



Live Well Today Webinar Series:
Managing Mood and Anxiety in Parkinson's
Recorded on July 20, 2021
Davis Phinney Foundation

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

We are going to be talking about mood managing mood and anxiety and Parkinson's, and I'm going to tell you a little bit more about Roseanne read her bio you can also get information from her on our website because Rosanne is actually part of our science advisory board, and we are busy right now because we are in the midst of reviewing applications for this grant round so it's a busy time here. Roseanne Dobkin is a licensed psychologist with a well-established clinical research program in Parkinson's mental health. The overarching goal of her research program is to help people with Parkinson's and their family members cope as effectively as possible with various challenges in order to enhance overall physical and emotional health and quality of life.

Her research and clinical work over the past 15 years is focused on the development and testing of non-pharmacological management approaches for the cognitive and psychiatric complications of Parkinson's, such as depression and anxiety. She has also systematically explored the interactions between physical and mental health and Parkinson's and the impact of their intricate associations on quality of life and functional disability.

Moreover, she has begun to systematically examine barriers to mental health care utilization and Parkinson's the use of telemedicine, you may have seen her on our webinar earlier this year that we did on telemedicine to leverage access to specialized mental healthcare and Parkinson's and the impact of successful depression treatment on key outcomes such as cognition, physical disability, quality of life, and caregiver health.

So we have so much to talk about today, we're going to get right into it.

First, I want to just talk about mood in general. So, what do people mean when they talk about mood? And what's the difference between sort of that general comment of being in a bad mood versus having a mood disorder?

Roseanne Dobkin, PhD (Licensed Psychologist, Member of Davis Phinney Foundation Science Advisory Board):

Oh. So, great question and this is a topic that I am so, you know incredibly passionate about, so I just have to say once again that I'm thrilled to be here today and I see the number of participants rising on the screen and all the comments you know coming

into the chat box from people all over the country so that's just so exciting for me. But so going back to the question about mood. So when we say mood, mood is a very catch all phrase it's a very complex term.

So mood can encompass things like our emotions. So how we're feeling, if we're feeling sad, if we're feeling lonely. You know if we're feeling demoralized or anxious or angry, mood can also really encompass sort of our behaviors, because we may act in a certain way, that's in accordance with our emotions.

So if we are withdrawn, if we are avoiding you know people, places, and things that can be reflective of the type of mood right if we kind of just don't have that zest and that enthusiasm, you know, to go to the football game that we used to love to go to or to play with our grandkids, you know, or to return a phone call to a close friend. That's part of our mood and our mood also can speak to our thoughts, you know how we're thinking about things and the meaning and the interpretation, the value that we're finding, day in and day out. So mood is is pretty complicated and it can really encompass emotions, it can encompass our behaviors, what we're doing and not doing, as well as you know how we're thinking about things, and you know nobody has a mood that's a flatline.

We all experience a range of emotions all the time. And that means we are living breathing feeling sensing human beings and we want to feel emotions. So, if we experience a loss, you know, for example, if a loved one were to pass away, it's expected to feel sad and to feel down for a period of time, we certainly don't want to, you know, pathologize normal emotions but it's when these negative emotions persist, when they are above and beyond what might be reasonably expected given the life circumstances that somebody is facing, when these feelings begin to get in our way, slow us down make life harder when they cause us tremendous distress, that's when it becomes a much bigger problem.

Melani Dizon:

Oh goodness I did it, I did the mute thing, okay so you mentioned the reasonable expectation, like the reasonable level that a mood persists let's say it's deep sadness or depression, maybe you know you might categorize it as situational, right, you just got diagnosed. Here's the question I have that a lot of people ask, so they noticed depression, like in hindsight right they look back and they say oh I had that for a long time that's often a pre-motor sign of Parkinson's. But like what is now they look at it and they say what is a reasonable expectation of being in this place after diagnosis right I mean, when does it get to be not working for you anymore and you say wow, I need some real professional help. Or is part is it expected with Parkinson's to have a sort of low level of, you know, depression and sadness?

Roseanne Dobkin:

So, that's a really important question I think actually a couple of different questions that maybe are embedded in that first question so let me try to break it down a bit and if I leave an important piece out, you know, remind me that I left that important piece out.

So certainly, you know, being diagnosed with Parkinson's is a major life stressor, and there are challenges and understandable emotional reactions that people face you know at the time of diagnosis, as well as you know at various stages, on the journey living with Parkinson's as symptoms change, as reactions to medications change, you know as kids get older, as you retire from work potentially as some you know may pursue disability, so there's lots of changes and stages along the way and each change from the time of diagnosis to adjustment to new changes and challenges that Parkinson's presents can understandably be associated with feelings of sadness or anxiety or apprehension or frustration, and it's okay to sit with those feelings and to figure out how you feel about the diagnosis, about the changes to talk to your supports and find ways of coping to help alleviate some of that emotional distress, but when those symptoms persist and they're present, most of the day, nearly every day for weeks at a time. And it's really difficult to do anything to get those symptoms to abate, to get those symptoms under control.

