Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed the cure at michaeljfox.org.

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

Dr. Soania Mathur: Hi everyone, and thank you for joining us. I'm Dr. Soania Mathur, physician advocate and someone who has been living with Parkinson's Disease for about 26 years, having been diagnosed at the age of 28. It's so good to be here with you today. We have a special webinar, a special edition 90-minute webinar on emotions. To share with us today, we have a wonderful group of panelists to hear from and there will be extra time now to answer your questions. During webinars, we get to hear a lot about the newest treatments and advancements. We learn about specific aspects of the disease, logistical information, how to manage our PD, but one of the most important aspects of our lived experience with this disease is how we emotionally feel, how we emotionally cope with this diagnosis. So we will be going deep today into all of the many emotions that come along with the Parkinson's journey and how those have looked for each of us. We've got a lot to discuss, so let's get started.

Let me start by introducing our panelists. Fiona Davis is a bestselling author of several novels set in New York City. She sat on boards of the Columbia Journalism School and the Manhattan Theatre Club. She was diagnosed with PD in 2020. Jim Hurtsellers is a marine veteran and former preacher. He's a husband and a father and was diagnosed with PD in 2020 as well. And Bret Parker. Bret is the executive director of the New York Bar Association. He was diagnosed with PD in 2007 at the age of 38. He's an athlete and a Parkinson's advocate and serves as co-chair of The Michael J. Fox Patient Council. He's based in New York City.

Yvonne Jackson is a businessperson and advocate. She served as C-suite executive for Fortune 500 companies and has sat on many nonprofit boards including chair of board of Spelman College. She was diagnosed with Parkinson's about 11 years ago, and her late husband was diagnosed within two years of her own. And to give us a professional perspective is Dr. Laura Marsh, a geriatric neuropsychiatrist who specialized in research and care for people of Parkinson's. She's a professor and the Menninger Department of Psychiatry at Baylor College of Medicine and is the executive director of the mental health service at the Michael E. DeBakey Veterans Affairs Medical Center. Thank you all for joining in this discussion today.

So I want to start off with Michael. Michael has this quote and he says, "Acceptance doesn't mean resignation. It means understanding that something is what it is and that there's got to be a way through it." That acceptance always doesn't come easy though. We all have expectations. Expectations of a normal life trajectory, unencumbered by limitations. We expect to meet our goals socially, family-wise, occupationally. So when we are diagnosed with a disease that impacts every part of life, it can hit hard. An acceptance can be difficult.

For me, my diagnosis couldn't have come at a more inconvenient time. I'd just finished my residency in family medicine, had started a new practice and was pregnant with my first daughter, but a tad bit busy to try and fit PD into my life I'd have to say. I know that for the first decade of my diagnosis, I was angry. I was fearful, and I was in denial. Of course, I knew that I had Parkinson's disease from an intellectual perspective, medical standpoint, but it took a long time and a great deal of introspection before I could emotionally accept my diagnosis, what I call true acceptance, not lay down and accept you have no role to play that you're resigned to a life devoid of [inaudible 00:04:14]. That to me is resignation. I'm speaking about the type of acceptance that allows you to move forward to take an active role in your management to look beyond your diagnosis. So let's start there.

I want to ask each of you a little bit about your stories and what your emotional journey has been like with PD, and I'm curious if that quote that I just read from Michael about acceptance holds resonance for you or what the concept of acceptance means to you. Maybe Fiona, you can start us off?

Fiona Davis: Yeah, sure. I'm thrilled to be here today and thank you. I think the quote's terrific. I know for me, acceptance, it's about integrating my diagnosis into my identity. In a way, when I was first diagnosed, I was in shock, of course. I was very fearful. And it was a separate thing from me. It was something to be conquered, something to be ignored, something to be angry at. But I think within about two years similar, it took a couple of years for it to sink in and to just be part of me and suddenly it's integrated and it's something that I deal with day to day, but certainly doesn't drive my life or overwhelm my life anymore. And so it made it easier for me to manage it, I would say.

Dr. Soania Mathur: Allowed you to move forward beyond your diagnosis. Jim, what was your experience?

Jim Hurtsellers: Much similar to yours, actually. I was shocked that I Parkinson's and initially I was so healthy. I started showing symptoms when I was in my forties. But it was something that the doctors thought, "That's just because you're an endurance athlete and you're stressing your body or your fatigue."

Dr. Soania Mathur: Yvonne?

Yvonne Jackson: Much like Jim, I was an athlete. I had retired from my corporate life, I was on boards, but I was an athlete. I was doing triathlons. I even rode my bicycle across New Zealand. So I had this little tremor and I thought nothing about it. But I went to the doctor of course and asked all the right questions, was sent to a movement disorder specialist, and then was diagnosed, which I didn't accept, and said, "Wait a minute here. How is that possible? Look at me." And then took a DaTscan, which confirmed the diagnosis, ended up with a doctor here in California who was really great movement specialist. But that initial moment, I was completely stunned. I had no concept that I had anything like Parkinson's.

So I got through that and I immediately started doing a lot of research and talking to people that had Parkinson's and accepted it. Then two years later, my husband was diagnosed with Parkinson's, and that was a while. Now, he would say, if he were here, he would say as he sat through, as my care partner had sat through my meetings with my doctor, that all those questions that were asked of me, he was answering them in his own head about himself, and he was answering yes to those same questions, but of course he wasn't talking to me about that. Obviously, he immediately went on the medication. Initially, I didn't go on medication. My doctor said, "Keep doing what you're doing with the exercise."

And then we both found Rock Steady Boxing through my research and started boxing. I started boxing and then got him to go through boxing with me. I began to be more comfortable talking about Parkinson's, and I talked about it in terms of my boxing. That was my short initial journey.

Dr. Soania Mathur: So Yvonne, I just wanted to ask you based on what you said, I'm interested to know, was it easier for you to accept your diagnosis or for you to accept your diagnosis of your husband? Because I've often said the care partners to me are the ultimate because I couldn't bear to really see this disease in someone that I love so much. It's easier, I feel like, to bear my own disease.

Yvonne Jackson: It was easier to accept my husband's diagnosis for two reasons. One, I knew a lot more about the disease by that point. And second, I could see his gait change. I could see his balance was off. There were things that was pointing to the fact that he had Parkinson's. In fact, when I sent a note to my neurologist to say, "Would you see my husband? He's showing these symptoms." And he said, "I'm not sure that I'm the right person, but yeah, when he comes in, when you guys come in, I'll devote some extra time to talk to him as a patient."

But it was clear to me, having now learned a lot about the disease, that Fred also had Parkinson's, we were just waiting for... I was just waiting for that diagnosis. And I wouldn't tell him what I knew, what I thought, what I was experiencing, nor would he tell me that he had answered those questions some two years earlier that he was answering yes, yes, yes some of the same questions that I was having to answer yes to, giving my information to. So it was an interesting [inaudible 00:09:45]. I think he was trying to protect me and there we were.

