



**The Victory Summit® Virtual Event: Mental Health and Wellness**

**Managing Mood, Depression, and Anxiety in Parkinson's**

With Gregory Pontone, MD, MHS

Recorded on September 17, 2021

Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

I would love to introduce you to our friend Dr. Greg Pontone. Dr. Greg Pontone is an Associate Professor in the Departments of psychiatry and neurology at Johns Hopkins University School of Medicine in Baltimore Maryland. Dr. Pontone is the Director of the Johns Hopkins Parkinson's disease Neuropsychiatry Clinic which focuses on diagnosing and treating the neuropsychiatric aspects of Parkinson's and related disorders. So, to start off I'm always curious uh with those of you who have spent your life really thinking about what we care passionately about, how did you get into this work? What drew you to neuropsychiatry and what we care about Parkinson's in particular? Tell us about your journey.

Gregory Pontone, MD, MHS (Director of Parkinson's Disease Neuropsychiatry Clinic and Associate Professor of Neuropsychiatry and Behavioral Sciences, Johns Hopkins University):

Sure yeah. Well a lot of it was you know the people you know and work with. So I happen to be really lucky to work with Dr. Laura Marsh and she had a real passion for working with people with Parkinson's disease and she was taking care of people clinically and doing research on the disease and I started shadowing her and then working with her and you know you just kind of fall in love with the population and then you know as I developed my own sort of scientific interests I began to see that many of the things we do in psychiatry cause neurological side effects and many of the things we do in neurology cause psychiatric side effects and I thought if I lived right here in this between land I might be able to figure something out that helps both sides and so that's sort of been the basis for my clinical and research career.



Polly Dawkins:

That's fascinating, how many people are there like you out there in the world that really focus on that inner section?

Gregory Pontone:

Yeah it's a growing, I would say a growing handful.

Polly Dawkins:

So you're really a trendsetter there.

Gregory Pontone:

Yeah and I had great mentoring and you know at a great institution so very fortunate and hopefully we'll grow a few more to put out in the world.

Polly Dawkins:

That's great I mentioned to you on an email last week... last time you were here a year ago you recommended an app for brain health and I downloaded that app a year ago and it's called Elevate and certainly we're not sponsored by this app, but I found it really fun to challenge my brain and try to get better at these games and it's increasingly hard and frustrating and I just got reminded that it's time to purchase another year's subscription, I didn't realize I've been playing this for a year and I usually do it before bed which is probably not the right time to do brain training so my husband will say Polly, turn it off, and I'm like I'm doing my brain training, I gotta do it before bed. So I would recommend to folks in the audience if you you know, 40 dollars a year is in your budget and you want to do some brain training that's a fun app to do, so thanks for that recommendation last year. So let's start off sort of ground setting for folks and getting us onto the same understanding of this topic of mental health, what does mental health really mean?

Gregory Pontone:

Yeah so you know there's probably a number of definitions but the way I like to think about it and it's consistent with the world health organization's take on health in general is that mental health is sort of the optimal state of well-being, not just the absence of disease, not just the

absence of depression or anxiety but truly sort of living at the highest quality of mental and emotional life that you're capable of.

Polly Dawkins:

Interesting, I don't know if you are our expert to answer this question but we hear the difference between wellness and well-being, do you have any thoughts on that, on those topics?

Gregory Pontone:

Yeah so you know it is one of those sort of words that I think is becoming more important and you know more mainstream but I like to think of wellness as a verb and it's sort of the active pursuit of activities, a lifestyle that leads to an optimal state of health.

Polly Dawkins:

Got it got it. So when somebody is optimal health or mentally healthy, what does that look like, what does that mean?

Gregory Pontone:

Well you know we're all um dealing with things in our lives right there's social dilemmas, there's diseases, there's you know all sorts of pressures on everyone and so mental health is the ability to sort of manage and cope with whatever you're saddled with, you know, and then people with Parkinson's you know they've got already a sort of a big wagon to pull in addition to everything else all the rest of us deal with and so you know achieving mental health and wellness really has to be an active pursuit of managing these things and making choices that lead to the highest quality of life attainable.

Polly Dawkins:

Interesting. The people who talk about mental illness, so on the flip side of mental health tell us a little bit about what is mental illness then?