That's when it becomes important to reach out, not just your friends and family, but to a trained mental health professional, when the symptoms are pervasive, when they're there, most of the day, nearly every day for an extended period of time and they're having a clear and lasting impact on your social life, on your important relationships, and on your ability to engage with your day. You know to volunteer to continue to work on your job, you know when that functional impairment is significantly increased because of your mood. That's when we really need to reach out and and to seek help, and to your earlier point Mel, you know, depression and anxiety, a lot of these mood symptoms they are part of Parkinson's. It's not like people, okay, you've got this diagnosis of a movement disorder and then in addition, you know you're experiencing some depression or anxiety or some insomnia, those are all important non-motor features of Parkinson's, so when people think about Parkinson's, sometimes, and inaccurately so, they think Parkinson's, it's just the movement disorder you know it's all about you know tremor or being stiff or being slower and yes it is about all of those things but it's just as much about sometimes feeling sad or feeling anxious, you know, feeling unsure of yourself in social situations and when we can identify and we can treat those non motor features that are associated with PD, we can improve all aspects of quality of life, and really enhance you know every single component of PD care.

Melani Dizon:

So a lot of times people will ask, you know, am I depressed because of Parkinson's, or am I just depressed and also have Parkinson's? So, I want to talk a little bit about that and we'll talk about treatments a little bit but I'm curious. So, as somebody who's maybe caring for somebody who's been diagnosed.

Some people will describe a situation where they get diagnosed and that person sort of goes into denial.

And is that often related to, it's like a behavior of depression like what is that and how do people that are caring for somebody like that help, because not dealing with it is not helpful, but they also are like, they might be flitting around and pretending like nothing's wrong and they're just denying it all, so what do you do in that situation?

Roseanne Dobkin:

So the first thing I have to say is everybody copes in very different ways and there's not one, you know, right response, you know, we tend to think about you know healthy coping versus you know less healthy coping. So certainly, you know, in the short run, you know maybe for a couple of days a couple of weeks, you know, maybe a month or so maybe denial's adaptive, it gives the person some time to kind of adjust and to process and to figure out a path forward but when something like denial persists, and it maybe prevents people from, you know, joining Rocksteady boxing, or pursuing other aspects of PD related care that we know are incredibly beneficial.

You know, that's when it becomes problematic. And I think a lot of the differences that we see with respect to coping ability right you have some people, the minute they walk out of that appointment yeah, they're disappointed and you know that they were wishing that that was not the news that they received, but they leave the movement disorder specialist office with a stack of literature, and they're on the phone and they're calling PT and they're calling speech even if they feel like they don't quite need it yet just because they want to build their skill set, and they're calling the support group and they're going to rock steady, so they're taking a very different more empowered more proactive approach that's going to lead to a very different most definitely more optimal outcome, whereas other folks who may be think oh well, this isn't real or, there's nothing I can do, this is a lost cause, why try? They're not going to follow up with all of those referrals, they're not going to learn from other people that have been living well with Parkinson's and have an awful lot to share about how they can now, learn to live well with Parkinson's. So a lot of it comes back to our mindset and our thoughts.

So I was speaking earlier about the fact that mood is like this very complex, you know multi-faceted phenomenon. The interpretation of what's happening what the diagnosis means an individual's ability to deal with it and find a healthy positive path forward, that mindset can make all the difference in the world with respect to an individual's coping response, because if somebody leaves that initial appointment, and says to themselves you know what this is really tough, but I'm going to have a good life starting today, independent of this diagnosis, they're going to be much more proactive in their self-care. If an individual doesn't come to terms with the fact that they have to deal with this medical condition, or they tell themselves well there's nothing I can do to make things better so why try, then their outcome is going to look very, very different. So, the mindset, the interpretation of what it means to live with Parkinson's as well as

an individual's ability to cope proactively and find meaning and find value makes huge difference because everybody can live an amazing life.

But a lot of it depends on how individuals are thinking about themselves, thinking about their situation, and their ability to realistically appraise the strengths and the resources that they have to push forward invite.

Melani Dizon:

Great. So, let's go dive a little deep into two of the things that we often talk about when we talk about mood so we're talking about depression and anxiety. Can you talk about what what are they, how are they different, do they often come together are they very frequently just one or the other and yeah, just give us a little debrief?

Roseanne Dobkin:

That's a great question and that's actually a question that I answer for people, you know, very frequently in my office I'm really happy that I have the opportunity to kind of share some of this information to so many on the webinar today.

So, depression and anxiety are, they're both negative emotions, negative feelings, though at times both could be very appropriate to the circumstances that we're facing, and that we're dealing with. They can occur separately, but they frequently co-occur. In terms of what distinguishes them when we're talking about depression we're talking usually about feelings of sadness, feeling as if your moods not as good as you'd like it to be, decreased interests and activities that you once enjoyed. Not having that zest and that enthusiasm to go and do and experience. Depression can also be associated with lots of feelings of helplessness, hopelessness, changes and sleep and appetite, feeling that life lacks meaning or purpose you know feeling very worthless or fatigued and in more serious cases, feeling that life is not worth living or actually having thoughts about harming oneself and, you know, we'll just say if anybody's having thoughts of heart of self-harm or thinking that life is not worth living, that's a red flag to immediately reach out to a family member, as well as to a professional in order to talk through those feelings. So that that characterizes depression.