Dr. Soania Mathur: Wow. Thank you for that interesting perspective. Jim, so maybe go back to that question. What does acceptance mean to you and does that word resonate or would you describe it differently?

Jim Hurtsellers: It does now. Initially, I refused to accept the outcome. When I was in the Marines, it was always about accomplishing the mission. So you did whatever you needed to do to get that mission accomplished. And with Parkinson's, I treated it the same way. Okay, so I have Parkinson's, so I'm just going to do whatever I can to beat this disease. And I still think we have to have a positive attitude, but we have to be realistic and say, "It is a disease," and no matter what you do or how hard you try medications, medical treatments, so forth, you have to really come to a point in your mind where you say, "I have to accept this," but that doesn't mean it has to define you.

Dr. Soania Mathur: And then talking about the definition, one of the most frustrating things for me to adjust to is feeling limited by this disease. I've always been on the go very type A, on this unrealistic to-do list that didn't stop until I tried to get everything done. But as you know, PD doesn't care about your to-do list. Nor does it care about how you envision filling those roles and responsibilities that you have as a mother or a wife or a doctor or whatever profession or a daughter or a friend. You have to learn to accept and to be adaptable. You have to in some ways redefine, as you mentioned, your vision for yourself, define yourself by what's truly important, those things that really may not actually be dependent on your physical abilities. But what were your emotions like at the start of your journey? When and how did you share your diagnosis?

Bret Parker: So at the start of it, it was very shocking. I was really young. I went to the doctor not expecting this to be what I was going to hear. And so when I heard that I had Parkinson's, I actually didn't even have my wife with me at the doctor's appointment. I thought it was going to get a carpal tunnel diagnosis [inaudible 00:11:44] a slight tremor. So I had to go home and tell her, but she didn't even know I was at the doctor. So that was a very upsetting, emotional experience. It was very shocking. After we got over the crying phase, one of the things that we thought about was it was a ticking time bomb. That's a phrase that hits my mind. Because my symptoms were so minor, but we knew that down the road they were going to get really bad.

So for the first five years, I didn't do much acceptance. I did mostly denial, I think is the word you used [inaudible 00:12:11]. And so for five years, we didn't tell anybody, I didn't do anything, and my symptoms were very minor. And so acceptance has changed for me over time. When I started to tell people, as Soania knows, at first I told one person at a time and it was just too exhausting. So I basically wrote a blog. I published it on the Forbes website and send everyone the link, and that's how I told everybody. So that was quite an emotional roller coaster.

Dr. Soania Mathur: Must have been indeed. Fiona, you were diagnosed about five years ago, but you had symptoms I understand before that? Were you expecting a diagnosis like this? Where were you in your life before you heard those words and what changed after that day from an emotional perspective?

Fiona Davis: Yeah, that's a great question. It was 2020, so we were all in lockdown, and I just noticed that my right hand would shake as I held my phone. And because we were in lockdown, we weren't seeing anyone, we weren't interacting with other people. So it was very easy to just think, "Oh, I have a book coming out. It must be anxiety or something." And then I had this interesting time where the book came out and one day I got a call from my editor saying, "Oh, it hit the New York Times bestseller list," which was very exciting. And then the very next day I went in to see a movement disorder specialist because they said, "Just go check it out." And they said, "Oh yeah, you have Parkinson's." And so I went on this kind of emotional roller coaster of elation to shock and fear.

And so at that time, I had the same symptoms of course, but there was this whole other resonance to it. It wasn't essential tremor, it was something more serious.

And so for me, I immediately came home and went into researcher mode of, "Okay, what is this? What's it all about?" And it was a little scary because you read things that are... You think, "Okay, I'll possibly be in a wheelchair in the next 10 weeks." And that's not true. You still are where you are when you were diagnosed. And so it took a lot of education to figure out, "Okay, here's where I am and it's okay for now, and let's just be in control of what we can right now."

Dr. Soania Mathur: Yeah, that's an empowering way to look at it for sure. And Yvonne, I know you were someone living with the disease as well as care partner for your husband. I know you were both diagnosed within two years of each other. But how did your emotional reaction to the need to adapt to a new normal with PD differ or overlap with your husband's?

Yvonne Jackson: First of all when I was diagnosed, I went back to my primary care doctor and I said, "How can you help me with this?" I remember crying in his office and saying, "How can you help me with this? What do I do? What am I supposed to do? I know I'm not ready for medication yet, but what do I do about this?" And unfortunately, he couldn't answer many of my questions. I guess I was looking for somebody to tell me, "okay, here's what you do next. Here's what you do next." And that wasn't possible. So that's when I went about trying to research it myself and understand more about PD and what are we different. Again, with Fred, my husband, I would tell him all my research and this and that and that. So he was well into understanding the disease by the time he was diagnosed. Much more calmer personality than I am. He's cool. He was a cool guy and he was a guy. He was a guy.

We had very different reactions. One, because he knew a lot more about it. I knew nothing about Parkinson's when I was first diagnosed. I just didn't even know where to go to find the answers. And I had worked at a pharmaceutical company for a number of years, so I knew a lot about research and all that kind of stuff, and I just started going at it. Then I found out about Rock Steady Boxing, and that was the turning point in terms of knowing other people who had Parkinson's, who are fighting Parkinson's. And so that really got me connected to a community where people were fighting the disease and I liked that.

Dr. Soania Mathur: And Jim, you're also an endurance athlete and you were a veteran, or you are a veteran, very high functioning. Do you have the guy's cool side, or how do you think your life experience impacted your emotions around your diagnosis?

Jim Hurtsellers: For me, it was like a shutdown. I did not want to let Parkinson's define who I was. And I was actually quite good initially of hiding the symptoms from people. I would hold something in my hand or put my hand in my pocket, the different things that... Because the emotional side of it was that I'm losing who I am. It took me a long time to process the fact that I was still the person that I was born to be. It's just a matter of letting go of that fear that you're not going to be you anymore.

Dr. Soania Mathur: Right. Yeah, no, I like that, I'm the person that I was meant to be is really... And you talked a little bit about the subject of disclosure, telling others, and it took me... I'll tell you, I'm a slow learner. It actually took me a decade to actually disclose my diagnosis beyond my husband and a couple of close people. I didn't want that pity party. I also had a lot of self-stigma or fear of judgment that I wouldn't be thought of as capable enough. So it was difficult to disclose, but when I did, it was like a sense of freedom. A burden had been lifted. No pity party was [inaudible 00:18:03] out for me. The audience has a question for this issue. They asked, "Does acceptance mean telling others, telling work, for instance?" Anyone want to tackle that one?

