

Episode 84: Managing Anxiety with PD

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Dan Keller: Welcome to this episode of *Substantial Matters: Life and Science of Parkinson's*. I'm your host, Dan Keller. At the Parkinson's Foundation, we want all people with Parkinson's and their families to get the care and support they need. Better care starts with better research and leads to better lives. In this podcast series, we highlight the fruits of that research, the treatments, and techniques that can help you live a better life now as well as research that can bring a better tomorrow.

Anxiety and depression are common non-motor symptoms of Parkinson's disease. They are not only a reaction to the disease but are also related to changes in the chemistry of the brain. The Parkinson's Outcomes Project, which has tracked more than 13,000 people with PD for more than 10 years, has found that as many as 40% of people with PD will experience some form of anxiety.

While some worry is natural when a person has a chronic disease. I asked clinical psychologist, Dr. Roseanne Dobkin, about when an appropriate level of worry becomes the mental health condition of anxiety.

Roseanne: That's a really great question. As a clinical psychologist, I think it's important for us to embrace our emotions because they're important and they tell us something. They're going to be certain circumstances in life where feeling a little bit anxious or nervous or worried is quite appropriate. Those feelings cross the threshold into problematic when they become all-consuming, when the feelings, the negative feelings, start to occur more of the time versus not, when they start to become incredibly distressing, when they start to interfere with day-to-day life and activities.

Dan: How common is anxiety across the course of having Parkinson's disease?

Roseanne: Anxiety is one of the most common non-motor symptoms that we see in Parkinson's disease. Published estimates suggest that about 30% of people living with Parkinson's will experience anxiety at some point during the course of the medical condition. In my experience, I think the 30% is definitely an underestimate because there are so many folks with Parkinson's who have anxiety that goes undetected and untreated. If I had to put a number on it, I would probably put it somewhere between 50 and 60%.

Dan: Is it really just a reaction to having a disease, or is there something going on in the brain which facilitates or exacerbates anxiety?

Roseanne: The short answer to that question is, yes, all of the above. In general, it's a complicated mix of neurochemical factors, many of which are inherent in the disease process plus all of the challenges that go hand in hand living day in and day out with Parkinson's and a lot of the limitations and difficulties that it causes for people and their families.

Dan: Do depression and anxiety coexist and if they do, how do you tell the difference?

Roseanne: That's a great question that I get in the clinic all of the time. Depression and anxiety very commonly co-occur. Oftentimes, folks are pretty confused, trying to figure out what exactly am I feeling and what type of symptom might it be most helpful to report to my doctor. While there's a lot of overlap, I think the easiest way to distinguish them if we're trying to separate the emotions is that depression is characterized primarily by feelings of sadness, loss of enjoyment, loss of interest in things that one traditionally really likes to do whereas anxiety is characterized more by worry, nervousness, apprehension.

Both of these conditions are associated with a lot of negative thoughts and unhealthy thinking patterns. In the case of depression, the negative thoughts tend to center on the self, the world, the future, so somebody who is depressed might think, "I'm not good enough or my future is bleak."

A person who's having a lot of anxiety-provoking thoughts tends to focus on worst possible case scenario, tends to overestimate the likelihood of bad outcome so an anxiety-provoking thought might sound more like, "Oh, nobody at the party will talk to me. My symptoms make my friends very uncomfortable, so it's safer for me to just stay home."

Dan: What forms does anxiety take? What do people do?

Roseanne: Anxiety presents in very, very different ways. The phrase, "If you've met one person with Parkinson's disease, you've met one person with Parkinson's disease," it applies with anxiety just like all other manifestations of the medical condition. Anxiety could present cognitively in the form of excessive worry and rumination about day to day events. It could present physiologically in terms of increased feelings of physical tension, rapid heart rate, difficulty breathing, feeling dizzy. It could present emotionally in terms of inner feelings of angst or extreme discomfort, and it can also present behaviorally in terms of avoidance and withdrawal, and that's something that I really want to draw people's attention to.

I can't tell you how many times I'll be meeting an individual for the first time, and I'll be asking them about their mood, and if they're worried or nervous, and they'll say, "Oh, no, Dr. Dobkin, I'm cool as a cucumber. Nothing bothers me." The more I learn about their history, and the more I learn about their day, nothing bothers them because they don't leave the house or they're in the basement all day because they're avoiding exposure to any person, place, or thing that could possibly lead to them feeling uneasy. When people start avoiding and withdrawing, it makes their world smaller and smaller and that's not healthy in the long run.

Dan: You describe some physiological responses to anxiety, rapid heart, and stress, and probably muscular tension, I would think, can it have actual health consequences, physical health consequences to be anxious?