So whereas depression is more defined by sadness, anxiety is more defined by worry.

So worrying about daily things maybe above and beyond what would be dictated by the situation, anxiety can also be characterized by what I call you know what if thinking, what if I dropped the letter on the way to the mailbox, what if I forgot to put the stamp on, what if I run out of milk before the end of the week and I have to go the grocery store again. So a lot of excessive worry about everyday things. A lot of "what if-ing." Anxiety can also be characterized by additional feelings of physical tension, and you know above and beyond what Parkinson's itself may create, it can be a fear about a specific place or situation. Oftentimes people with Parkinson's will share with me they're very fearful of having physical symptoms, you know of

trauma or dyskinesia let's say in public. Sometimes the fear might be of speaking in public or could be a fear that isn't so much Parkinson's related, but it's occurring in the context of Parkinson so fear of traveling or flying.

So it can be an intense fear about a specific event or person or place. Oftentimes anxiety can also manifest with a lot of what we call physical symptoms and individuals hearts racing they may feel short of breath, they may feel very sweaty, they may start to experience internal sensations of panic, and the other big criteria that we see with anxiety is avoidance, people, they opt out of life. They stopped, they stopped doing, they stop engaging, they say they say no when they could otherwise say yes.

Melani Dizon:

Okay. That made me think, what, how is that side of apathy, oh sorry, of anxiety, is it related to apathy? Because it's the sort of that opting out, but is apathy, the same thing?

Roseanne Dobkin:

So apathy is a related but it's actually its own unique construct so when we think about like the non-motor or the neuro psychiatric aspects of PD, you know, depression, anxiety and apathy would all fall under that umbrella but they are different emotional experiences and the best way I can explain it is if somebody is anxious, and because they're anxious, they are not engaging in a certain activity let's say that they declined to picnic they're not going to go the family picnic because they're anxious, it's because they're scared, it's because they're afraid, so it's that fear that is keeping them from going and engaging and doing, whereas if they're apathetic, there's no fear, but it's almost the absence of emotion.

So it's not that they don't want to go because they're too scared to go. It's not that they don't want to go because you know maybe they're just feeling so sad and, you know, they don't see the point because they fear that they will not enjoy themselves, but it's more that they feel very little.

Melani Dizon:

They just don't care.

Roseanne Dobkin:

They just don't care. I mean that that's an oversimplification right but it's really like feeling sad versus feeling scared, versus not feeling.

Melani Dizon:

Yeah. So let's talk a little bit about the pharmacological and non-pharmacological ways of treating depression and anxiety. What, first of all is the biggest challenge for people with

Parkinson's who experience depression and anxiety? What is so difficult about maybe diagnosing this or treating it alongside all of their also, you know, motor symptoms?

Roseanne Dobkin:

Mm hmm. So I'm going to get on my soapbox for a moment here. So, that I think your question like again hits the nail on the head I think one of the biggest challenges is that despite the fact that anxiety and depression are so common and in fact the overwhelming majority of people with Parkinson's disease, more, more so than the average person without Parkinson's disease, you know, of the same age, these conditions are under diagnosed, and they are sub optimally treated. So, in my opinion, that's one of the biggest challenges is as a Parkinson's community, as healthcare professionals, working with people with Parkinson's and their family members, we have to do a better job recognizing and detecting the presence of the depression, the presence of the anxiety, so that appropriate treatment and recommendations can be made.

And this goes back to something that we're speaking about earlier, oftentimes these non-motor symptoms will present themselves decades before the onset of the motor symptoms or the physical symptoms of Parkinson's and so what ends up happening is that even though these symptoms are comfortable, people kind of get used to it, and they're not really experiencing something you know that's new or different it's kind of it becomes the person's baseline. So they're visiting with their neurologist or with their family doctor and oftentimes the doctor will ask oh, has anything changed you know any new symptoms, since we last got together? And it's not a new symptom so it doesn't get reported because people get used to it but trust me when I tell you we can do better than just getting by.

So if you don't like how you're feeling, even if it's something that you have been feeling for years. It's still so important to speak up and let somebody know because there are effective treatments out there so that's the biggest challenge is that I think healthcare professionals need to do a better job, recognizing depression and anxiety, not just simply discounting it, as you know, par for the course because yes, these are common features of Parkinson's, but they are treatable features of Parkinson's,

You know if some if you went to the movement disorder specialist and you said oh I think you know you need to take a closer look at my tremor, because it's really impacting my daily functioning, well of course that tremor's going to be looked at quite, quite closely, so that medication adjustments can be made.

Same thing goes for depression or anxiety, we have to focus on treating those symptoms just as much as we focus on treating you know balance or tremor or making recommendations related to walking.

So that's a really big challenge and I you know I cannot overstate that even if these symptoms have been, you know, in play for you for quite some time, now is the time to speak up because our effective treatments are available, there's no reason to suffer in silence.

If we can improve depression and anxiety, we can improve all aspects of living with Parkinson's. I know there were other questions embedded in that question so reorient me.

Melani Dizon:

I will get back to that I just want to speak to this piece. So, you know, with your experience working with movement disorder specialists and you know having that cross functional team piece, is it something that you think is starting there? You know it's the movement disorder specialist or the neurologists that are asking question in a way that's not getting to the heart of it and it would be better for them to, do they proactively asked about things like quick screen screenings regarding depression and anxiety that would have those issues come out more than saying did something change? Is that?