Yvonne Jackson: This is Yvonne. I'll just say this. I wasn't working full time, I was on two public company boards, and I told them immediately. I just decided after I went through that crying spell in the doctor's office and then doing my research. And after I started boxing, I introduced myself as saying, "I have Parkinson's, but guess what I'm doing to deal with the disease? And it's boxing." And they would all get a kick out of that. Of course, I couldn't do it while I was traveling. So I told friends, family, everybody after about two months of discovering what this disease was.

Dr. Soania Mathur: Right. And Bret took control and wrote that blog for his disclosure.

Bret Parker: Like I said, for the first five years, I didn't tell anybody. And especially my work, I really didn't want people making decisions about me and about what I could or couldn't do. [inaudible 00:19:13] right in the thick of my career and I did not want that to be something that people would be thinking about.

Dr. Soania Mathur: That makes sense. Fiona, when did you disclose to your greater circle?

Fiona Davis: Yeah, I was in a way lucky that I was diagnosed during COVID because I was on Zoom all the time and you couldn't see the arm flapping, so I didn't really have to tell anyone. I was very open with it with friends and family. But then in terms of wanting to share it with the greater world, I did end up writing an article for Good Morning America for their website that they published, which was really wonderful because it was about how the diagnosis came about. And once that was out, suddenly it was just wonderful to go to an author talk and have someone come up to me and secretly say, "Yes, I have it, but I haven't told anyone." And just be able to share that load with other people who I understand why sometimes you need to wait.

Yvonne Jackson: Yeah, absolutely.

Dr. Soania Mathur: Yeah.

Yvonne Jackson: Everybody's got to do it in their own timeline. There's no one way to... I talked to many people since then. I get calls. Now I'm among my friends and colleagues, I'm the Parkinson's person that everybody tells, "Oh, call Yvonne." So I talk to a lot of people and some people say, "I can't tell anybody." You can't tell anybody, that's okay. Whatever works for you In terms of that disclosure.

Dr. Soania Mathur: Yes. Dr. Marsh, we hear that everyone's life experience is different. We all recognize the heterogeneity of Parkinson's disease in terms of symptoms, in terms of life experience. And you're in a position where you see many people at various points of their PD journey. What are some common threads and have you noticed some commonalities based on different groups like young onset versus older onset men versus women, for example?

Dr. Laura Marsh: One of the things that's really important to remember is that a number of people do have pre-diagnosis depressive disorder. It's not because they're depressed because they have Parkinson's, it's because Parkinson's is a disorder of the brain, and brain disorders can lead to mood dysregulation and depression and anxiety are part of Parkinson's, and they're more common than in the general population. So I think the first thing is that one of the common threads I see of people, when they're presenting with the early symptoms of Parkinson's disease and they have a mood disorder, it's so important that that is recognized. And we'll talk a little bit more about how to tell the difference between just regular moods and something that needs more. But when you treat that, many people will say, "I can cope with Parkinson's, but not if I'm depressed." So that's kind of the first thing that is so critical.

Then there's this fundamental existential aspects of having this condition, as others have talked about, the sense of identity that gets changed and is there a shift in oneself that occurs? And so I found, as others have said, there's this fear, this fear of the unknown. Are you not talking about it or not accepting it because you're afraid that if you do accept it, something else will happen? We know that in therapy that if you don't talk about it, you can't do anything about it. So it's often important to talk about what you have. There's one other group that I've often found... Someone will come in, "I'm going to beat this Parkinson's disease," and someone else health says, "I'm going to conquer it. I'm going to not let it get the best of me." And the more they push against it, the more it rears its head. So that is the antithesis of acceptance is saying you're going to beat it. Because others have said when it's there, it's there. Whether you're trying to beat it or not, it's still there.

So I often have talked to patients about Parkinson's can be this monkey on your back, and at some point you have to say it's your friend and you're going to hold its hand and you're going to walk together. So that aspect of how do you get to that point may be something that if you're afraid of getting to know that monkey, that's when you need to begin to talk about it more and to talk to Yvonne and then walk with that.

Dr. Soania Mathur: Now, one of the audience members who's listening in talked about one of the most debilitating features of their Parkinson's disease is the impact on their ability to speak clearly, like I'm having trouble right now, simply to form words, and that's to articulate their thinking. So they feel cut off and isolated. So they're wondering how to cope with that feeling of isolation. Do you have any thoughts on that?

Dr. Laura Marsh: Coping, it's a topic that's so interesting. I said the other day, the way I've learned about coping is really from... Everything I've learned about coping with Parkinson's has been from the people who have Parkinson's. And so one thing that I think is important is if it's something that you can change, then you should change it. But if it's something you can't change, trying to change it is not an effective coping strategy. So some of the things you can change when you're looking at speaking is what are the circumstances? If you are anxious about speaking, so you have anticipatory anxiety, and then that makes your voice even softer. That's the kind of thing that you can work on managing anticipatory anxiety. Is it because you're trying to speak in groups? And so really understand the nuances of that and what is the role of the emotions and how do they impact those kinds of problems. And then there's lots of speech opportunities that can be... We're talking about the emotions and how they affect things.

Dr. Soania Mathur: And that brings us to navigating those challenging emotions. And you've all expressed a range of emotions, and I really honestly do thank you sincerely for being so open and sharing your experiences is not always easy. But let's take a look at how you cope with those emotions. For me, I would say above and beyond my sometimes successful attempt to keep a consistent routine of self-care, the sense of community, the strength of sharing life experiences with those that intrinsically understand is enormously helpful. Talking to others, being able to relate to their struggles and learning from them in how to navigate certain hurdles has been key for me. And that's why I think this part of the discussion is really important because that can happen in person or it can happen online.

Jim, you mentioned to me before that the strength you get from support groups talking with like-minded individuals has been helpful in your journey. Could you tell us a little bit about that? Because sometimes newly diagnosed people can find that intimidating. And what else do you do to cope with your stress of PD and then navigating those emotions?

Jim Hurtsellers: Yeah, absolutely. I found it very helpful when I finally got to that point where I could be open about the illness and not try to keep it hidden away from people because I felt like they were going to look at me and say, "He's not the same man that he used to be." So when I got past that, I was able to join a Parkinson's support group with other people who have Parkinson's. We meet regularly to share where we are on our journey. And it's also helpful for my wife, who is my primary care provider, because she can have an outlet too. There are groups for caregivers, and it's a place where you can go to have special support with people who walk the same places, they know the same journey, and they can be a source of comfort and friendship. And additionally, my church has been very helpful to me. It's a source of comfort for me during my journey with Parkinson's.

Dr. Soania Mathur: Of course. Yvonne, you've spoken about... I feel like boxing has also been a bit of a support group for you as well.

