

Dr. Karen Jaffe: So when a person experiences mood changes such as anxiety and depression, a diagnosis of Parkinson's disease would not be the first thing to come to mind. Yet, for many, it is the mood changes that are the first signs of Parkinson's disease, sometimes beginning years before the classic motor symptoms such as tremor and rigidity. So Sebastian, would you mind kicking off this conversation by sharing your story and what you were dealing with up to the point of getting diagnosed?

Sebastian Krys: Yeah. I was diagnosed in March of last year and I had been experiencing depression and anxiety probably since about four or five years ago. And one of the things that didn't make sense to me is I was working on what was kind of my dream project in 2018 and was just depressed, anxious, moody, and it was just things didn't add up for me. It made no sense that I would be feeling that way while really realizing this wonderful project that I was working in. You know I have a Gaucher's disease, so I knew that Parkinson's was a possibility and I

started just looking into it. Just 'cause I saw you know, when I read up about it and I saw that depression and anxiety were part of the symptoms.

Dr. Karen Jaffe: So you, so you think you had it for four or five years before you got diagnosed with Parkinson's disease?

Sebastian Kryz: The depression and anxiety for sure. You know, I have a wife, two kids. My job is basically what my hobby was when I was a kid. You know on paper there's no reason for me to be depressed or anxious about anything. So, so that's that, that was a big red flag for me.

Dr. Karen Jaffe: Dr. Roseanne Dobkin, what percentage of people with Parkinson's develop anxiety, and or, depression, and does the incidence increase with the length of diagnosis?

Dr. Roseanne Dobkin: Those are really great questions. So statistics that you read will vary based on the type of study that was done and the setting in which it was conducted, but I would say it's completely accurate and probably a conservative estimate to say that majority, 50% or greater, of people with Parkinson's will experience symptoms of depression or anxiety that impact their day to day. Then another percentage of individuals will experience maybe milder symptoms of depression and anxiety that may be aren't there, most of the time, but nonetheless will rear their ugly head from time to time, and make life harder than it needs to be. With respect to depression and anxiety increasing over the course of the illness, I think the interesting thing to consider here is that depression and anxiety can impact people with Parkinson's really at any point.

So we do see very high levels from pre-diagnosis, as we just heard, to early mid and late stage disease, and it is really dependent on really a mix of biological factors that are implicated in the onset and maintenance of depression and anxiety, as well as an individual's coping response to the various challenges that they're facing day in and day out.

Dr. Karen Jaffe: How often do they present together depression and anxiety?

Dr. Roseanne Dobkin: They are highly co-morbid, which is the fancy term for saying they present together at very high rates. So again, I would like to say just from my own clinical experience, as well as from reviewing latest research studies, they are probably there together at least half of the time.

Dr. Karen Jaffe: Dr. Richard, we had a listener who just asked if apathy a part of this picture?

Dr. Irene Richard: Yeah, so that's a good question because apathy, meaning I guess really some people are created with a lack of motivation but really just not caring and kind of being blah. But apathy can either occur in the setting in the context of depression as one of the symptoms, but it also can occur as its own entity. So apathy in and of itself can occur in Parkinson's disease, outside of the context of

depression or anxiety, and so it's tricky, apathy when people just aren't don't seem to have motivation to do things. The patients themselves tend not to complain of it because by definition they're apathetic, they you know, they don't really care, there's not really a [inaudible 00:07:00].

But it's usually to be honest with you, it's a care partner who he or she just doesn't really want to do anything, doesn't seem to get over the hump, "But I just want to get them to do something. I think they'd feel better if they did". So, those cases, we try to delve a little bit deeper and we try to find out is there actually a negative mood? In other words, when I say balance, kind of just direction, so for example, when I asked the patient to themselves, "Do you feel bad?", in other words, "Do you feel emotionally, either down or distant"?, you know something negative. That's actually one of the key distinctions I think, as opposed to "No, I'm fine. I just don't really feel like doing anything."

There are ways to approach both, but what I would say is that it's because we do not have a specific treatment for apathy, I mean, there are certain behavioral modifications and some things being studied. Whereas, as we'll get to later, we do have specific treatments for depression. I think when apathy comes up, it's important to do a full screening for depression just to make sure it's actually not what you're dealing with since that is easy to treat.

Dr. Karen Jaffe:

Okay. So let's look at, just like Parkinson's symptoms, mood symptoms show up in different ways for different people. Dr. Roseanne Dobkin looking at this next slide, we can see that there's some crossover, depression and anxiety can look alike, but while our audience takes it in this slide, let me ask you as a clinician who has practiced, focuses on the mental health of people with Parkinson's disease. Can you please elaborate on what it is about Parkinson's disease that brings on depression or anxiety above and beyond what we see with other serious conditions?