Roseanne Dobkin:

So it's everybody's job to screen and to assess and to intervene as appropriate. And I think there's a lot of variation in terms of what happens, you know across doctor's offices. So there are some movement disorder specialists you know many that will ask each and every time and do a systematic screen for depression and anxiety and other neuro psychiatric complications, you know, using a standardized interview or a self-report questionnaire that the individual fills out you know every single time they go into the office in order to track changes in depression or anxiety and sleep, and then I'll be honest, there's some other doctors that probably don't mention it at all.

So I think it really varies practice to practice and center to center, which is why I think everybody in the Parkinson's community has to assume some ownership here. People living with PD, you know, we're talking a little bit about family members earlier, sometimes the spouse or the child or the close friends will notice a change in their loved one and it's okay to bring that to the attention of the movement disorder specialist during that appointment or I get calls, and I'm so happy to say this, from physical therapists or speech therapists that I know because the neurologist didn't pick up on it but the speech therapist did and makes the referral.

So I think it's the job of everybody who is part of the multi-disciplinary team to be on the lookout for red flags or warning signs that maybe mood is not as good as it could be, and that there's room for improvement.

Melani Dizon:

Yeah, and I think it's really important for everyone on the call, whether you're a care partner or you are somebody living with Parkinson's that you bring it up. If your doctor is not bringing it up, bring it up because the reality is the downstream impacts of being able to have treatment

for depression and anxiety are huge so if you are experiencing really bad motor symptoms, but your depression or anxiety is preventing you from exercising, let's say, well, then it's just going to be a cycle that's going to continue to get worse. But if you can treat the, and then your motor symptoms are also going to be worse, but if you treat the anxiety and depression, and you get that under control what makes you be more have more initiative in your life and you want to work out, then you will not only help with that piece but you will also help with the motor so it is super important to be an advocate for that.

Roseanne Dobkin:

That's a great point and I actually just want to highlight and underscore that for another moment or two. That is actually what often what will tip off, let's say the speech therapist or the physical therapist or the support group leader, if somebody is kind of stuck in the mud and they can't get going and they can't follow through.

Or maybe the care partner notices well they have all these exercises they can do but they're not, you know, setting up a schedule they're not practicing. If you can't move forward with your goals, if you can't engage in the behaviors that are important to you and are very much aligned with your personal values and aspirations. That's a really big red flag that we need to take a closer look at depression and anxiety.

Melani Dizon:

Great, thanks. Let's talk about treatments. Let's talk about depression first. What are some of the common treatments, pharmacological and non-pharmacological, for depression that you see in your practice?

Roseanne Dobkin:

Sure. So as far as treatment is concerned, we usually think about antidepressants and or psychotherapy, talk therapy, being first line interventions. And if an individual were to start treatment with a medication or with psychotherapy, or with both, very much depends on kind of the nature and the severity of the symptom presentation as well as preference.

You know there are some people that just prefer to do talk therapy, which is wonderful and others that would just prefer to take a medication which is perfectly fine as well. So as far as medications go there are different classes of antidepressants that are out there and available, and I get this question a lot like what's the one best antidepressant for people who are living with Parkinson's. There isn't one best anti-depressant. I think, a very open and honest conversation with your doctor about the types of symptoms that you are experiencing because just like Parkinson's is different person to person, depression and Parkinson's is different person to person.

So sometimes people may be sleeping a lot and overeating, whereas other times if they're depressed, they may be hardly sleeping at all and they've lost 20 pounds in two months, even though they're not trying.

So a doctor can sometimes select the right antidepressant in order to best target the specific types of depressive symptoms that each unique individual is having because certain types of antidepressants are better, let's say if you're sleeping a lot versus sleeping a little, or if you have very low energy, etc. So matching the selection of the drug to individual history, maybe what's worked for other family members, what has worked or not worked for that particular person in the past, as well as with sort of key consideration for active symptoms of depression that are currently at play. So some of the common classes you know we have the SSRI or SNRI, which would include things like Prozac, Zoloft, Lexapro, Effexor, Cymbalta these may be medications that you've heard, sometimes in Parkinson's they even use an older class of antidepressant medication is called tricyclics, which includes a drug called Nortriptyline which has actually been studied systematically in PD depression and has found to be helpful.

So those are some of the medications that are out there but again the best antidepressant is the one that works for you and in order to get to the one that works for you, it's really important to be very open and forthcoming about all of the symptoms of depression that you're experiencing, as well as past medications that you've tried, and if they helped or made some certain symptoms worse if there were side effects and then using that personalized data that's collected, the doctor can make an informed decision. I will say there have been you know case reports, and when I first got into this field, you know almost 20 years ago now at this point, there was a lot of discussion about antidepressants and the need for more systematic study because there was some concern well maybe it'll make motor functioning worse you know maybe it'll make cognition worse.