Yvonne Jackson: Once we started boxing, we were in a neighborhood of people who were like us, and different symptoms obviously and different issues. We all experienced Parkinson differently. From my husband, it was his gait, he was falling, and ultimately swallowing. But we were surrounded with people who have the disease, who we're boxing with and all of that. And that was really the best find, I would say, for me, and ultimately for Fred. It took him a while to get into Rock Steady Boxing, but he did. So yeah, that group became our network. And everybody is there after class talking about their medication or this or that, their constipation, all those things that we all experience as Parkinson's patients. So it was wonderful.

Dr. Soania Mathur: That's definitely a support crew for sure. Now, just to focus on the exercise part of that, I know that exercise is helpful and I'm very vocal to say that I don't enjoy exercise at all even after all these years. But nevertheless, I know it's important for my physical and mental health. So I force myself to do it daily. Fiona and Fred. Fred, I know your accomplishments when it comes to exercise, but how does it affect your mood when you exercise?

Bret Parker: I'll say when I'm exercising and I'm a serial exercise person, I'll exercise [inaudible 00:28:13] not exercising. I always feel better physically and emotionally when I'm exercising, I actually literally feel, I wouldn't call it a runner's high, but a little bit of the endorphins and the effect on your brain. I feel better. I feel more optimistic, I feel more upbeat. And when I'm not exercising, I feel the opposite. What I have to do is avoid that spiral of getting so far out of shape that it's hard to come back. So for me, exercise is important. I just don't listen to my own advice a lot of times.

Dr. Soania Mathur: Oh gosh, I hear you. Fiona?

Fiona Davis: Yeah, I'm such a rule follower. So I follow the Parkinson's guidelines that were put out in terms of doing four times a week about 30 minutes of usually peloton or fast walking, a couple sessions of strength training, some stretching. And I find it makes such a huge difference. I was injured earlier and I couldn't do it. And the difference between being able to sleep well, just being able to keep an emotional steadiness, and also just the way I move through the world is different when I feel strong and that I've worked out. And I just want to throw out one more thing in terms of navigating these emotions. I think finding an art form, whether it's writing short stories or poems or dancing or singing, just finding something where you can put all of that into and have something creative come out, I think is a really powerful tool as well.

Dr. Soania Mathur: I couldn't agree more. Dr. Marsh, there's a lot of questions that are asking about how to navigate overwhelming anxiety and crying and that sort of thing. Could you maybe address those issues for me?

Dr. Laura Marsh: So I'll first talk about anxiety. Anxiety is fairly common in Parkinson's, and studies have even shown that it can occur again before Parkinson's is actually diagnosed. And there can be higher rates of different kinds of anxiety disorders in patients. And I still remember one of the first patients I saw who worked on an electrical line. He was going up in those cherry pickers and he was a fearless guy. Before he got diagnosed as Parkinson's, about a year before he started having claustrophobia inside a restroom stall and he got stuck in there and if he had freezing. So this is when his Parkinson's became apparent.

So these are the kinds. There's just several types of anxiety. Sometimes there's, as I mentioned earlier, anticipatory anxiety. And someone had said that, can emotions make symptoms worse? So when someone is anxious, will I be able to get to my doctor's appointment on time? And they wake up early and then they're so worried they're not going to get that they then freeze and then they can't get there. That's one type of anxiety. And then there's another one that's very situational like in close places or certain kinds of what would be phobias or high areas, et cetera, that when they didn't have those when they were younger, but they have them later on, or only in certain situations. So that's a different one where you begin to manage that situation differently or you mitigate it.

And then there's those anxieties that occur as your medicines wear on and off that are really related to fluctuations in the dopaminergic medicines. And then some people have anxiety that can be also part of a mood disorder where they're also having depression. But anxiety doesn't mean that you're feeling depressed and down all the time necessarily, it can be separate. The first thing about anxiety I want to tell people is that often when we treat anxiety in the absence of depression, it's often done with behavioral methods. And what's great about that is they're already taking a lot of medicines when you have Parkinson's. So if you can do anything that doesn't have another med-med interaction, that's a great thing.

And so people have mentioned mindfulness and breathing. And one of the findings in the studies looking at cognitive behavior therapies for anxiety is that one of the things that people with Parkinson's really like are the breathing exercises. So a couple things with anxiety, if it's something you can either be apprehensive or you can avoid it. One of the best ways to manage your anxiety about something is to avoid it. What happens when you avoid what makes you anxious? You get more anxious. So you have to begin to confront that. And we've had some other situations like that, like should you tell people and things.

So when you're fearing something, often every behavior is in service of a need. So if your need is to have people think about you a certain way or that you're afraid of what people will think about you. If that's the fear that every time you then go into a social situation, you're going to be thinking about that and not necessarily enjoying that situation. So really managing that anxiety in a very behavioral way. Other times, it needs other kinds of intervention, but those are some quick snippets where I look at anxiety as being helpful. Now, all of these exercise approaches are also wonderful and they can also help mitigate anxiety.

Dr. Soania Mathur: So when we're talking about either anxiety or depression, when is a time for people to seek professional help and what does that help look like?

Dr. Laura Marsh: Yes. So I'm going to give an example that was just very impressive to me of a patient. He was a man who had actually a pallidotomy. It's where instead of having deep brain stimulation, they just would put a lesion or go into the globus pallidum, a little section of the brain, and it would also relieve the Parkinson's symptoms. It's done in some cases. Still not as much once deep brain stimulation became available. So this guy, he had a fantastic outcome, but after the surgery, he was very depressed and he kept calling up his doctors and saying, "I'm doing horribly. I can't walk, I can't move." And what was actually happening was that he was depressed. So when you have a big mood disorder, you're really looking at the world as if through mud-color glasses. It doesn't matter what happens, persistent and pervasive symptoms of everything is negative, that can be a sign of depression.

Also, persistent and pervasive changes in that mood, that ability or desire to do something, again, different than apathy. Because someone's asked about that. Apathy is where the person doesn't have the same response, but if you put them in a situation where they're doing something, they go along with it, the person with who's depressed really more [inaudible 00:34:42]. And so anytime those are there, persistent and pervasive. And again, I've treated so many patients with Parkinson's and depression. I know that time and time again, they say, "I can cope with Parkinson's when I'm not depressed." And they get their identity back. They still have values and things that are important to them that come out as who they are, and it's when they get back to that that's a sign that they're really getting better.

Dr. Soania Mathur: Right. So I think the message is basically that depression and anxiety occur at a higher frequency in people with PD. And if you have that added burden of a mood disorder that you have to be cautious about recognizing that in order to prevent some of the complications that can occur because of that mood disorder. I think that's an important message to get across for sure.

Dr. Laura Marsh: One other thing is that that also helps you stay motivated to do that exercise every day or just four times a week, as Fiona said, and follow those guidelines because when you're feeling depressed, you can become more [inaudible 00:35:50] I don't care.