Dr. Roseanne Dobkin:

That's a great question, and there are multiple factors that are involved in both sort of the onset and maintenance of depression and anxiety in Parkinson's. First and foremost, we know that there are a lot of biological and neurochemical changes that result from the disease process that characterizes Parkinson's. So we see changes in sort of the amount and the availability of the feel good chemicals called neurotransmitters, that are available in the brain. We also see changes, or traffic jams, or interruptions across some of the highways that connects different areas of the brain, as well as, some decreased activity in certain brain regions that are related to mood. But in addition to those biological and neurochemical changes, there are also behavioral factors and cognitive factors that are implicated in mood.

So what do I mean by that? So when I say behavioral factors, what a person is doing, or not doing in response to the various and very real challenges that they're experiencing, day in and day out. Does an individual have kind of enough exposure to the people, places and things that provide them with a sense of satisfaction or reward or meaning or productivity in their day to day. Parkinson's

can really change the landscape of the day, and we really have to think creatively, think outside of the box, sometimes build a better box to figure out, how we really can expose ourselves to that those life experiences that are going to enable us to feel good about ourselves.

So as an individual, exercising. Are they engaged in meaningful social connections? Do they have hobbies or leisure activities that enable them to feel good about themselves? So we really need to look kind of behaviorally at what an individual doing, as well as consider how they're thinking about themselves and their world and their future. What Parkinson's may mean or not mean for them and ability to cope with the changes and difficulties that they're going to be experiencing from time to time. So really depression and anxiety are multifactorial, the biology sets the stage, but how an individual reacts and copes with the changes and the challenges that Parkinson's presents also plays a really important role. So, learning coping skills to best manage stress and negative feelings, as well as becoming aware of how we're talking to ourselves. What are the messages that we're giving to ourselves? Are we speaking to ourselves with the same kind, gentle, compassionate tone that we would speak to a dear friend, or are we being overly critical and harsh towards ourselves? Oftentimes those self-critical messages play a very important role in maintaining these negative mood states.

Dr. Karen Jaffe: Sebastian, if you look at this laundry list. What were some of the things that you were experiencing and has this list changed over time for you?

Sebastian Kryz: I mean, the sleep problems are definitely an issue, the irritability. I worry all the time, just mood swings, and just feeling really down. I mean for me, it really helps to exercise, I don't take a day off, I exercise seven days a week, and like this morning I did not want to, I just forced myself to do it. I look at it as part of my treatment just like the medicine I have to take every day, that's part of the medicine.

Dr. Karen Jaffe: Were you an exerciser before you had Parkinson's?

Sebastian Kryz: I was, but it had a different meaning to me. Now I, again, I just looked at it as, as medicine, I just have to be regimented about it. I don't give myself the option. So that's a big part of it. I think one of the things is, for me, is to be able to... I'm also taking medicine for the depression and I go to therapy. So I really, I feel like I, I have to attack this from all sides, and to really talk about it with my family and for people to understand that this is a real aspect of it. And to be honest with you, when I got diagnosed, it was kind of a relief to understand that, okay, my depression's coming from this disease and not something else. To have that question answered was really a weight off of my shoulders, and I was able to look at it in a different way.

Dr. Karen Jaffe: That's an important thing to remember as we go through and talk about this, because a lot of people, for some people talking about what was going on is easier said than done, it's hard to do it. It's so important that we do talk about

mood changes that we're experiencing, because this is not about pulling yourself up by the bootstraps. Depression and anxiety are medical conditions, just like diabetes or heart disease. But unlike diabetes and heart disease, the stigma that still hangs over a mental health diagnosis, those have the ability keep some people from asking for help.

Dr. Richard, do you find that most Parkinson's clients will address these issues of depression, anxiety directly with you, or is it more likely that a care partner will be the one to initiate conversations?

Dr. Irene Richard: I mean, that's very, everything you just said is all very important, very relevant.

So if I will, first just to kind of agree with you, I think it's so important for people to understand that depression, regardless of whether you have Parkinson's disease or not, depression is an illness just as any other illnesses, and I think that just as diabetes is. And in this case, depression is an actual symptom of Parkinson's disease that can occur years before, that can occur at the onset, that can occur during, and just like term or just like anything else. So, and I think that there is a misconception about that actually, there's a widely held misconception about depression, that in some way

Dr. Irene Richard: ... section about depression, that in some way, it's the same as sadness, or that someone actually has the ability to, like you just said, pull yourself up by the bootstraps. Sometimes I ask people, "Well ... " If I start the inquiry and say, "Are you depressed?" "Oh, no, I'm a very positive thinker." You know what I mean? In other words, as if they're ... which is a good thing to be a positive thinker, mind you, as Dr. [Dobkin 00:16:29] will talk. That is an important factor, but the converse of that is that if somebody does have depression, they feel as though somehow they're letting it get to them and they're not taking a positive enough attitude and somehow they caused this.