Gregory Pontone:

Yeah I think this is really important especially now in the age of social media when I think people sort of use certain terms casually, so you don't want to over pathologize things, so for instance, you know it's normal to be depressed or sad when someone dies or when something

really bad happens. It's normal to be anxious when you're under tremendous acute stress so many of the things that we experience in day-to-day life have the same names as some of the disorders that we treat. The difference is disorders are a state that's persistent usually or has at least a longer duration than a transient emotional change and leads to dysfunction, an inability to function as you usually do and I think it's really important to recognize that while external stress and situational events can trigger these emotions and maybe even trigger an episode of a major depression for the most part mental illness is biological, just like you know cancer or thyroid problems or diabetes, it's just in a you know different organ in the body, you know, most likely the brain, and so that's the other important thing is that we really have to embrace the idea that you know the mind and body are one. So how you take care of your body and we'll talk about this more I'm sure as as this interview goes on but you really have to take care of your body for your mind to function optimally and if you take care of your mind, your body will function better as well and that sort of transition and that's sort of what I told you about the start of my career is I thought geez you know if you handle your emotions better, you perform physically better and vice versa and there's many examples of that now.

Polly Dawkins:

Interesting so let's let's talk a little bit more specifically about Parkinson's. What are the most common mental health issues related to Parkinson's?

Gregory Pontone:

The big two just in terms of prevalence are anxiety and depression. At least half of people who suffer from Parkinson's will experience anxiety and or depression over the course of the illness.

Polly Dawkins:

Perhaps we could dissect that a little bit for our audience, what's the difference or tell us a little bit about what is depression versus what is anxiety?

Gregory Pontone:

So yeah, that's a great point, so these are just general terms. So let's start with depression so depression is really a syndrome, it's a collection of symptoms that usually occur together and then as I mentioned result in dysfunction and inability to sort of live optimally and you know

complete your day-to-day tasks. And so for instance a very common collection of symptoms in someone who is depressed would be a lack of the ability to enjoy things or a diminished ability to enjoy things. We sometimes call that anhedonia. Sometimes people have disruption of sleep, most often, that's an inability to fall asleep or stay asleep so insomnia, but very occasionally people will have the reverse, they'll have hypersomnolence where they sleep you know 15 16 hours out of the day they're always in bed. That's sometimes even called an atypical depression. So disruption of sleep. Disruption of appetite is also very common so people will say I just don't feel like eating or if I do I have to force myself or I'm only doing it because you know my spouse says it's time to eat. They tend to lose a lot of weight and again very rarely sometimes people will eat for comfort and again that's a little more atypical, the majority of people will lose their appetite. People will have low energy when they're depressed, they'll lack initiative they won't want to you know start any activity and even if they do after just a few minutes they'll throw in the towel and and stop. Another symptom that's a little more conspicuous is feelings of worthlessness or helplessness or even in severe cases people start thinking that life isn't worth living or even contemplate harming themselves and so that sort of collection of symptoms is usually what you'd see when someone has a major depressive disorder. Now you know maybe fewer elements of less severity might be what's called a minor depressive episode so when we talk about depression that's predominantly what we mean is that you either have a major or a smaller more minor depressive episode.

And same thing with anxiety except for it's a little more varied. So when we say anxiety within that there's very distinct syndromes. Some people have anxiety that's always there, it's literally, they're always worried about something, it could be anything you know mundane things and sometimes they feel tense or have butterflies in their stomach while they're worrying maybe even heart palpitations, but it's constant, it's a persistent, we call that generalized anxiety. And then there's other people who as long as they're not having an episode they feel pretty normal but then they can have sudden sometimes out of the blue acute attacks of anxiety with physical symptoms, hyperventilation, palpitations, that we call panic disorder, and so, that's a more episodic type of anxiety. And then there's people who only experience anxiety in certain

situations or context so for instance they're fine when they're just at home alone or with family members but if they go out into a social setting they become very anxious and sometimes they'll avoid that the social context because of the anxiety it triggers and so, you know, knowing what type of anxiety or depressive disturbance an individual has can be very important.

Polly Dawkins:

So in your practice and experience what are some strategies that you've seen work really well to help with depression related to Parkinson's. Yeah, the first thing is to recognize it, so it's not uncommon at all not just in people with Parkinson's but people in general will often say that they don't feel frankly sad. So they assume they're not depressed. It turns out that a fair number of people never have frank sadness but what they do have is that sort of lack of interest or lack of enjoyment in their usual activities. So what you'll see is someone who's not participating, having all these dark thoughts, probably some disruption of appetite and sleep, but not recognizing it because they don't feel sad. So I can't emphasize enough how important it is to first recognize the depression, because you're not going to manage anything that you don't recognize you have, so that's probably the key and you know sometimes it's you know family members or caregivers or spouses who come to us and not the person suffering themselves. The other barrier we sometimes see is even if they recognize it, they feel like it's admitting weakness, you know, or that they've done something wrong you know or there's a stigma you know I'm not crazy there's nothing wrong with me. And again that's the other reason why I would make this argument that just like a stroke is biological or any other medical illness diabetes is biological, in the majority of cases so is depression, it's just a chemical change in the brain that if we manage it, usually with medications and other treatments it can get better just like you manage diabetes, and so, you know, you really have to sort of say okay I have this medical symptom just like any other I'll recognize it for what it is and then engage in treatment and in the treatment that's where we're pretty lucky frankly, because I would say that we can do more for depression than we can for many of the other symptoms of Parkinson's so if you can identify it, we can help.