Dr. Soania Mathur: Yvonne, I just want to switch gears for a second because there's probably a lot of care partners listening in as well. So from a care partner perspective, how did you go about supporting your husband with PD and what should a care partner know or do to encourage a loved one to stay positive without being dismissive of their Parkinson's disease? How did you approach

Yvonne Jackson: As a care partner and as a person with Parkinson's, I was very positive about how to help him do things in the house that he couldn't do and supportive of what he didn't want to do because he had pretty strong opinions. Fred had pretty strong opinions about what he was and wasn't going to do. And then towards the end of his life, he had swallow issues, so we had to puree his food and all that kind of stuff. And he was a kind man, and generous in his thoughts, and so he knew that we needed to get some help in the house to manage some of that, which we did, but it's about being positive and getting him out to do the things that he wanted to do that I shared. We didn't do hiking anymore and all that kind of stuff. He wasn't able to do that. I was able to do that. And he encouraged me to do those things that I wanted to do, and it's about listening and just hearing what was on his mind. So that was how I dealt with being a care partner.

Dr. Soania Mathur: That's really great, Yvonne. Bret, how do you feel you want to be approached sometimes? You have a lovely, lovely wife that I've met several occasions, but is there anything that... For me, I'm very volatile. Sometimes I want help, sometimes I don't want help.

Bret Parker: I don't envy her having to deal with me at all because it's a yin and yang. On the one hand, she wants to be supportive and encouraging. On the other hand, I want to be understood that sometimes I'm not up to doing something, and that's a really delicate balance that she nails, but I'm difficult. I'm not easy. So she has to know when I need a little push to go out and do some exercise, and when I'm feeling symptomatic and I don't want to be pushed out to do exercise, and she also has to not let me use it as an excuse, so I can't say, "I have symptoms, so I can't run today" when it's really just that I'm lazy. We're at a really good balance between encouraging but supporting me when I'm not up to something.

Dr. Soania Mathur: Fiona, do you want to take that on?

Fiona Davis: Yeah, yeah. My partner is really terrific. I find what helps is we just do a check-in every couple months, not when I'm freaking out about something or when things are calm, just to have a check-in so I can express what I'm going through, listen. Who sees me and sees what's progressing or what's not. There as a cheerleader is really just powerful, just to do a check-in.

Dr. Soania Mathur: Yeah, no, I agree. They can't read our minds as much as we'd like them to. I wanted to take a moment to call out the PPMI study, the Parkinson's Progression Markers Initiative, also known as PPMI as I just mentioned, which is recruiting volunteers. And people from all backgrounds without Parkinson's can help move research forward. It's an amazing study. It's given us a lot of information. So join the study that's changing everything. It really is. Yvonne, since now you unfortunately have lost your husband, which very, very sorry to hear. "Do you have any special advice for living alone? Somebody in the audience is asking.

Yvonne Jackson: That's a tough one. I'm still trying to figure it out, I have to admit. It's been a year, a little over a year, and I keep myself busy with, of course, going to my boxing three days a week, going out with friends for lunch. Ironically, the Parkinson's community is my family in this sense that I spent a lot of time with various people. We were supposed to go to dinner last night with a couple. He is in the Rock Steady Boxing class, and his wife and I have become really good friends. So I'm just trying to space it. I've gotten myself involved in some community activities here. I live half the year in Rancho Mirage, California, and half the year on Martha's Vineyard. I have different set of friends in each places. My kids come to visit. They come to the desert about three times this year since Fred died. A girlfriend is going to come and visit me on the vineyard when I get there and all that kind of stuff.

So I plan my social life, I will say that. I have control of my workout life pretty well. Every day I'm doing something either boxing, stretching, or all of that kind of stuff, but it's a social life that I have to work at. That's all I can say. It's a journey.

Dr. Soania Mathur: It's definitely a journey in terms of creating a new way of facing your life. We often take it for granted that we have care partners in our lives that sometimes we don't end up having. So it's very sage advice that you're giving and a great perspective, and I thank you so much for that, Yvonne. So we asked the audience, "Which of these emotions have you experienced as part of your PD journey?" And it seems like there's more anger and grief than optimism. Sadness and acceptance. So it's fairly even across the board a little bit more of the what we would call negative emotions, and that's only negative in terms of your own wellbeing, and optimism and acceptance are still pretty high. What do you think of these results, Jim?

Jim Hurtsellers: Oh, I identify with all of these because I've experienced them at some point in time, primarily anger and sadness I think. For me, those seem to be the ones that overwhelmed me initially. And then eventually you get to acceptance, and that's where you take the optimism and you accept it. Today is the beginning of the rest of my life, I'm going to live today and not worry about what's tomorrow.

Dr. Soania Mathur: Right.

Yvonne Jackson: I will jump in here and say sadness was predominant for me. Acceptance next. I was looking at anger and I was trying to think was I ever angry? And I don't recall being angry at all. I just realized I just had to do something about this. I had to keep moving. I had to keep pushing myself to accept this and then figure out how I was going to live with it. And then of course, the same with Fred. In some ways, having two people in one household with the same disease, we understood each other really well and so our life together was more meaningful. But anyway, I'll just say that.

Dr. Soania Mathur: Thank you. Now I wanted to talk a little bit about getting engaged and taking action in the community. When I had to leave clinical practice as a physician, I was devastated because it wasn't my choice to end it. The disease was progressing to the point that I couldn't maintain the pace as well as concentrate on my health. I remember my husband saying, "Oh, you have all this free time now to do stuff." I'm like, "Well." [inaudible 00:43:51] instead of saying, "Please let me be busy with another chapter in my life." And I guess be careful what you wish for because now I think I'm busier than when I was working as a physician. But truthfully, in all the ways I've had the privilege of being involved with this community, whether it's education or writing or speaking or research or advocacy, it's given me a sense of purpose.

And by focusing on the needs of others, I really have found my life's true passion and focus, not to mention the benefits of being part of this remarkable community, and the inspiration and the support that you receive are everything. So how have each of you gotten involved and how has your involvement impacted your emotions? Bret, do you want to take that one?

Bret Parker: Yeah. And thanks. At first, I was not involved at all. In fact, I think you or someone mentioned the early days of being afraid of support groups or being around others with Parkinson's. So it took me a while to get there. But once I got involved, it felt great. The burden of having to hide it was gone. And the feeling of doing something productive was gaining a lot of optimism because I'm not a researcher, I'm not a scientist, I'm not going to find the cure, but I can engage with the community. And so the [inaudible 00:45:02] support groups were very helpful. Research participation, I jumped in on that over time. Advocacy, I got involved with that and got involved with the foundation and all of these things.

And then obviously, Team Fox, which is the grassroots sports and fundraising activity, for me has been the silver lining of Parkinson's and has given me a chance to have some experiences that I wouldn't normally have and get to know people and get to know the community you're talking about, which is really more support than anything else for me.