You know, maybe there will be an adverse interaction with other medications that the individual needs to take, and fortunately is more research has taken place over time, you know, while everybody's different and some people will experience more side effects than others in general, these medications are really safe, and they tend to not worsen cognition. They don't worsen you know, motor effects, most of the time. And, you know, there's typically not, while there's some precautions that folks need to take, there's typically not drug to drug interaction. Sometimes you have to be a little bit more careful if you're taking an MAO-B inhibitor. Just look out for the interaction there but apart from that, they're pretty well tolerated. So antidepressants are safe, and they can be really helpful for many people.

I actually study a non-pharmacological intervention, called cognitive behavioral therapy, which is just a type of talk therapy, and it addresses a lot of what we were discussing earlier in terms of coping skills, helping people to learn healthier habits that they can utilize to manage their reactions to the understandable stressors and challenges that they're facing day in and day out.

So, some cognitive behavioral therapy techniques, would be things like daily goal setting, working to very systematically and appropriately, you know, increase involvement and meaningful and pleasurable and social activities. Maybe learning some mindfulness or some relaxation strategies that an individual can use in order to slow down their breathing, to come back to the here and now and focus on one's breath and then also really importantly, really stopping to pause and reflect on what we're saying to ourselves because the reality is we are constantly talking to ourselves. I know I constantly talk to myself all the time.

We're constantly making meaning and interpreting what's going on around us and oftentimes what we say can be kind of harmful and kind of negative, we can be pretty hard on ourselves. Most of the time we would not speak to our loved ones, under ordinary circumstances, in the way we may speak to ourselves so being able to pause and reflect on what we're saying, how we're interpreting, what's going on around us and what's going on in our world and kind of pressing pause on some of those really extreme negative thoughts that are going to slow us down and impede healthy coping efforts and sort of rewind them and try to replay those thoughts in a more balanced, more compassionate way, can be incredibly helpful, and the research shows that cognitive behavioral therapy can really lead to significant improvements in depression and anxiety in quality of life, and also in physical functioning and physical health and I think that's because of the point that we were addressing earlier, if an individual can feel less depressed, they're going to be more proactive in their self-care, they're going to take their meds on time they're going to exercise, they're going to do PT and OT they're going to engage with the community, and that's going to help physical functioning as well as emotional functioning and mental health.

Melani Dizon:

Yeah, thank you. That's great. For those of you interested, we will talk a little bit about how to find different types of therapists later on the call so if that's something that you're interested in, we'll talk about that.

Can you tell us just a little bit about how long typical CDT treatment is, and no it's not something you know people can expect to go in and oh I got it, you know Tuesday, I'm all good like what is the expectation for people?

Roseanne Dobkin:

Yeah, so there's no, that's a really good point for medications as well, that we don't have the magic wand, we have a lot of excellent skills and strategies and suggestions that we can share, but it's not the magic eraser.

So as far as an antidepressant goes, let me start there, since I was talking about the pharmacological treatments first. Unfortunately you know taking a Zoloft is not like taking an Advil you take an Advil, and the headache is probably going to disappear. You know, maybe after two tabs and two hours and a glass of water. With antidepressant medications they need

to build up in your system and get to a therapeutic level and it can usually take up to six weeks in order to feel initial effects, and then people will continue to feel better and better as the dosage continues to be monitored and optimized over time.

And that's really important with antidepressant medications is making sure that you're on the right dosage, oftentimes, especially if the antidepressant is prescribed, let's say by a family doctor who doesn't have a lot of specialized expertise in either depression or Parkinson's the dosage tends to be too low. So people think oh this is not helping you but it's really the dosage needs to be brought up to therapeutic level so that's always an important thing to consider but it takes about six weeks to start to feel initial effects.

Melani Dizon:

Let's talk about that piece of it really quickly because I do think that some people you know will take it and it's not working. So what is the expectation of what they're going to feel? What are some maybe things to look out for that are good signs that it's not working? Or, yes, this is not, it's not a fun process to go through getting to that therapeutic level but hang in there, like what are some good things to be looking for?

Roseanne Dobkin:

So we take that six-week period of time that I just outlined as an estimate we want to kind of break that down, maybe into two-week intervals. So for the first two weeks, you're probably not going to notice much of a change but right about 14 days maybe if a medication's working, you're going to start to notice a mild or modest improvement. So maybe if the intensity of your depression let's say was an eight out of 10 well now maybe it's a six out of 10, you know, so not a huge change but it's starting to trend in the right direction.

And then maybe by four weeks, you're down to like a five out of 10 or four out of 10, and by six to eight weeks now maybe you're at a two out of 10 because it's really helping and it's really kicking in.

So you're sort of gradually moving in the right direction. There should be a little bit of symptom relief, but it's probably realistically going to be minimal, the first two to four weeks, and then you'll start to see bigger changes after that.

The other thing that's important to keep in mind is sometimes those first couple weeks, you may have more side effects, as your body is getting used to the medication, but the side effects will go away as your body adjusts. So in the beginning, sometimes people get very frustrated because they have side effects and they're not experiencing a ton of benefits like I'm gonna throw this bottle out the window because it's not doing anything for me, but we have to remember is that with time the side effects will get less and less, and the therapeutic benefit will get more and more.

If you don't notice that trend after let's say four weeks if you're not starting to notice some improvement. Then it either means the dose has to be increased sooner rather than later, or the doctor has to consider changing the medication, but it really is it's a slow journey, those first 2, 4, 6 weeks but then you should start to feel some effect.