Polly Dawkins:

That gives a lot of hope. So can you tell us about the causes of depression in Parkinson's? Why does this happen for so many people with Parkinson's?

Gregory Pontone:

Yeah, so that's, in terms of the mechanism, we strongly suspect there's some overlap in the cause of Parkinson's, in the cause of depression and Parkinson's and so I'm going to tell this to you in two ways that I find fascinating, and I hope will eventually lead to some solutions if we figure out why this association occurs. So one of the things we've noticed with both anxiety and depression is if they happen before Parkinson's, this is before you even know you have Parkinson's, people who have anxiety and depression are at an increased risk for Parkinson's later in life, so the question is, is having a depressive episode or having anxiety somehow weakening your resistance to whatever's causing the Parkinson's? Sort of like an open window and then something flies in that causes the Parkinson's so that would be more of a true risk factor right lowering the threshold for disease incidence or and this is the one that I think is equally likely, is this already the Parkinson's underway in the brain? So you know Parkinson's disease almost certainly for most people exists 10 to 20 years before they notice their first movement symptom before you see a tremor or bradykinesia, the slow movement, almost certainly the Lewy bodies and other processes of Parkinson's are underway lower down in the brain and so we're wondering now if in some people who have anxiety and depression before their motor symptoms, if that's the same disease process, And so I think it's very likely that the same biological and chemical process that ultimately results in the movement symptoms in some of these, in some people, is causing the anxiety and depression.

Polly Dawkins:

And does a person generally present with both depression and anxiety, or are they really, are they concurrent or separate or is it as individual as Parkinson's is?

Gregory Pontone:

I like your last statement. So this is one of those situations where although we describe them as discrete entities, you know here's anxiety and here's depression, in general anxiety and depression co-occur quite often. And in Parkinson's, it's even more true. So what we always say

is if you see anxiety in Parkinson's or you see depression, look for the other one because they're most often both gonna be there but just as you said it's fairly individual too so I've seen individuals with only one and not the other, but the lion's share are a little of both.

Polly Dawkins:

Interesting. Before we dive into questions from the audience, I wonder... I've heard this phrase from one of your colleagues, Dr. Maya Katz, she's a movement disorder neurologist out in San Francisco and she once said, you know you can't just tell a person with Parkinson's to pull themselves up by the bootstraps because they're missing the bootstraps. You've got to do some therapies and treatments to help provide those bootstraps. Could you expound on that analogy and what that means to you as a doc?

Gregory Pontone:

I love that and I think it really gets to the point that this is not a foible, this isn't a character weakness, this isn't because you aren't trying hard enough, you literally are lacking the bootstraps, you're lacking the neurochemicals to maintain a normal mood and let's be clear I'm not saying that you know that we're not giving you a happy pill, you're not going to be happy all the time you're just going to experience the normal range of emotions that all the rest of us do. You just don't have the capacity anymore because you need treatment and so I love that idea that the bootstraps are missing and that's exactly what's happened is either due to chemical changes or some other biological change you're going to need assistance usually in the form of medications to maintain the normal range of mood.

Polly Dawkins:

So when let's say somebody walks into your office and meets with you if that's even a possibility, you're probably pretty busy, how do you go about discerning when it's time for treatment, when it's time for talk therapy? How do you or how would somebody go about seeking that path for themselves?

Gregory Pontone:

Absolutely so finding providers has become increasingly difficult, simply because there are too few, mental health care workers at every level, you know, whether it's you know therapists,



social workers, psychiatrists, psychologists, all of them are great options, it's just the the access because especially now with the pandemic I think utilization of these services has gone up. But when you can find them we think that doing more than one thing is important so I sort of think the traditional division is two arms of treatment. You know non-pharmacological and pharmacological is sort of one way to think about it and I think you should probably in most cases do both in tandem and so talk therapy, cognitive behavioral therapy, in particular, no doubt, that it's effective for both anxiety and depression specifically in Parkinson's. It's been tested and proven again and again to be helpful. Medications, there's tons of evidence for depression even in Parkinson's specifically, anxiety less so, but medications for many people are very important and then one of my favorites and I think Davis you know himself would 100% agree, I don't know if anybody's seen him recently you know the people on the call but he is still a specimen and you know he hasn't been you know riding professionally for a while, but exercise is one of the best medicines for Parkinson's and it you know everything from slowing disease progression to helping day-to-day symptoms and oh by the way there are formal studies that it helps cognition and mood as well, and in Parkinson's specifically. And so this is sort of the triad, you know get into therapy, get a good therapist or social worker, get the right kind of medication if you have a severe disorder, and then the thing you can do on your own is exercise and sleep well.