Dr. Soania Mathur: Yeah. You're being a little modest. You attack a serious goal every year pretty much. Can you just share some of the stuff that you've done?

Bret Parker: Yeah, so I really didn't want Parkinson's to define me, so I decided that I would try to do one... Originally, just thought of a bucket list item a year, do a run. When I was a kid, I fell into the water and I've been terrified of the water ever since, and I can't dive face first. So I trained and learned how to swim and did a triathlon. I've done some marathons. And then of course I did this... There's a World Marathon Challenge, which was seven marathons on seven continents in seven straight days, which I did five years ago when I was fully symptomatic and with Parkinson's. I got so much satisfaction out of conquering that and all the support and love that I got from all the people who were with me, both in person and virtually. I feel like I've gotten a lot. It's been a real, real [inaudible 00:46:27] supply for me.

Dr. Soania Mathur: Oh, there you go. Making me look bad again, Bret.

Bret Parker: By the way, that was a long time ago. I've not run that far or even close to that for a long time.

Dr. Soania Mathur: No, that's amazing. That's amazing. Fiona, how have you got involved and how has that helped you dealing with the emotions of this disease?

Fiona Davis: Yeah, I would say clinical trials, getting involved and feeling like you're helping the science move forward is a big part of it. But also, I have a group of women who are all of my age, and we do dinners every so often here in New York. It's wonderful. And I have to say, we laugh. The emotion I get out of it is just laughing because there's so much you have in common and so much is just utterly ridiculous that comparing stories will [inaudible 00:47:13]. It's wonderful. And the same with the Michael J. Fox Patient Council, being involved in that way and being in a room with 40 people who all have it, who are all dynamic and trying to help figure this out is just so powerful. And I know I leave there just feeling like I'm on the top of the world.

Bret Parker: You were pretty modest yourself. You co-chaired the Patient Council with me for a while. And you're busy with your kids and everything else. So you're being a little too modest too.

Dr. Soania Mathur: I wouldn't say that. Thank you. And Fiona, I'm going to hit you up for an invite to those dinners when I'm in New York next time. Yvonne, how about you?

Yvonne Jackson: I was doing these triathlons. Really I would do them on my birthday. I remember when I did the first one, and I said to my husband, "I am a swimmer. I could ride a bike." I wasn't a runner, I was a walker. And I said, "I'm going to do this." He says, "What do you want to do for your birthday?" I said, "I think I'm going to do a triathlon." "How are you going to do that?" And I said, "I swim. I bike. I don't run, I walk." And I do that, and I continue to do that. On these milestone birthdays I will take on a triathlon and do it in my own time. I don't race, I just get in the water, swim that mile, go to the next one, get on that bike, and then walk the rest of it. So it keeps me focused on being healthy.

But relative to the Parkinson's community, I'm just starting to dig into that now. I became the go-to person in my community. Everybody would call me, "Call Yvonne, talk to her. You got to talk to Yvonne." Because people felt I was positive about working through the issues of this disease and managing it through exercise. But I'm beginning to now get my toe in the water relative to the community itself. As you know, I've joined the Patient Council. I'm looking forward to that. I'm used to this kind of stuff, working to solve problems and have goals. So I'm looking forward to more involvement.

Dr. Soania Mathur: We're looking forward to you as well. And Jim, how have you become engaged in the community or what's been helpful for you?

Jim Hurtsellers: It really started a couple of years ago. One of my sons gave me Michael Fox's most recent book that he had written. And I read it. And I was so inspired by him that I started looking at the foundation. I realized that there were so many opportunities to be a part of a broad community through the foundation. And my wife and I became donors, and we began to get involved as advocacy, writing letters to our senators and congresspeople to try and move progress along in Washington. And then now I'm currently looking for ways to join teams like Team Fox and other things to push myself. And like Yvonne said, I try to find something every year that I can look forward to. On my birthday, I try to do something. And what I've learned to do is to modify what I can and what I can't do. So if I can't run 10 miles, maybe I can do a 5K or something like that. But you just look for those opportunities.

Dr. Soania Mathur: I think that's a really important point, and I'd like to reiterate that to our audience. I don't run triathlons, I don't even run 10K, but it's all about what your goals are. The point is to have a goal that's something that you're trying to reach. And that can be honestly something like just feeling well enough to go walk your dog or go get the mail from the mailbox, but just challenging yourself in whatever capacity. That's success. We don't all have to be doing triathlons and marathons.

Yvonne Jackson: Marathons. I had a friend who taught me that, and she said, "Oh, I did a marathon the other day." And I said, "Wow." She said, "My husband put X number of balloons on our mailbox, and I just walked around the corner. It was a mile around the block." And she said, "And I burst a balloon every time." My grandkids came and they walked with me, and my neighbors came and they walked a couple miles with me. So she says, "So don't buy into this you have to get into a race." It's your walk.

Dr. Soania Mathur: I love that. I love that. And I think that's really important to recognize and to say, because you don't want... I feel a little bit bad that I haven't run a marathon yet. I don't want anyone else to feel that they have to. It's all about your own goal, what makes sense to your life and the situation that you're in, but just have a goal of some sort that you wish to reach.

Yvonne Jackson: Have a goal. Have a goal.

Dr. Soania Mathur: So I want to ask each of our panelists what lifts them up. Fiona, do you want to start with that?

Fiona Davis: Yeah, sure. For me, it's something really simple. I think about three years into the diagnosis, I remember walking down the street, and I live in New York, so you walk a lot. You're walking to go get milk. That's great. And just to live in that moment and be grateful for what it is, instead of worrying about, "In 7 years or in 10 years, will I be able to do it?" Just to stay rooted in that moment and enjoy it while it's there.

Dr. Soania Mathur: Absolutely. I love that. Bret?

Bret Parker: All this stuff that we've been talking about helps me. But one thing which is sometimes a nice relief for me emotionally is I love comedy. There's a comedy place about 10 blocks from my apartment. I go there probably at least once a month. And so I go to comedy shows. I like watching comedy. Being able to laugh is a great escape for me [inaudible 00:53:21] the tough parts of Parkinson's. And so for me, that helps me balance my mood out.

Dr. Soania Mathur: That's great. Ar and I are coming with you guys next time we're there. Jim, what is something that lifts you up?

Jim Hurtsellers: I've learned to enjoy the gift of the ordinary day. I get up in the morning and I just say, "Today is the day." And I live to the most of my ability of that day. And like Fiona said, I'm not worried about tomorrow because I've got today. And as long as I can focus on today, I'm just thankful. I have an attitude of gratitude. The mindset is like if I focus on what I can do instead of what I can't do, I'm going to do a lot better.

Dr. Soania Mathur: I love that. Michael J. Fox has a quote, and I'm going to actually mess it up now probably, but he says, "If you worry about something, then if it happens, you've worried twice. If it doesn't happen, you've worried for nothing." Basically don't worry about it because it is what it is. It's going to happen, it's going to happen. And Yvonne, what lifts you up?