Melani Dizon:
Great.

Roseanne Dobkin:

As far as cognitive therapy goes for all of the studies that I've done and I have done three fairly large, randomized control trials to date as well as a couple of smaller treatment development pilot studies, we studied about a three-month course of therapy so individuals receiving counseling that focused on the principles that I just outlined, you know, improving behaviors, pausing thoughts, learning meditation, relaxation, improving healthy sleep habits. So about, I'd say 10 to 14 sessions would be considered like the acute dose of the psychotherapy but then most people find it beneficial to continue to receive care, you know, over time, maybe every other week instead of initially weekly, and then sometimes once a month and booster sessions but again we're talking about, you know, weeks and a few months of practice.

And what's so important about therapy is not just learning the skills and the techniques and maybe new and new and innovative ways of thinking and behaving and session but taking what you learn and practicing it day in and day out, implementing those changes into your daily life. That's really what makes a big difference over time, and I've shared this analogy before so if you've heard me give other talks you've heard me, you know, use this analogy, but I think it's an important one, you know if you go to the pharmacy, and you fill your prescription for a carbidopa/levodopa and you come home and you stick the pill bottle in the cabinet you just look at it, you're probably going to be pretty symptomatic you have to take those Parkinson's meds on time every time in order to have physical benefit physical relief.

Same thing goes with any skill or strategy that an individual might learn under the umbrella of CBT or another type of non-pharmacological intervention if you don't take those skills and figure out a way to implement them day in and day out into your daily life, just knowing that isn't going to be enough in order to be truly helpful for you.

Melani Dizon:

Right. What role have you seen exercise and food play in depression and working with depression?

Roseanne Dobkin:

Huge. So, exercise is incredible, not just for improving motor control in Parkinson's but also with respect to enhancing mood. So when it comes to exercise there's actually some very interesting studies that have been done in individuals without Parkinson's where they've

compared, you know what are the long, the short and longer term impacts on mood for individuals who exercise, you know at that critical threshold of about 150 minutes a week of cardio, compared to those who don't exercise, and they start antidepressant medication and exercise, did the same or better than the antidepressant medications, in terms of alleviating depression and anxiety over time.

For that reason, and because of what I've just learned you know from working with people over the past two decades, not only in research but in my clinical practice, exercise is a key component to the cognitive behavioral treatment package that I utilize in my programs.

So like session one day one exercises, the first thing that we talk about. I really consider it the low hanging fruit if we can get people more engaged in exercise, any type of exercise that they find, you know, physically safe, that they're able to do, it doesn't have to be anything, you know so crazy or strenuous. You know if Rock Steady's too much, it could be yoga, it could be a walk around the block, it could be jumping on the exercise bike, but some exercise every day is foundational to the program that I run, you know, in addition to setting other daily goals related to socialization.

And you know, meaning and pleasure and reward so that that is key, and I definitely see the effects. The interesting thing with cognitive behavioral therapy we're talking about like the timeline for medication effects to kick in. Usually around two to three weeks is when you will also find an initial improvement in mood and response to cognitive therapy and it's in my case, in my programs, it's because we're pushing exercise and becoming more active, and that's the quickest way to improve your mood.

And there's definitely literature out there regarding nutrition, as well and the importance of probiotics and really eating, you know, clean and green and trying to limit a lot of the sugary processed foods the refined carbs, you know, there had been some, some studies that have shown you know more mood enhancing effects from like a Mediterranean or mind type diet that really emphasizes fruits and vegetables and healthy fats, lean proteins, like fish and chicken versus the higher fat meats like state, and hamburger. You know, nuts and seeds are really good. So, there can be maybe even simple nutritional changes that people make on a regular basis that can really improve their overall quality of life as well as their mood and their Parkinson's motor control over time.

Melani Dizon:

Right. Okay, let's move to the same questions around anxiety, what sort of medications are used to treat anxiety, are there antianxiety and you know antidepressants that are used together commonly, and what are some non-pharmacological ways to help with things?

Roseanne Dobkin:

So starting on the medication side again, I think it's really important to mention that antidepressants, most of them also have really nice anti-anxiety effects, and sometimes if we're using an antidepressant for the primary treatment of anxiety and again there's a lot of individual variability here.

So a lot of this will be determined by a given person's you know unique symptom profile, but sometimes we might use antidepressants and lower doses if we are using them for the primary indication of anxiety, sometimes we have to use them and higher doses it depends on the medication, it depends on the person, but that's actually, like the SSRIs like the Prozac and Zoloft and the Celexa and Lexapro. I would consider those to be the first line intervention pharmacologically for anxiety.

There are other shorter acting medications that fall under the category anti-anxiety or sometimes we'll call them tranquilizers or benzodiazepines, medications you may be familiar with like Xanax or Klonopin, those medications are kind of like that Advil example, they'll kick in really quickly when you take them, and you may get a very short period of anxiety reduction, but the medication is in and out of your system very quickly so whereas the antidepressants they build up in your system and you have therapeutic levels that kind of maintain you know at a steady level for 24 hours, most of these anti-anxiety medications are benzodiazepines they're very very fast acting so in and out of your system in only a couple of hours. So people are just using like a Xanax type medication for symptom relief. They may find that they're taking it several times a day, because the half-life is so short, and they're metabolizing that medication so very quickly.