I think it's just so important to understand that while you can work on changing the ways in which ... cognitive therapy, behavioral therapy, the ways in which you think about things, it's really important first to just understand that there ... I have patients who are far more affected physically and far more disabled who are not depressed than patients who have almost no symptoms, or in some cases, haven't even developed physical symptoms yet and have depression.

It is definitely something that people do not ... It is not a reflection of one's, certainly not one's moral character, but [inaudible 00:17:35] one's desire to combat something or not. That was the first thing I would say, just because I think that's so important. I do think there still is a stigma. I think, fortunately, although it's, like many other things in our society, is slow to change in the positive direction, I think it is, what I would say is that it really depends upon the individual and their partner. I think sometimes the individual will bring it up. Sometimes the partner will. Sometimes neither will. Very often, particularly when the clinician is a neurology practice anyway, and I guess we should specify that Dr. Roseanne Dobkin is a psychologist and I'm a neurologist, which we both

do research, just slightly different in the sense that maybe what the focus of what we do is. I don't know about the time given. I know that certain ... In our case, we're being asked to do more and more in less and less time. People sometimes will skip over that.

I think that, I would say that in general, depression is under-recognized and because of that, it's undertreated. I think that it is important, as you say, for the patients and their loved ones to bring it up if their clinician does not bring it up, just as when I talk to clinicians, I say it's a very important part of a screening question to ask, "Are there symptoms of depression or anxiety?" Because they can be treated and because they have a huge impact on everything else. Again, it really varies, but the more we can educate people and the more that we can get people to try to forget that stigma, try to understand that it's an actual symptom, and then to try to feel free to talk about it, the more we can do that, the better.

Dr. Karen Jaffe: It's too bad that Parkinson's in itself has a stigma. We've got a double whammy here. Sebastian, I'm curious how your relationship with your spouse and your children ... do they, when you're having a bad day, do they just say, "Oh, this is Parkinson's," or do they say ... Do you mind them bringing it up or do you mind them asking you to talk about it at all or how you're feeling, meaning would you rather be left to your own devices to try to fix it, or is it helpful to have your care partner and your family participate in this part of your Parkinson's disease?

Sebastian Kryz: I let my spouse know, "I'm feeling down today," just to let them understand that there's not anything particular that they have to worry about or be concerned about, just know that I'm having an off day. It just helps me to not have to have them feel like they need to treat me any differently or whatnot.

Dr. Karen Jaffe: Right.

Sebastian Kryz: It's more just like, "Hey-"

Dr. Karen Jaffe: It's important.

Sebastian Kryz: Yeah, "Today's an off day, no particular reason."

Dr. Karen Jaffe: Right.

Sebastian Kryz: I also found that there are things that trigger the depression that are very trivial. I walk it back and try to figure out why I'm having a bad day, if it was something specific that triggered it. The smallest thing can just make me just go down a rabbit hole. Once I'm able to trace it back it helps me get out of it, but I do talk to them about it and I do talk to even my clients about it. I work in music, so what the mood is while you're making music is important, and I bring it up. I mean, it's just part of it, I think. I think that bringing it up helps everybody understand everything differently. Even if it's a little bit uncomfortable for

people in the beginning, I think that for me, I can't speak for anybody else, but for me it just helps me have things out in the open.

Dr. Karen Jaffe: Dr. Roseanne Dobkin, we have a question coming from the audience. They want to know, as a husband and caretaker, how should we help with mood swings?

Dr. Roseanne Dobkin: Another-

Dr. Karen Jaffe: [crosstalk 00:22:40] question, how would you suggest that the care partner participate in this whole issue of anxiety, depression, mood disorders?

Dr. Irene Richard: Can I-

Dr. Roseanne Dobkin: [crosstalk 00:22:51] Dr. Richard.

Dr. Irene Richard: I feel like this might be, and I apologize for changing the order, but I wanted to mention something that I think might set the stage and also is an important distinction, even prior to Dr. Roseanne Dobkin answering that question, just to say that when we talk about swings, there's depressive disorders and anxiety disorders, meaning you can have depression that is present maybe every day for a period of time. It might be mild. It might be more severe. You may have some days that are better than others or some parts of some days that are better than others. Same thing with anxiety, but in most folks we consider it more of a disorder. I think the one important thing I just want to point out is that there's another phenomenon that is unique to people who have slightly more advanced disease and who are taking medications, generally they're taking Carbidopa/Levodopa or Sinemet, and they have what we refer to as fluctuations.