Polly Dawkins:

That is a lot to think about. I love that you bring in exercise because we hear time and time again for every single symptom of Parkinson's, exercise is one of the answers, yeah. All right I'm going to turn my attention really quickly to our audience questions before I get into sort of other mood disorders and apathy because I think that's another area that we'll want to explore together. Could you speak to something called amplified anxiety? Is that a thing, could you answer that?

Gregory Pontone:

Well yeah there's several ways that I think it can be amplified. I like that term in Parkinson's specifically. So you know we talked about the fact that certain situations, so the classic example

is that certain situations can trigger anxiety. So in people with a social phobia that sets it off and people with a specific phobia it can be something like a spider sets it off or heights or closed spaces. In Parkinson's one of the ways that anxiety is often triggered and it may actually be a clue as to what causes anxiety in some people with Parkinson's is dopamine fluctuations. So when people are taking their dopamine medications you know you take the oral medication and the symptoms get better as the medication is absorbed but at some point for most people they experience a wearing OFF. Usually it's gradual so we say it's an end of dose wearing OFF and not only can they feel their symptoms start to come back but sometimes they start to get a little anxious during that same interval of the dose cycle. And other people can have abrupt or sudden OFFs you know unpredictable OFFs and that is also associated not only with the return of motor symptoms but with anxiety. And so we do think that that is one of the ways that anxiety can really be triggered or amplified in people who either already have an anxiety disorder or people who don't necessarily have anxiety outside of that fluctuation cycle and I think that's a really particularly important type of anxiety in Parkinson's. Are there things that you recommend? Let's say it's a wearing OFF of your dose or sudden OFF, are there things that you recommend or strategies to deal with that anxiety in the moment?

Gregory Pontone:

Yeah absolutely. So there was just a funded study of a a very specific type of cognitive behavioral therapy that was literally engineered for Parkinson's and the particular types of anxiety that happens in Parkinson's. So Roseanne Dobkin has a manual that has all these specific things in it and it's literally helping people recognize the thoughts they have going into the dosing cycle and then when they start to have sensations of wearing OFF and then ways to allay their anxiety before it ramps up and gets out of control, so that's one. The other is to you know identify these yourself through journaling to make sure that they're reliably happening at a certain part of the interval, take that to your neurologist and there are some neurologists who can just work magic on you know getting better continuity so that you don't experience the wearing OFF in the first place.

Polly Dawkins:

Got it. Do any of the sort of wearing OFF or rescue medications help with the anxiety symptoms?

Gregory Pontone:

For some people they absolutely do, this is sort of back to your statement of you know everybody's a little different, but I would say the general trend is that many times rescue medications or just better tighter management absolutely provide relief. I mean in the best case scenario, the anxiety goes away in people who didn't have other types of anxiety and this was the only anxiety they had, managing that ON/OFF fluctuation better sometimes completely alleviates the anxiety and others you get maybe just moderate improvement but it's you know all helpful.

Polly Dawkins:

That's great, great to know. Somebody has just asked going back to the the analogy or metaphor of bootstraps, somebody has just asked, how do I find those bootstraps to start exercising, to start to do social things, I know I need to, but I can't get over that hump. Do you have any specific actions or recommendations?

Gregory Pontone:

Yeah absolutely I mean I think you know the first step really is sort of recognizing it and then assembling your team so to speak, okay. And there's going to be a home team and there's going to be an away team. The home team is the people around you that are going to help you re-engage with activities, socialization, and exercise. Okay and so that's going to look different for every individual. So for instance if there was a leisure activity like walking or tennis or cycling that you enjoyed doing before, sort of re-engaging in that and ideally doing it in a social way okay so if you can do it with a group rather than individually that's even better. We know that socialization prevents isolation which is a risk factor for depression and all sorts of bad health outcomes. So that's your home team, just putting yourself around people who are going to help you and support your participation in activities. And then your away team is if you can identify a therapist or a psychologist or a psychiatrist, someone to sort of help you professionally with maybe specific types of talk therapy, like cognitive behavioral therapy or interpersonal therapy



is another one that can be helpful. Medications in most people I think with Parkinson's like I said I really do believe for many people it's biological and so it's not just that you're not trying hard enough sometimes you need that missing piece.

Polly Dawkins:

For those folks who don't have a specialist like you in their backyard what are your thoughts on telehealth or telemedicine to receive the types of support that you're referring to.

Gregory Pontone:

Absolutely, so this is, you know, I think if there's one silver lining to what we're in the middle of here with the pandemic it's that our facility with zoom and other types of telemedicine vehicles has increased dramatically and so I still prefer the in-person contact but I think if you don't have ready access to specialists, telemedicine is definitely becoming more robust. Again you know talking about some of Roseanne Dobkin's initiatives, she has a tele health intervention specifically for Parkinson's anxiety and depression that seems to perform equally well to the in-person examinations and definitely has a broader reach in terms of distance.