Roseanne: It can. Unfortunately, anxiety can have a detrimental impact on all aspects of physical health. It can exacerbate the presentation of Parkinson's disease

symptoms both physically and cognitively, and it can have a really negative impact on quality of life and family relationships.

Dan: What kind of situations can provoke anxiety?

Roseanne: Anything and everything. It's a very personalized phenomenon. For some people, it may be excessive worry about day-to-day things like paying the bills, picking up food at the grocery store, finding a parking spot at the local church. For others, anxiety may be triggered by something very specific, being in public, speaking in front of a crowd, potentially concerns related to Parkinson's symptoms be they physical, emotional, or cognitive.

It's not uncommon for individuals with Parkinson's that I work with to share that they get very nervous around the time that they are expected to take their Parkinson's medication for fear that it might not kick in or that it may lead to side effects. There can be a whole host of factors that can contribute to and can cause anxiety to hang around for a lot longer than we'd like it to.

Dan: What are some of the treatment options?

Roseanne: This is the really good news is that we do have effective treatments and medication as well as an evidence-based type of psychotherapy called cognitive behavioral treatment have both been shown to be effective in the general population, and there's some preliminary research that's showing that these types of treatments may also be very helpful for individuals living with Parkinson's disease.

Medication is certainly something that would involve careful evaluation and discussion with the individual's physician and personal health care team. Cognitive behavioral therapy is something that could be accessed in the community from a licensed clinical psychologist like myself or a social worker or a mental health counselor. The really great thing about cognitive behavioral therapy is it arms people with tools, with coping skills that they can use to manage their stress and their anxiety as effectively as possible.

Dan: Are they most effective when combined cognitive behavioral therapy with some drugs, maybe for a short time, maybe a little longer?

Roseanne: Ideal treatment selection, again, it really depends on the individual person and their unique history. As a rule of thumb, though, I usually suggest that if an individual is experiencing symptoms that are quite distressing and quite pervasive, and they're there more of the time than not, that they combine medication under doctor supervision with the cognitive behavioral therapy to get the quickest, most robust response.

Dan: Is the goal to use the medication short-term, hopefully, give them those tools that will allow them to handle it themselves without the drugs?

Roseanne: Again, it's really a case-by-case decision. Some people use medications like low dose antidepressants to manage anxiety for a very short period of time while they're learning the coping skills and then the coping skills carry them forward.

Others find that they do best if they stay on a low dose of the medication for a longer period of time as they continue to learn healthier ways to deal with life challenges.

Dan: What have we missed, or that's important or interesting to add?

Roseanne: I think one of the most important messages that I try to convey to all of the individuals that I work with who are dealing with Parkinson's and anxiety is that nobody with this medical condition had any choice in the diagnosis, but they have every choice in the coping response. There are so many things that people can do today to reduce anxiety and to improve their quality of life. Things like increasing exercise, finding some time to take some slow deep breaths, maybe learning some meditations. The good news is in the age of digital technology and the internet, there are a lot of free downloads that are high quality. Just googling mindfulness and meditation and finding some three to five minute breathing exercises that an individual might like and could practice a couple times a day could be incredibly beneficial.

Then as a cognitive therapist, one of the main objectives for me when I'm sitting down and working with somebody one-on-one is to help them to learn to leave the judgment and the criticism at the door, and to speak to themselves with the same kind, compassionate words that they would use when they're speaking to a friend because negative thoughts can really fuel the fire when it comes to anxiety, and we really want to talk back to those negative thoughts and ultimately crush them like a bug.

Dan: Great, thank you.

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Anxiety is a common non-movement symptom of Parkinson's disease and recognition of it is the key to getting help. For an idea of what to look for, visit parkinson.org/anxiety. Here you'll find a list of common symptoms along with an explanation of the psychological and biological factors underlying the condition, how it's diagnosed and treatment options including non-conventional ones. You can also find tips for living with anxiety along with archived expert briefing webinars when selecting the topic of anxiety at parkinson.org/library. In the same search, you can find a fact sheet titled stress management for PD, which talks about some useful complimentary techniques, such as yoga, tai chi, breathing exercises, and massage therapy. Along these same lines are free PD Health @ Home virtual educational and wellness programs continue online including Mindfulness Mondays. You can register for upcoming ones or see past ones at parkinson.org/pdhealth.

Podcasts 78 and 80 describe what mindfulness is and what it can do for you, and episode 38 talks about mood and coping. As always, our PD information specialists can answer questions and provide information in English or Spanish about today's topics or anything else having to do with Parkinson's. You can reach them at 1-800-4PD-INFO. To receive news and updates about future events and resources, you can opt into our email list at the bottom of our website's homepage. If you have questions or want to leave feedback on this podcast or any other subject, you can do it at parkinson.org/feedback, or if you prefer, email us at podcast@parkinson.org. If

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