And there is a place for them and sometimes people will use the anti-anxiety and antidepressant medications together. The one word of caution that I have to offer, is that especially in the context of Parkinson's disease. We have to be mindful that anti-anxiety medications, the benzodiazepines, the Xanax, Klonopin, can sometimes increase risk for falls as people get older and as they become less steady on their feet, whereas the antidepressant medications that may be used for anxiety control don't have that same type of side effects associated with them, so. And again, the anti-anxieties, the benzodiazepines, they're safe. As long as you're taking them as prescribed by your doctor and following guidance and reporting any difficulties or side effects, you're gonna be okay.

I'm just cautioning that we don't want to overuse, because there is that risk of potentially increasing falls, which we don't want to happen to anybody, certainly not anybody living with Parkinson's.

Melani Dizon:

Yeah. And also, another important thing to talk about is just, if you're taking any of these especially something like Xanax or that like you don't want to go off of it, without your doc, you know without talking to your doctor anytime you don't want to say hey I'm done with it,

because there are going to be a repercussions for that so definitely work with your doctor on that.

Roseanne Dobkin:

Exactly, you don't want to shock our system just like hey you're going to start, you're going to start low and slow if you're beginning of medication, you're going to go off the medication slowly if you decide that it's not really working for you or you're not noticing the intended effects because again we don't want to do any harm and sometimes if we stop something abruptly we're going to feel a lot worse. And there can be better ways to approach changing our meds than just an abrupt discontinuation.

And as far as non-pharmacological for anxiety, a lot of the strategies, pretty much all of the strategies that I talked about for depression are also helpful for anxiety, but they would be applied in a slightly different way. So if I was working with somebody with primary anxiety I would probably spend more of my time focusing on the relaxation training and the breathing and mindfulness and yoga maybe earlier in treatment whereas with depression I would layer in those strategies and techniques a little bit later later on in the course of therapy.

That's really important and also the content of our thoughts differs, so there are certain types of thoughts that you know trigger depression there's certain types of thoughts that trigger anxiety so cognitive behavioral therapy for anxiety would really focus on the content of those anxiety provoking thoughts, which is usually a little bit different than the content of thoughts that lead to depression so usually thoughts that lead to depression, and again, this is an overgeneralization, but but tends to sort of fall in the categories of negative thoughts about the self, about the world about the future. Anxiety provoking thoughts tend to evolve a lot of uncertainty, a lot of fear, a lot of what if.

Melani Dizon:

Okay, interesting and then I got this question that I just want to talk about the person said that her husband has PD, but they were told, he had had depression for a really long time and told that, unlike other people with depression who might take meds for six months or you know a couple years that people with PD don't get off their antidepressants, they're on them for life.

That was sort of what their doctor said, is that typical for you to see when you see patients that they end up if they if they do have depression related to, that's a big non motor symptom for them that they end up staying on forever?

Roseanne Dobkin:

So not necessarily and again everybody is different, and I think this goes for people with or without Parkinson's disease. Some people in order you know, once you kind of get to a place where your mood's improved, you want to keep doing whatever it was that you were doing that got you there.

So if that's therapy or meds or combination oftentimes I will encourage my clients I work with Parkinson's or not if this is working. I want you to stay on it because it's helping you, so let there's no reason to go off of the antidepressant because it's not harmful, it's not addictive, it's not going to you know predispose you to other risks or side effects. So I'm not so sure that's just not Parkinson's clinical point but in general it's good clinical practice that once we help an individual to feel well. We want to keep you well.

So Parkinson's or not, as a general rule of thumb, once we have an individual close to remission, you know, meaning very few symptoms, we usually say stay on your current regimen, at least 12 more months before we even talk about beginning to back it up a bit, because it's working. Now because of the stressors and challenges unique to Parkinson's, that an individual without Parkinson's may not face there may be additional mood vulnerability there.

So, individuals with Parkinson's may need to be that much more considerate about the unintended consequences of stopping an antidepressant medication once they're feeling better, but it's absolutely not a must, or a mandate, so yes you're probably going to be taking Sinemet or something like it for dopaminergic replacement. You know, for your journey with Parkinson's, but no, absolutely not. It's not a universal mandate that a person with Parkinson's must stay on antidepressants forever in order to keep their mood under control. It's really a case by case.

Melani Dizon:

Yeah. And we, I mean I feel like we hear a lot of people that say they they got on the medication because they were just in a really bad spot, and they were in such a bad spot that they weren't able to do the nonpharmacological things that can help them so that once they had that and then they started a habit of exercising and a habit of eating differently, then they could slowly go off, but they had those other things, too, that are sort of aligned with minimizing their depression and anxiety.

Roseanne Dobkin:

There has to be something in place, for maintenance of your gains and for prevention, and I see a similar trend like oftentimes people will need to start medication, in order to feel well enough, in order to learn the skills and learn the techniques, and then once they learn the techniques, they can roll with them. But some people need to continue to practice those skills day in day out along with continuing to take medication because that's the package that works for them, and others might not need to or might not choose to. But it's very individual and it's really based on your unique pattern of response.