Polly Dawkins:

Yeah great, all right looking at other other questions here. I want to wait to get to apathy because I think that's a whole other area. Can you say something about the differences in medications for anxiety?

Gregory Pontone:

Yeah so this is really tricky. So I'm gonna tell you something, benzodiazepines, okay, 90% of prescribing habits in North America if you have anxiety whether you go to a primary care doctor, a mental health specialist, your neurologist, at some point almost everybody reaches for a benzodiazepine. They are absolutely something to be cautious of especially in Parkinson's because they're sedating, in certain cases they can increase the risk of falls and confusion. That said, nothing seems to work as quickly or as well for anxiety as the benzodiazepines. So just so you can hear some of the specific names that are very common ones that are used in Parkinson's are clonazepam, lorazepam, and occasionally you're going to see people use alprazolam. Now these are all different types of benzodiazepines with the key difference being

their half-life or the duration that they're active in the bloodstream and so it turns out that the longer acting they are the better they are and the less habit forming, okay, so that alprazolam which is marketed under Xanax is like playing with fire because if you were talking about which one you're most likely to become dependent on it's the Xanax. And then if you have anxiety that's more persistent instead of just like a panic disorder you know you take one Xanax, alprazolam, you get three or four hours of relief and then it comes down and then you need another one and another one and you're kind of back on the roller coaster whereas the other ones are long-acting. So I'm not necessarily saying these are the best medications to use in fact I would say use them only with caution and for a short duration but I'm going to tell you the truth is most people with anxiety have had these prescribed at some point. The ideal use is that they're temporary while more long-term medications are used and these, here's the downside of the long term ones, if you take a benzodiazepine you're going to feel relief from almost any type of anxiety within 20 or 30 minutes. They work and they work pretty quickly. If you take the other type which are mostly antidepressants that are repurposed for anxiety. They can take weeks after achieving a therapeutic dose before they do their best work, but when they do work, they're going to give you a more consistent relief of that anxiety. The problem is imagine somebody who's having either panic or really high anxiety and you're giving them this medication and nothing's happening and nothing's happening and nothing's happening and you go up a little and nothing's happening because it can take four to eight weeks for them to do their best work, weeks. And so what we usually do is a low dose of a benzodiazepine just to help people tolerate that four to eight week period until the long-term medication kicks in and then we slowly taper and ideally get rid of those benzodiazepines and that's the best sort of option we have right now.

Polly Dawkins:

That's an art and a science together, yeah. What about, have you heard about dystonia that's been brought on by anxiety? I have seen almost every motor complication of Parkinson's triggered by anxiety. You know whether it's dyskinesia, dystonia, you name it and it's uh not just triggering the onset but the severity can be influenced. We've had people who rate their

dystonic pain as more painful when they're anxious. And so you know this is sort of the you know I mentioned before it's a bi-directional association between mental health issues and physical performance. We've shown that people who are depressed function less well physically, in eating, bathing, walking, speaking, for being depressed even holding their motor function comparable between two individuals. So the depressed individual is physically functioning less well than the non-depressed even if they otherwise have the same amount of Parkinson's motor symptoms. And we haven't demonstrated this is clearly yet in Parkinson's but this is another big one, so you know in cancer populations like breast cancer, we know that if you treat depression in breast cancer patients, their survival is 62 percent, north of 60 percent better, than those who have depression that's not treated. And so I suspect a very similar thing in Parkinson's that not only is it going to help you function better on a day-to-day basis, I'll bet there's implications for survival over time as well. We haven't proven that, we have proven in a longitudinal way that you can function better, that's our work that was published about 10 years ago and we're hoping to eventually be able to publish some mortality data too showing that treating the depression just like in cancer and other diseases has a global benefit for overall health.

Polly Dawkins:

That's pretty compelling. Somebody else asks about compulsive thoughts, is that a mental health issue, is that a dopamine agonist issue? Tell us a little bit about compulsive thoughts, what that is, what to look out for and strategies.