Yvonne Jackson: I would say gratitude. Despite the loss of my partner and lover and husband for many, many, many years, over 37 years, I'm grateful. I'm grateful to be here, I'm grateful to be able to do those triathlons and grateful to be able to walk into the boxing studios. And I'm grateful for my kids, my grandkids in particular. They're grown men now, young men, and they come all the time and call all the time. And I'm just grateful for the relationships that I have. My sisters, I have a twin sister, and she and I are still very close. And so it's gratitude that I'm inspired by.

Dr. Soania Mathur: And as this crazy world is around us, as crazy as it is that tons of gratitude is especially important. I totally agree.

Yvonne Jackson: Right?

Dr. Soania Mathur: Dr. Marsh, we've had lots of audience questions about coping with fear. Fear in particular. What do you recommend?

Dr. Laura Marsh: So again, fear of what? There's lots of fears. So sometimes there are fears that [inaudible 00:55:41] important to understand what that fear is and to kind of name it. Because if you name it, you can begin to do something about it. Is it fear of falling? Is it fear of, again, what people think about me, et cetera? Or is it something that is not as trivial? Like I had a patient who was, should I bring 13 Kleenex or should I bring 12 Kleenex? And things that are really insignificant. So people have a range of things that they can become paralyzed by, and it's all fear. So one is, again, to understand it and to see... Again, I look at there's also the existential fear, what's coming up in the future? What does my life hold? What's going to happen to my family? Even though can live for the day, there are still things you have to plan for and be a part of.

So I think that, again, making sure that if you have a mood disorder, et cetera, that is treated. Because if you haven't treated that mood disorder and it's pervasive and it's persistent, it is going to color that fear. You will not be looking at the world... It'll be very hard to have a sense of gratitude when everything is looking bleak. However, there are times when you don't have a major mood disorder and you can still have those moments of bleakness or fear. And so the things that people have talked about, having that attitude of gratitude, we know that when you do those kinds of things that you can be... Particularly gratitude, that those are things that make people feel better ultimately. They actually can calm you down. They talk about you have your autonomic nervous system, your sympathetic and your parasympathetic, just let's say the rest and digest one.

When you do the deep breathing and you rest and digest, you slow things down and you have time to focus on the moment. Whereas if you're in the fight or flight mode all the time, you're probably not thinking about what you can do. So you start with that breathing and laugh. So these are things that you can do and they're coming up with when you're out in public, if you notice people staring at you, humor is something that you get your snappy answers to stupid questions kind of way of... That'll disarm people and they can begin to accept you and they move on. I think Yvonne gave examples of that.

I do want to mention the one thing about isolation, because that has also come up with the fear, and I think fear of being alone is something. The Parkinson's community is really tremendous in terms of all that's out there. There are so many online groups. And even if you're having trouble getting out on your own to take part in some of the things, the online groups, whether that's boxing. I know that in my local community, we have all sorts of exercise programs, speech programs, book clubs that are online and that people can take part of. And you get to know the people that are on there and they become part of your social life, and then they'll help you figure out how you can get out of the house with you.

So working together, none of us do this alone, and I think no one should be trying to do this alone. And there is a tremendous community out there, whether it's through research and or taking part in just the community.

Dr. Soania Mathur: Right. And that actually, when you talk about online support communities, the Fox Foundation has the Buddy Network online, which is a very vibrant and supportive community in which you can join and ask questions of people that are experiencing the same life circumstance as you are. You also mentioned the whole public thing, and there was a question from our audience that when you're out in public because of your symptoms, tremor or difficulty walking, do you notice strangers staring at you? And how do you deal with that emotionally? Any of the panelists have dealt with that?

Yvonne Jackson: Yeah, I don't deal with it.

Dr. Soania Mathur: No?

Yvonne Jackson: Doesn't bother me.

Dr. Soania Mathur: Okay.

Yvonne Jackson: I would say this, I was just going to add to what was said before about joking. I got in someone's car the other day and I said... I had to put my seatbelt on and you know how long it takes to put your seatbelt on. So I said, "You can always tell a Parkinson's person by how long it takes them to put their seatbelt on." And they'd laugh. And they said, "Oh, wow. I had never thought about that."

So I joked about this kind of thing. I remember I was giving a presentation to a group a few years ago and my hand started shaking and I was at the podium and I said, "Despite the fact that I came in last night, I didn't have too much to drink, what you see is I have Parkinson's and I have a tremor in my right hand." The whole group laughed and I made a joke of it so they could understand what I was dealing with up there and what we can deal with. So try to make a joke of it and it releases attention when they're watching you, and also you get to release your own tension so you can stop shaking.

Dr. Soania Mathur: Right. No, that's a very [inaudible 01:00:54] coping with it. It's very positive. I'm 26 years into it and I still feel self-conscious though when I go out in public, and that's probably a great deal of self-stigma that I have. But is anyone else in that boat and how do you deal with those emotions when they come up?

Jim Hurtsellers: a lot of times when we go out to dinner, sometimes my hands will shake and it sometimes becomes difficult to eat. So my wife sometimes has to cut the piece of meat for me or make some adjustments. Recently, I had a gentleman who just recently had become diagnosed with Parkinson's, and he said, "When you're out eating, what do you do?" And I told him, "I don't eat soup." And then he laughed and I laughed and it was our way of saying, "We just have to make a joke of it." And if people are going to look at you, you have to come to the place to recognize this is who I am and this is what I'm dealing with. When they find out that you have Parkinson's, most people are compassionate and they don't give you a hard time and they don't make fun of you. It's really about us accepting that and really just being honest with people.

Yvonne Jackson: And I have had that experience in restaurants where I will say to the waiter, "Make sure he chops his salad well." Said, "Tell him he has a Parkinson's patient out here." They respond to it, and so therefore I put it out there. Everybody's at the table. They know. If my sisters or family members, my kids are with me, then they'll try to cut up stuff sometimes. You just put it out there and people go, "Okay." And that's how it works.

Dr. Soania Mathur: Yeah. Michael says that you can't be vain with a disease like Parkinson's disease. I'm still I think learning. I'm still learning, I think. Fiona and Bret, do you have anything you'd like to add to that?

Bret Parker: No, I think jokes are helpful. Yvonne said it makes everyone feel more relaxed. Sometimes someone will say, "How are you?" And I'll just make a joke. [inaudible 01:03:06] blood this morning and the nurse said, "Which arm do you want?" And I said, "You definitely want my left arm because I Parkinson's and my right arm is a moving target."

Dr. Soania Mathur: Fiona?