We usually think of those as motor fluctuations, meaning in the beginning their Levodopa it works nice and evenly and mimics how our brain would normally release it, so things are nice and steady, with regard to our motor functioning anyway. Over time, however, because there are fewer dopamine neurons and because of changes that happen, you start to get swings in the levels of dopamine and people's motor function therefore starts to dramatically change throughout the day. It may start off as just, let's say you wear off, meaning your symptoms of Parkinson's disease, [inaudible 00:08:40], tremor or whatever, start to reemerge before you're ready for your next dose.

The other component of that is that in the beginning, you may not get ... The amount of Sinemet that you take works just right. You feel fine, but over time you become more susceptible to getting extra movements and we call those dyskinesias. Over time, these can be so dramatic that patients can be rendered immobile, literally within five minutes of looking normal, or looking normal but having extra movements. What's important to realize is that there are also non motor fluctuations, which not always, but often parallel the motor fluctuations, but are not a response to them. For example, anxiety and decreased mood are

very common when people's medicine is wearing off, so during off periods. Studies have been done that show it's not just that you are anxious or depressed because your symptoms re-emerged, because the symptoms of anxiety and depression actually start about 5 to 10 minutes before the motor symptoms do.

In this case, it really is mood swings, but in particular, we refer to them as fluctuations. The reason why that's important is if that's what's going on, you first want to, first of all, identify it as such and you want to first try to level out the dopamine and fix those motor fluctuations to see if that will also fix the mood and anxiety fluctuations. Both can exist. I just thought that that was important because I know there are certainly swings and good days and bad days and provocations, even within a more chronic kind of anxiety and depressive disorder, but Parkinson's disease is probably the only disease in which there is this other unique phenomenon called motor and mood fluctuations associated with advancing disease and medications.

Dr. Karen Jaffe: I would like to just jump in there and say probably the best way to manage this is to just have a discussion with the neurologist regarding when is it happening and in what context is it happening.

Dr. Irene Richard: Yes, absolutely. That's exactly what happened. I am a neurologist, and when my patient tells me ... Oftentimes a resident will see the patient first and they'll say, "Well, they're anxious." I'll say to them, "Well, what time of the day does that happen? How does that happen in relation to the timing of their Sinemet dosage?" I have them map it out in a diary. Sometimes it's as simple as changing their dopamine ... their medication regimen, and we can smooth that out, or we can at least get rid of that component and then see if there is still an underlying, more chronic anxiety or depressive disorder.

Dr. Karen Jaffe: Dr. Roseanne Dobkin, I'm going to hang that one up for right now. We'll come back to it if we need to, but I'd like to move into this next slide, because there's a lot on here that I want us all to talk about. This slide outlines, let's see ... No, I want this one. This slide outlines the many therapeutic interventions, both pharmacologic as well as nonpharmacologic. Dr. Richard, I'm getting a lot of questions in the queue regarding medications. Let me start with you. What are the best medications for anxiety and depression with Parkinson's disease and which antidepressants ease depression without worsening movement symptoms?

Dr. Irene Richard: Right. Great question. Basically, the one thing about ... Although depression and anxiety are frequently coexistent, depression and the treatment for depression has been better studied. Anxiety is about maybe 10 years behind. What I will say about depression is that we know, based on the SAD-PD study is one of them, that was done a number of years ago, published in 2012, which showed that frequently used antidepressants, the serotonergic specific ones, we call them SSRIs, as well as ones that affect both serotonin and norepinephrine, SNRIs, what we looked at was we happened to pick Paxil or paroxetine as our SSRI and



Effexor or venlafaxine as the SNRI. It was proven that each of those medications was more effective than placebo on every single measure of depression, self rated, objective rated, every single measure.

It was actually a pretty clear cut study. That was despite a very high placebo response. That's kind of a technicality, but suffice it to say, SSRIs, so again, medications, like in this case, the only one we can say for sure is paroxetine because ... There may be some conflicting results just because that was chosen, but in all likelihood, I think one could surmise that other medications of that class might also be affected and it's reasonable to look at the side effect profile. Other medications would include, for example, sertraline, which is Zoloft, or fluoxetine, which is Prozac, Celexa, although one must be careful in people over the age of 60 with regards to any higher dosage, because of some potential cardiac effects, but anyway, all of those, so what's used in the general population who doesn't have Parkinson's disease, and then the SNRIs, I would say the one to use would be venlafaxine or Effexor.