Gregory Pontone:

Yeah so you know compulsive, you know, we again, this is one where the terms themselves can be a little tricky. So when someone's compelled to do something that's because they don't want to suffer some consequence or they're compelled to alleviate some consequence they're already experiencing, whereas we also see some impulsive behaviors where people just can't inhibit themselves and so you know not debating the term too much, but I would say that classically impulsive, compulsive, spectrum behaviors have been associated with dopamine agonists like pramipexol and ropinirole, but certainly have also been seen with other levodopa

compounds as well, just not as commonly, but certainly with the agonist medications. Now that said, some people can have compulsive thoughts unrelated to their dopamine and that might be more truly an obsessive compulsive disorder, so usually that individual is going to have sort of this unwanted distressing thought that is repetitive and then they feel compelled to do something to alleviate the tension that thought is causing. So the classic example is contamination, right, you touch something and you're worried there's germs, so you wash your hands and washing them once isn't good enough, so let's count let's wash them ten times, you know and so that's the classic. And what I see in Parkinson's is less that than impulsive, but I've seen both and I think and again it's still an area of debate but I think the one that's more sort of consistently linked to Parkinson's is the impulsiveness and that's another one where sometimes people don't recognize the link, or they're embarrassed, and so it oftentimes doesn't come and get the attention it should.

Polly Dawkins:

Sure sure. Do you, are there strategies that you would recommend if somebody is seeing that in their partner or feeling in themselves even if it has shame around it? What would you recommend somebody do?

Gregory Pontone:

Yeah, this is going to be more of a global recommendation that will address that as well, I encourage, I'll tell you, you know, if you have a visit with me, I want to meet your family. So you know, and I bill the same, so if you come and you come with your family I should give a family discount because that's more resources for me. I would really encourage you to go with a spouse a family member whoever is closest with you to your visits in general whether it's your neurologist or your mental health worker because then you know then you can really have an open conversation about the things that are going on and sometimes it's not even that you're trying to hide anything you might not recognize it as a problem. It might not feel problematic to you and so it also adds perspective and so I think my global recommendation is that in general you should always you know have someone attend the visits with you, but especially if you

suspect that one of these impulsive or compulsive behaviors is occurring, you definitely sort of need an additional perspective or some kind of you know collaborative input.

Polly Dawkins:

Great thanks for that. Let's, this is a topic you may not want to touch on, but there's a question that we get so often as about medical marijuana or CBD to treat anxiety or depression and you're welcome to punt on that if you don't want to answer that.

Gregory Pontone:

Well no, let me, I think you actually have given me an opportunity and so let me tell you the way I think about medical marijuana, cannabinoids of every variety, alternative treatments, you know what I guess what's called alternative treatments or naturopathic treatments or any of that. I'm completely open to all of these things. I think at this point if one way if one little narrow way was the way to solve all problems we'd already have all the answers and we clearly don't, so I think we have to keep an open mind. But I think all treatments, anything that I'd expose my patients to, has to have the same standards for safety and efficacy, I would not give my patient anything that I wasn't confident had passed a certain standard of safety and because I don't want to waste their time. I have to have some indication, some evidence of efficacy, and so whether it's the most sophisticated unpronounceable pharmaceutical compound known to man, right, that's in latin or some other language I don't know or if it's blueberry powder that some you know five thousand years ago they found in China helped with something, we have the same standard and let me tell you I think what's called, you know, alternative has an equal chance of being helpful I just want the same level of scrutiny. I mean I can tell you exercise, I got to tell you, you can name 10 drugs, and I'd rather have exercise and there's better evidence. You know, so this is one of those things where I just think we have to have a standard for safety and efficacy and an open mind because I guarantee you there's things hiding in plain sight that we just haven't tried rigorously, to answer some of these questions, so getting back in a long-winded way to your medical marijuana question. I am confident there are so many sort of native cannabinoid receptors in the brain, that if we can learn how to use these molecules or derivatives of these molecules appropriately, I guarantee



there's some symptoms that will be helped by these type of compounds, but without this type of testing and you know rigor I worry that we'd expose people inappropriately to some risks.

Polly Dawkins:

That's a great way to answer that question. You brought exercise back into the picture.

Aomebody has asked are there any particular exercises that you would recommend that alleviate the symptoms of depression or anxiety?

Gregory Pontone:

Absolutely, so if you guys will humor me, actually I have a little list of literature here on the screen in front of me on purpose because my goal was to say exercise till you guys were tired of hearing it because here's what happens... we get people who come in and they say look I'm desperate what do you got, do you have anything new that I could give you and I go how desperate are you, and they go desperate, and I go desperate enough to exercise? It's that important and I mean, you know, I don't want to be a nuisance but this is one where we know it helps day-to-day symptoms slows down disease progression and helps almost every aspect of mental life and this gets back to that you know transition between emotional and physical life or mental and physical life. It turns out that if you have Alzheimer's right now, one of the best things you can do for your cognitive health, for your brain health, is physical exercise and so in Parkinson's specifically I think you're going to be surprised when I tell you these numbers, because I was surprised when I looked this up. It turns out that right now there's been 18 high quality studies of aerobic exercise so cycling, running, swimming, anything that gets the heart rate up, specifically in Parkinson's right and they've been shown to help specific types of cognitive functioning, like executive function, which is one of the biggest ones affected by Parkinson's, it helps with language. You know people always tell me with Parkinson's they say I'm having trouble finding words sometimes. Turns out exercise helps a little bit with finding words and I mean these are things that I mean you don't have to win a ton of medals like Davis did, you know you just do the things you enjoy and get your heart rate up and you know maybe do it with friends and it helps and then, oh by the way, all these studies have also shown that it helps with depression, so you're helping yourself mentally, you're helping with the depression,