Melani Dizon:

Right, so I know people are going to ask, and some people have already asked but if you're taking patients and I know you're not taking any new patients right now. But how can people



look for a good therapist, somebody who understands Parkinson's and understands all of the different non motor symptoms that go along with it so that they can help them have a better quality of life, what are some steps people can take?

Roseanne Dobkin:

So, any good therapist will educate themselves about Parkinson's they will read, they will ask you, you know, give me resources I want to learn from you.

There are, you know, certainly there's some of us out there that know a lot about Parkinson's, but most therapists most mental health professionals don't. That being said, there are sort of subgroups of mental health professionals and counselors that may have experience in what we call Behavioral Medicine or health psychology, so they might not work with Parkinson's, specifically, but they have a lot of specialized training and expertise in working with individuals with other types of chronic medical conditions. So if you're looking up psychologist or social workers, you know in your local area and you're reading about their backgrounds.

If they say that they have any expertise or training working with individuals with chronic medical conditions, or they mentioned health psychology or Behavioral Medicine, then that's kind of a good sign that suggests hey maybe I'll make a phone call and learn a little bit more about whether or not this could be a match. Each state also has, I mean, there could be some exceptions but in general each state has their own Psychological Association, so in New Jersey we have something called the New Jersey Psychological Association and those associations tend to keep a referral directory of all the licensed mental health providers in their area. And then you can search to see okay who has expertise in medical conditions who lives in my county who takes Medicare, and they're usually vetted before they're posted on the website for the local psychological association so that's like a hidden little secret. So, I would consult with your state's psychological board, and they are a really good source of names and resources.

There's also a website called Psychology Today, where again you can search and filter based on area of expertise. And again, the people tend to be pretty happy with some of the referrals that they connect with on that platform.

And there's also an association of behavioral and cognitive therapists, and it's called ABC T, and they maintain a national directory as does the American Psychological Association, the API so those would be some good resources to get started with.

Of course if your movement disorder specialist or Parkinson's doctor has local mental health professionals that they work with that would be the low hanging fruit that I would start with I asked for a personal recommendation and then if you can't get a personal recommendation from your neurologist or from your family doctor then I would go to some of these outside resources that I just mentioned.

Melani Dizon:

Great, thank you. I know we only have a couple minutes left but just really quickly wanted to talk a little bit about telemedicine because I know that right now, your practice is almost entirely telemedicine, can you talk to people a little bit about how does therapy work over telemedicine, is it just as effective what are the, you know, what should they look out for is it something that they can really begin to see somebody new over telemedicine? That kind of thing.

Roseanne Dobkin:

So I am, and Mel knows this I have been a huge advocate of telemedicine even long before the pandemic started and I've done a lot of research in this area and just, you know, super briefly, you know my research has shown that whether we administer, you know, cognitive therapy like in person sitting in my office versus on a zoom screen like we're all speaking right now, versus over the phone, even without that video capability, the results are almost identical, like we couldn't make up data that that looked more similar. So there's no efficacy or effectiveness that seems to be lost by receiving treatment on a remote platform.

That being said it's not for everybody. So it really depends on your needs and your preferences and your comfort level, there are some people that really just prefer being in person and being in the room, and that's fine. There are others, where it's a major convenience to not have to travel an hour and a half each way, you know to sit in a therapist office and they're perfectly comfortable, you know on the zoom screen so I think as long as you're working with a skilled and competent clinician, that is willing to learn and grow with you, whether that therapy is happening on the screen, or over the phone or in the office. Doesn't really matter. What matters is that you feel comfortable with the way in which the treatment is being implemented. And even more importantly that you feel comfortable with the person that you're sitting across from.

Melani Dizon:

Yeah, I think it's so important that you made that note that a lot of therapists are open to learning from you. So you might be in an area of in your state where there aren't people who specialize in Parkinson's or anything like that, but therapists tend to be a very proactive learned bunch and they're willing to learn and they want, you know, if somebody comes to them they want to learn what Parkinson's about they want to be able to use that with other people so don't be afraid to, you know, ask those questions of your therapist and say you know this is my situation. Do you have any experience with that? And if not, and and they're, you know, that's the person that's local to you, are you willing to, and how can I help you learn more about Parkinson's? So I think that's a really important point to make.

Roseanne Dobkin:

And any skilled therapist would capitalize on that opportunity and if they don't embrace the chance then you know you need to look someplace else.



Melani Dizon:

Absolutely, absolutely. Great. Well, thank you so much. I know that I could talk to you forever about this topic and maybe we'll get to do so again, and I appreciate everybody, we got to many of the questions that were that were asked I know we didn't get to everything but hopefully we provided some usefulness to all of you out there. If you have any questions, feel free to email us at blog@dpf.org.

I would love to thank our sponsors, our peak partners, Amneal, and Adamas, Lundbeck and Sunovion. They make it possible for us to host these events and to make it free to everybody, so thank you so much for that. And thank you all for showing up today, it was a big group and we're really really grateful to have you.

Roseanne Dobkin:

And it was my pleasure to be with you guys this afternoon.

Melani Dizon: Thanks so much.

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