What I would say is that, in general, most people will start with one or the other. I tend to start, myself, with ... I would tend to start with an SSRI like Paxil, and then if, despite optimizing the dosage of that, it doesn't work, I will then move to an SNRI, which would be venlafaxine or Effexor. Now, there are older medications though, called the tricyclic antidepressants, such as nortriptyline, which is definitely effective, but because it's associated with really less tolerability, a little bit more in the way of side effects, as well as a higher potential to cause some heart arrhythmias, that's generally not first or second line treatment. The other possibility would be something like bupropion or Wellbutrin. Having said that, it has not been specifically studied for depression and Parkinson's disease so we don't really know about it.

Dr. Irene Richard:

Having said that we do try it. As the last thing I'd say would be Pramipexole, which actually is a medication called the dopamine agonist, which is part of the cache or arsenal, I guess, if you want to call it, part of the choices of medications used to treat motor symptoms. Now, it just so happens that that does have some antidepressant effect. Probably not as much, but if you have somebody and you want to try to get a two for one, let's say, or let's say they are somebody who has these fluctuations, you could consider a Pramipexole or Miripex. Again, being aware that there are specific side effects associated with that.

Anxiety, on the other hand, while you'll often hear that the SSRS and SNRIs are effective for anxiety as well, well, that's true in the non-Parkinson's population, again, not for everybody by the way, but you know, two thirds of people generally respond. There are about a third of people who may not respond to the first or second trial, but as it turns out, nobody has studied that. And it just so happens that in that said PD study, I referred to while all of the depression measures improved, the anxiety measures did not. Now I must preface this by saying that those were individuals who did not have significant anxiety. So for

example, they were chosen because they had depression without a separate anxiety disorder. So, but nonetheless, they didn't improve.

So we recently looked at a medication that is widely prescribed by psychiatrists and primary care doctors and the general population called buspirone, or Buspar, which is an anti-anxiety medication. We did a small pilot study that was funded by the Michael J. Fox Foundation because we thought this has a potential to help anxiety, possibly even help dyskinesia, but could worsen motor function.

And we have not yet published it, although we had our abstract accepted and what I would say about that was very interesting that it turns out that it really, it was not as well tolerated as we had hoped. And that in fact, did cause some worsening of motor function at relatively low dosages for more people than we would have expected, which was totally reversible as soon as they stopped it. But other people were able to tolerate it. And interestingly, the people who finished the study on it, there was a signal showing that it did help the anxiety. The other caveat to this is that there were, it was, I thought it was very interesting that 85% of the people who enrolled in our study were already on one of those SSRIs or SNRIs, which has two implications. One of them is maybe buspirone from would've been better tolerated if they weren't on that.

But the other implication I thought was, wow, here's all these people who are on the medications that everybody thinks helps anxiety and Parkinson's, and yet they're still qualifying for our anxiety study. So I don't think we know what's a good medication to treat anxiety and Parkinson's disease yet. Commonly prescribed are medications called benzodiazepines. Those are things like Xanax and Valium and everything. And for sure they do help anxiety, but they have their own issues, obviously, particularly as people get older, but you can develop a tolerance to them where you have to increase dosages, they can affect balance. They can affect thinking, so while good in the short term or perhaps for other reasons, they're not really the best answer.

Having said all of that, do I still try an SSRI or SNRI? Yes, I do. Actually. And I start low because sometimes anxiety gets worse before it gets better. And I sometimes add a small benzodiazepine dose while I'm starting it. But by this point I've usually referred somebody to a psychiatrist.

Dr. Karen Jaffe:

Okay. This a lot of great information. And I think it answers a lot of the questions that were in the queue. So Dr. Dobkin, I'm going to turn to you now, we've got a whole long list there under prescription medications of things that patients can try to improve their mood function. What do you find that works well?

Dr. Roseanne Dobkin:

I think that it's really important to emphasize that in addition to all of the prescription medications that Dr. Richard so nicely just reviewed, there are a lot of non-medication approaches that people can also use either in self-help format or ideally in collaboration with a licensed clinical psychologist or social

worker to help them to boost their mood. So I practice and I have also extensively studied a type of psychotherapy called cognitive behavioral therapy for the treatment of depression and anxiety and Parkinson's disease. And I know that sounds like a mouthful. So I want to try to break it down a little bit so that people can walk away from this presentation with a nice understanding of some things they can start to implement in their lives, from one o'clock today, onward, to help them cope, as effectively as possible with, with mood changes and mood swings.