so that's aerobic exercise, you said what type? Turns out there's been not as many, but there's been a few studies I think three really high-quality ones that looked at resistance training. Okay, so you can do resistance training with weights, you can do resistance training with you know rubber bands, you know elastic bands sometimes, just your body weight and they've shown that that also improves executive functioning and attention, so cognitive improvement along with some mood and anxiety reduction. And then finally and this one's a little more tricky because yoga does so many things I mean yoga is not just flexibility, yoga is a little bit aerobic, yoga is a little bit strengthening, turns out that yoga looks really good for anxiety and depression and it might also be that there's that mindfulness element in yoga, balance and gait as well so I mean you name a type of exercise and it seems to have real concrete benefit in Parkinson's both for the physical symptoms and the mental symptoms and so everybody's got to be doing a little of this. And it doesn't matter what, I always tell people whatever you enjoy is the exercise type to do at this point and if we change our recommendations, I'll let you know, but find what you enjoy and start with that.

Polly Dawkins:

That complements exactly what Davis and Connie started with this morning. May I ask you to define, what does executive function mean? For audience some may not know what that term is.

Gregory Pontone:

Yeah deficit is, yeah that's, let me tell you, we have Jason Brant is just retiring from my institution, he's sort of this world renowned neuropsychologist, brilliant guy and he said you know if you ask 10 people what executive function is you'll get 10 different answers right and you know the more letters they have behind their name the more convoluted it'll be and so what I tell people is to the best of my ability to understand what it is, it's our ability to organize sequence and plan and so in a way it's involved in almost every aspect of your day-to-day life you know to some extent and so what we do know is that it's usually one of the earliest and most often affected domains or types of thought or cognition in Parkinson's and so learning to sort of manage the changes as they occur is important and so people use calendars more often



so even if you were never a person who used a daily planner or a calendar or a dry erase board with little check boxes that is a skill a strategy that you should start to implement maybe even before you recognize problems. That way it's already a habit before you need it.

Polly Dawkins:

Got it. Thank you. All right back to a question about a depression from the audience uh can depression result from inadequately treated low dopamine states and can depression improve with better treatment of Parkinson's?

Gregory Pontone:

Yeah so yes globally and I'm gonna give you some concrete examples here. So what I will say is that we just published some treatment recommendations, treatment algorithms for both depression and anxiety in Parkinson's and our treatment starts with optimization of motor function, so to answer the end part of that question, absolutely. You want to have optimally treated motor symptoms renders your anxiety and depression more amenable to treatment and so that's a definite. Now the direct link between dopamine levels and depression is a little in some people it's really important and other people it might not be as important but there was a really great series of experiments back in the mid 90s. It was published, the first author was Miracle but it was Jay Nuts group out in the Oregon health system and Dr Nut has just I think he's emeritus now but he's a brilliant guy who did Parkinson's research for many many years and he did these dopamine or levodopa infusion studies and he looked at everything from motor function and the kinetics of levodopa I mean really it's groundbreaking stuff and it's still incredibly relevant today and he noticed that if you gave people a levodopa infusion their mood got better as the dopamine went in along with their movement. So for many people with Parkinson's there's a clear association with their mood state.

Polly Dawkins:

Interesting. Y'all in the audience have got great questions thanks for for submitting them. We've got some more time. I want to get into the question that many people are asking about apathy and apathy seems to be such a troublesome symptom. Could you maybe help define

what is apathy and are there some strategies that either care partners or people who are experiencing apathy can utilize?

Gregory Pontone:

Yeah, so apathy and depression have a pretty significant overlap in symptoms. Remember I said depression is sort of a syndrome of many symptoms and so apathy has that anhedonia, that sort of lack of interest and pleasure as a central feature, but what it doesn't have is you know when you're depressed, you can feel guilty or bad or even suicidal right you have these negative emotions, the apathetic person is usually not the person coming to you to complain. It's their spouse they're like he only sits on the couch all day he doesn't do anything I ask him to do stuff sometimes he'll come along and then you know he doesn't care and so apathy is really this sort of energetic state where there's no initiative good or bad right and the problem is it probably happens in about a third of people with Parkinson's and I think it goes unrecognized because like I said the person who's apathetic isn't complaining so unless a family member or someone close to them brings it to clinical attention, it's unrecognized and I do think it's fundamentally mechanistically different than depression in most cases. And I can tell you that for two reasons. One is it seems to happen in parallel with disease progression and the emergence of cognitive impairment, so I think there's a bigger cognitive piece than a limbic or emotional piece with the apathy and two, and this again a lot of this is anecdotal but I think there's a literature to support this, I've tried all kinds of antidepressants in apathetic individuals and antidepressants don't seem to help apathy. So getting the diagnosis right, differentiating apathy from depression is really important because if you try to treat an apathetic person as if they have depression you're not going to have much luck. What we have had luck with and this there's formal, what's called randomized controlled studies that support this, is that acetylcholinesterase inhibitors, cognitive enhancing medications like rivastigmine or donepezil have shown some benefit in apathy situations. And so that's not an antidepressant that's a different mechanism you know different molecule to help the apathy, so that's shown some benefit in Parkinson's. And then in some people usually after deep brain stimulation with Parkinson's, dopamine agonists like pramipexol or ropinirole seem to help apathy in those cases

but that might be more specific to the post DBS case but it's definitely different than depression and requires different treatment, but is very common, maybe up to a third of people. It was you when you spoke for us in maybe it was up in Canada the last time we were together and you gave an example of apathy. It was a perhaps one of your patients who was watching the baseball game? Can you tell people and so it brings to light what is apathy...

Gregory Pontone:

Sure and I hope that you guys appreciate that I learn as much from the people I work with with Parkinson's and their families as I do from the book. So this was you know a spouse of one of my patients and she's telling me, so this is the classic example of apathy, she's telling me he comes in the office, and he tells me he's fine, he's got no problems, right, the world is beautiful. And you know she comes in and says all he does is sit on the couch. She says the other day the power went out, he was watching the ball game, it's the seventh inning, tie game, right, his two favorite teams and power goes out. When it comes back on the cable doesn't reconnect so he's just watching the snow on the television, sitting there on the couch and he didn't even care enough to get up off of the couch and try to change the channel or reset this you know the cable box to get the game going. And she said well maybe he's just being lazy I'm gonna wait and see how long it takes him to reset this thing and she says she waited an hour, she comes back he's still watching the snow as contentedly as he had been watching the game. And to me that really just anchored what apathy, what the experience of apathy was like for the patient in the family.

Polly Dawkins:

Yeah and the effects on the family, it's just so hard to watch your loved one not want to do anything.

Gregory Pontone:

Yeah something he loved, yeah absolutely. He used to, he was a you know paint his face type of baseball fan.

Polly Dawkins:

So how do you how did you or how do you coach the family member who's saying this is a terrible thing because it seems as though that treatment for that person or therapy or something for that person is equally important as for the person that's experiencing it, do you have strategies for the family?

Gregory Pontone:

Yeah so you know I think this is really important and this is sort of an emerging trend and treatment is not you know some people are more amenable to medication some people are more amenable to non-pharmacological therapies, some families are more involved in care and some are more removed and so I really think and this is why like I said I really encourage families to come to my meetings because I want to learn what works well for them you know I want to meet them sort of where they are and find out what works best for them and get to know them all and say well okay what would be the best way for us to implement this best evidence change to improve wellness and quality of life here and so I really do I think you got to get your hands dirty and roll up your sleeves and work with everybody who's affected by the disease which is more than just the patient.

Polly Dawkins:

Absolutely, thanks for that I'm going to go back to questions here. Why do you think resilience seems to be lower in people with Parkinson's?

Gregory Pontone:

Well you know, I don't know if I'd say that because you know, as a population, I do think this is maybe a little more, I hope it's a little more individual specific and not a trend in the disease because I have seen some individuals I mean if you were to look at you know motor symptoms or disease severity across people I've seen people of equal severity and one is just thriving and the other one same symptoms having a completely different experience and that's where I think resilience alters the equation because I've seen people where you think oh my goodness this guy's got to be miserable or you know suffering or and he comes in and he's happy and he's telling me jokes and making me laugh and I think resilience is, it's somewhat to do with temperament but I also think it's a skill that people cultivate over life and importantly I think it's



a skill that you can cultivate at any point of life and I think it can change your experience of any disease, Parkinson's, any disease and so I think learning that resilience is important and this is one of the things that we've really been thinking about is what is resilience and how can we teach and cultivate it and I think resilience is one of those things where it doesn't necessarily have to come from a medical professional. This is something that can come from within the community and so I think sometimes shared experience is going to be one of the important seeds of resilience because you know I can tell you any textbook thing you want to know about Parkinson's but I certainly can't share the parts that people who are suffering from it can with each other and I think that's where one of our hopes is that we can build or help facilitate communities of people with Parkinson's, to cultivate things like resilience and wellness and strategies to not just get over the next symptom in the pile, but to thrive, to go beyond just getting rid of a symptom and really experience you know the highest quality of life you can.

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