So when we say cognitive behavioral therapy, what we're really talking about is really drilling down on our thought process, as well as what we're doing and not doing in response to the challenges that we're facing. So when I work with individuals, I always like to first examine what is the behavioral repertoire of the day. And a lot of times my clients will tease me and they're like, "Oh, Dr. Dopkin, you're so mean," cause I always say, okay, I've got three basic rules of engagement here. If we're going to focus on three things to help to enhance your mood, these are my basic requirements. I think it's incredibly important for people to exercise every day. It doesn't have to be running a marathon or doing anything that is unsafe or overly strenuous, but a slow walk around the block, yoga, seated exercises, a Parkinson's dance class or a boxing class, whatever you can safely do. Every day I like to see some type of the physical exercise as part of the schedule.

Every day, I also like to see some type of social connection with other individuals who you actually like interacting with as part of the daily repertoire as well. When I say social connection, I don't mean making plans to go to the opera or hosting a dinner party for the entire neighborhood. It can be the small changes that we make day in and day out that can be incredibly powerful and incredibly meaningful. So answering the phone when it rings, rather than letting it go to voicemail, or responding to your emails and your text messages the day they come in rather than a week later, or possibly never. So trying to find small, but reasonable ways to connect and to stay in touch, touch with the people that are important to you.

And then also setting a goal every day around an area I touched briefly upon earlier, activities that are associated with meaning and reward and pleasure and satisfaction. Is there a certain type of music that you like to listen to and can you set aside 20 minutes a day to listen to that type of music? Or a certain book that you might enjoy reading or listen to an audio book format. Can you find pleasure in mindfully sipping your more cup of coffee, your tea, outside in your garden each day? So I suggest to people every day from a behavioral perspective, can we have an exercise goal? Can we have a social goal? And can we make sure there's something else we're working towards, that's going to enable us to feel good to find or derive meaning from the day or to experience a sense of pleasure? Often times people can also benefit from learning meditation techniques or relaxation skills.

So techniques such as deep breathing or visualization or learning different types of muscle relaxation exercises that maybe they can practice, ideally 10 or 15 minutes at a time, twice a day can be incredibly helpful. So behaviorally, those would be the top, I guess, four things I would recommend regarding mood: exercise, social connection, proactively scheduling your involvement each day in meaningful and pleasurable activities just like you would schedule your doctor's appointments. And then also maybe experimenting with some breathing, some muscle relaxation and meditation techniques. So that's the behavioral piece.

And then there's the cognitive piece. It's so important for people to be aware. As I mentioned earlier of that internal dialogue, what are they saying to themselves? How are they interpreting what's happening in their world day in and day out? It may be Parkinson's related or related to some other aspect of their life, but what's the meaning, what's the interpretation? And how can we maybe press pause on some of those really negative things that we may think or say to ourselves and then maybe examine that thought or that statement a little bit more closely and then rewind it and replay it in a healthier, more balanced direction.

And I want to just quickly share an example of this cognitive reframing that I just described that I hope will really drive the message home. So I share this example with permission from a client of mine, Bill, who I worked with probably 15 years ago at this point. And Bill had later stage Parkinson's and we were working together. He was experiencing a lot of mood and motor fluctuations like Dr. Richard had spoken about earlier as well as a lot of freezing.

So Bill came into my office one morning and he was looking very depressed and very demoralized. And we were talking about what triggered that low mood that he was experiencing. And he said, "Well, you know, Dr. Dobkin last night, you know, per usual, you know, I got up at three o'clock in the morning and you know, I went into the bathroom as I always do every night. And I was washing my hands and about ready to go back to the bedroom and I was frozen. I couldn't move my feet. And I recognized in that moment, how helpless I was."

And so he was labeling himself as helpless for being frozen in the bathroom in the middle of the night. And we spent an hour talking about this and breaking it down. And what Bill revealed to me in the context of that conversation then was that he actually took many, many steps to get himself out of that situation, even though he physically could not move his feet. So he was aware that the freezing was a really big problem for him. And this again is going back 15 years before we were all so addicted to our cell phones and our technology in the way that we are today, but he was forward thinking, he had his cell phone with him.

So even though he physically couldn't move his feet, he had his phone and he called his wife on the house phone, woke her up and asked her to come into the bathroom and to help him back to bed. And when she got up and went into the bathroom, she helped him to practice his PT techniques to break the freeze and he was able to move. So as we talk through the situation, Bill was able to

recognize that even though he specifically unable to move his feet in that situation, he was anything but helpless. So that's an example of the type of reframing that can be critically important and empowering for people to utilize in order to enhance their mood. All of these thoughts constantly are flooding through our minds. We don't have to accept them as the absolute truth just because they're there.

It can oftentimes be very important to take a step back and ask ourselves, "Huh? Might there be another way, think about this situation? Am I considering all of them, the pieces of evidence, all of the facts that are involved in this situation? And if I widen the lens and think about it more deeply, or think about it from an alternative perspective, maybe I can change a revise or reframe my thought. And if I change my thought, maybe that will also help to enhance my mood."

So in terms of nonpharmacological approaches, again, just to review cognitive behavioral therapy, he really incorporates a lot of these behaviors, changes and behavior modifications. Like I just mentioned; exercise, social connection, meditation, relaxation, pleasant activity, scheduling, writing out a daily schedule, having some structure and routine and really looking more closely okay. At our thoughts and not accepting all of those negative detrimental thoughts at face value, without trying to think about them a little bit more closely and reframe them as possible.

And this is a type of nonpharmacological treatment that I've actually studied a fair amount with respect to its impact on mental health, in people with Parkinson's disease. To date, I've done three large randomized studies where we've looked at the impact of this type of nonpharmacological treatment compared to just treatment as usual in the Parkinson's community, whatever was being prescribed by the personal health care team for the treatment of depression and anxiety. And we look to see how do people who receive cognitive behavioral therapy, how do they do in the short term and in the long run when they receive the CBT plus treatment as usual compared to those who just receive treatment as usual without the skill based psychotherapeutic approach. And what we found is that when people learn how to make behavior changes, learn how to respond differently to negative mood, learn how to talk back to their negative thoughts. We see really sharp reductions in depression and anxiety, as well as improvements in quality of life and physical functioning. And those effects tend to last even after the therapy stops.

Dr. Karen Jaffe:

So I think that in Parkinson's, when people get diagnosed with Parkinson's disease, they're often just told to "Take your medication and come back." I think that it's a very isolating disease for a lot of people. As a physician, getting diagnosed with Parkinson's disease at a young age, it became very clear to me pretty quickly that the services that people need for Parkinson's disease haven't really been developed across the board like they have for cancer patients, where there's a team of people waiting to take a cancer diagnosis patient right along the way and stay with them.

In Parkinson's, I don't believe that we've developed that yet, but as a physician, I recognized that that was missing, and so, as I mentioned earlier in my introduction, I'm a founder of InMotion, which is a wellness center for Parkinson's patients that has a lot of things under one roof. Not only is there physical activity there, but there's support groups that are run by licensed social workers, and there's art therapy and music therapy and singing and exercise. It's amazing how many people ... As a physician, I had a lot of people say, "Thank you. You helped save my life." But when I walk into InMotion, it's a constant "Thank you. Thank you," because people have been isolated for so long and they've had anxiety and depression that they couldn't get on top of, but just having the social interactions with other people with Parkinson's who understand what they're going through I think has also been a big help in helping our clients deal with the anxiety and depression.

Dr. Irene Richard: And it also helps, I might add to be honest with you, in treating Parkinson's disease to have a multidisciplinary care team, even I mean under one roof would be fantastic. Even if you can't though, that utilization of all of those resources including allied health professionals like meaning OTPT, the speech and swallowing as well as social workers and therapists, to have all those people communicating with each other as well as with the primary care doctor, I think is incredibly important, because some things that, if one person does something and another doesn't know, it can impact. So for example, I guess just to add that the concept of multidisciplinary care for all those reasons, I think is really important.

And just before I forget, one other thing that I wanted to say, because I know that one of the questions was asked in which antidepressants don't worsen the Parkinson motor symptoms. I did want to say that what I've been seeing is that a lot of primary care doctors and psychiatrists are using what we typically call antipsychotics, albeit atypical antipsychotics, for the treatment of anxiety and depression and for help with sleep, and they do help actually. And these would be medications such as aripiprazole or Abilify, for example. Things like that.

Now I have a biased perspective because obviously I see people who come in with Parkinsonian symptoms, but I can tell you that those medications cause Parkinsonism. And if they cause Parkinsonism in some people who don't have Parkinson's disease, they will likely worsen Parkinsonian motor function in anybody who does have Parkinson's disease. And very interestingly, as are our guest ... Sorry, I'm blanking on your name, but our EEO Grammy winner-

Dr. Karen Jaffe: It's Sebastian.

Dr. Irene Richard: Sebastian, sorry, sorry, had mentioned that he developed anxiety and depression prior to the onset. That's not uncommon. And one thing we saw is that patients without any motor symptoms, who developed depression or anxiety, were given a medication such as Abilify, develop Parkinsonism, and we ended up doing advanced studies like CAT scans. And in some of the cases,

actually, these patients did indeed have Parkinson's disease that likely came out earlier than it might have, being precipitated by these medications.

Some people ended up not having Parkinson's disease, but had what we would call drug-induced Parkinsonism caused by these medications. So I do think it's very important, because I do see this a lot where patients were being treated for anxiety and depression, with what we call quote, atypical antipsychotics, not for psychosis, and it definitely worsens Parkinson's. So just to put that out there.

Dr. Karen Jaffe: Sebastian, did you have any problems trying to find a medication that was effective for your anxiety and depression? Have you had to bounce around from medications that are ...

Sebastian Kryz: Yeah. No, I did, because I worked in music and when I first ... Before I knew I had Parkinson's, I started taking medication, and it made me just feel nothing, and that's very bad for if you're trying to make music, if you're just ... You know, I felt fine, but everything was fine, and it just creatively kind of stunted me. So I went off the medication, and what I found that worked for me was actually the Mirapex. It didn't actually for me with the motor part of it, but it works for me as far as the depression goes and the anxiety. So that's what I've been taking, because it's a fine line for me to be able to do my job. I kind of have to be able to really access emotionally, be emotionally available for the work that I do and not have anything muted. And the Mirapex was the one thing that I found kind of did that for me. So yeah, it wasn't right away that I was able to find something that works.

Dr. Karen Jaffe: And I think, as a physician, we know that not all medication is going to work for every person, so there has to be some patience in terms of waiting to see whether something is going to have an effect or not. But if it's not working, then it's probably time to talk to your physician and see whether they can make an improvement on what that drug regimen is. Going to move to the last block here-

Dr. Irene Richard: Yeah, that's how-

Dr. Karen Jaffe: ... which is talking about research. Maybe Dr. Roseanne Dobkin can start by talking about some of the research that she's done. I think in terms of using technology to deliver care, especially in this day and age when people can't leave their houses very easily. What are we doing to improve on Parkinson's care in that genre?

Dr. Irene Richard: Really important topic. I mentioned a few moments ago that I've done three, randomized control studies looking at the effects of cognitive behavioral therapy for the treatment of depression in Parkinson's disease. The first of those studies was traditional brick-and-mortar, "Come into the clinic in order to participate in this research program." The last two studies that were recently completed in the past year involved administering the cognitive behavioral

therapy on a telemedicine platform. So in one of the studies that was generously funded by the Fox Foundation, we administered the CBT treatment by telephone directly into people's homes. And in the second study, we administered the treatment via web-based video conferencing.

So both studies use the telemedicine platform to bring treatment directly to people's homes to really bypass access barriers to care. And in both of those studies, I think the really exciting and promising result is that not only was the treatment helpful administered remotely, but the magnitude of improvement was identical, like almost down to the 100th decimal point place, in terms of the benefit that we saw with respect to reduction in depression and anxiety. So nothing was lost in terms of effectiveness when we administered the psychotherapy via phone or via web-based, live-video conferencing, but so much was gained, because we could cast a much wider net, and we could offer treatment to individuals who otherwise would have been unable to access it if they had to travel to a clinic on a weekly basis and sit face-to-face in the same room with a counselor. And I think telemedicine is being used-

Dr. Karen Jaffe: Particularly when somebody trains.

Dr. Irene Richard: Yes, just [crosstalk 00:57:35].

Dr. Karen Jaffe: ... that very few people are trained as well as Dr. Roseanne Dobkin in the cognitive behavioral therapy for Parkinson's. It's pretty specific, and so, it's important and a very specific kind of, rather than supportive therapy, so just to add that.

Dr. Irene Richard: Yes, exactly. No, it's very structured. It's very skills based. And of course we are supportive, and we listen and we help people process their thoughts and feelings in addition to working on coping skills to address them. So I don't want to make it sound like people are signing up to take a class. It is a very interpersonal exchange. But that being said, I think in order to be effective in one's role as a counselor with individuals with Parkinson's, it's so important to be knowledgeable about Parkinson's and about the symptoms and the medications used to treat it, and the on/off fluctuations that may be physical or cognitive or emotional or all three.

I think telemedicine also offers promise, not just in terms of making specialized treatments more accessible, but it can also allow a pool of highly-specialized providers to reach the masses who otherwise might not be able to receive services. So I think recent research has shown that telemedicine is not second best. It's just as good, and then sometimes it might be better for the Parkinson's community to receive services via telemedicine, because it will allow them to access specialists and specialized care that they otherwise would not be able to be connected with.



Dr. Karen Jaffe:

Well, look at this. It looks like our time is up. I want to thank you again for being a part of our community and for joining us today, and thanks to our panelists for sharing your time and expertise on this very important topic. For those that view who do experience mood changes, this serves as an important reminder that in spite of what Parkinson's deals us, there is plenty that we can do to positively impact our overall quality of life. We'll be sending a link to the webinar on demand to listen again or share it as you'd like. We hope you found it helpful. Please mark your calendar for our next webinar, July 16th, and in the meantime, stay home, stay safe, stay connected. This is Dr. Karen Jaffe signing off. Good day.