Fiona Davis: Yeah, I guess for me, when I'm on the subway, I tend to tremor for some reason. And I used to always sit on my hand or put it in a pocket or something, and now I'm just like, "Yep, we're going to tremor here." I don't think about it as much or I'm not as self-conscious, which I assume is progress.

Dr. Soania Mathur: I think this is why I love these webinars because after all these years I still get inspired and learn from each and every one of you. Another audience question that's come in, which I think is actually a really important emotion to deal with, and they're asking, "Could someone speak to having feelings of guilt or despair at becoming an increasing burden to your partner or care partner?" Bret, I'll get you to start.

Bret Parker: Yeah. We talked about it, but again... First of all, I think dealing with parents who are going through health issues has been a good way for us to talk about our own futures. We all get something at some point. And so I think talking about it, being open about it is very helpful. I get it, adding some comedy. I've jokingly said that... There's an assisted living home across the street from our apartment building, and I said, "When it's my time, I'm ready. That building looks nicer than the one we live in, [inaudible 01:04:35] amenities and help. So I may one move in there sooner than you want me to." I don't mean to make light of it. It is very serious. For sickness and health becomes a real thing when you have [inaudible 01:04:53]. I think just communication is the key.

Dr. Soania Mathur: I couldn't agree more. It is something that we really need to stand back and really take note of as our care partners that decide to hold our shaky hands through this journey deserve an immense amount of respect. And I'm forever, forever grateful to mine. Fiona.

Fiona Davis: Yeah, I think it's all perspective. I've watched my mom take care of my dad for eight years with dementia. She really walked him through the stages to the very end, was incredibly moving. She had a very positive attitude of, "This is where I'm at right now and this is what's required of me right now, and so I'm going to put everything into it." And she didn't see a movie for eight years. She hardly did anything other than focus on him, and I think that's fairly dramatic, but it was a choice she made and that she wanted. So I feel like down the road we'll see what happens, but having seen that, I think it could be a really beautiful gift to give each other. And just hearing Yvonne talk about what she's gone through, I feel like it is an absolute gift both to be the caretaker for the one with the illness.

Dr. Soania Mathur: Right. Jim, I'd like to hear your feelings on.

Jim Hurtsellers: Yeah. My wife and I actually, we are seeing a therapist to help us with the communication aspect of that. I try to encourage my wife to take time away to find those moments where she can just be herself with her girlfriends or not have to worry about me. But it's very difficult. And oftentimes my wife is very sad because she sees my deterioration and knows that every day I get up and you never know what you're going to get. So helping us has been talking through therapy and how to communicate those needs and just to be honest and open with each other. So I would recommend anyone who's feeling that kind of overwhelming guilt, maybe you need to talk to someone who can help you walk through this together.

Dr. Soania Mathur: A very sage piece of advice. Yvonne, we've heard all about the loss that you've suffered recently, which again, I'm so very sorry for, but the next question I think should be directed to you. How do you now navigate your doctor's appointments or your management without a care partner? Because there are many people that are in that same situation.

Yvonne Jackson: Yeah. My sister, I have an identical twin sister, and she and I are very close and we live a couple hours apart. But for my major appointments, she puts it on her calendar and she goes with me particularly to the neurologist. She wants to take notes and makes sure I understand what I'm supposed to be doing. And she spends enough time with me to know what my issues are that I might not tell him, that Fred used to do for me. And then the other appointments, I just get there by myself. I had a general practitioner's appointment the other day, had a bone density test. I have osteoporosis, so now I've got to go on new medication. So those appointments, I can take care of myself, but the major appointment like to the neurologist, Yvette will go with me.

Dr. Soania Mathur: I think that's a great idea to have someone there, a second set of ears and eyes.

Yvonne Jackson: And she takes good notes, so she'll send me her notes. I said the other day, "I can't remember [inaudible 01:08:37]." She says, "No, it says this. You need to be doing this." And I said, "Okay." So it's good to have that second set of ears when you have important information you need to. And she's in the medical field herself or was, she's retired. So she knows medications and she'll ask questions about that and things that I don't know to do.

Dr. Soania Mathur: Now we're winding up this discussion that we had. There were lots of questions from the audience about motivation, a feeling of tiredness and having no one to help motivate them, what should they do? Have any of you been in that situation? And maybe Dr. Marsh can also weigh in on what do you do when you just don't feel motivated and you don't have anyone to necessarily push you?

Dr. Laura Marsh: I can start with a couple of general things. One, looking at the smallest, this is assuming other things are equal, but we have this community and the community can be very motivating to you. So just the fact that you're on this webinar is a sign that you're already showing some motivation. There are some things that people have talked about. So getting that small goal, whether it's attending or going to an online program that involves exercise. Exercise is very good. Anything, the smallest level of activation that you can have, and then you can build on that. There can be also a tendency to overdo it. And this is probably what I see most is people, they finally get motivated and then they do everything and they speed up to 100 and then they're exhausted for five days.

So I think what I've had people do is actually get information on yourself, learn about yourself and sort of keeping a log of what you're doing on each day. Get a spiral notebook and you've got all the hours of the day that you're up and what you're doing and when things are going when things are not going when you get more tired, are you actually taking your medicine on time? Those small things that you can begin to change. So those are just a start with getting rid of the things that are actually easy fixes and then start from there.

Dr. Soania Mathur: Right. What about you, what do you do when you're feeling down and not motivated?

Bret Parker: So I try to pick small goals. I think similarly with exercise of you don't have to run a marathon, you can walk around the block. And so I try to pick small goals that are objective and attainable. Literally it's like, "I'm going to clean out this part of the closet," or I just think that I can feel good about it, achieving them, to me is very [inaudible 01:11:24] productive.

Dr. Soania Mathur: That's a great suggestion. Fiona?

Fiona Davis: Yeah, I find just having a to-do list somehow. The satisfaction of checking things off for certain people, I'm one of them, is a really powerful motivator just to be able to check it off even. And there are some days keep in mind that you just don't feel like doing anything and you're just having [inaudible 01:11:44] day. And that's perfectly fine. "Yep, I'm going to Netflix all day. That's okay."

Dr. Soania Mathur: I agree. Absolutely. Jim?

Jim Hurtsellers: I have this mantra that you need someone to love, something to do, and something to look forward to. Like Bret, I try to make little goals, but I also have a reward system. So if I accomplish my little goal, my reward system usually involves Ben & Jerry's ice cream. For others it might be something else. But I think that's important to set these little goals and then also have some way of rewarding yourself when you achieve those goals.

Dr. Soania Mathur: I couldn't agree more. And Yvonne?

Yvonne Jackson: Yeah, turn on a good movie. When I don't feel motivated, when I feel tired, I'll lay on that couch, I'll turn on a good movie or series. I call it binging. I have my goals, here's what I want to accomplish here over the next period of time, but there are times you just don't feel like pushing yourself. And I binge. I binge.

Dr. Soania Mathur: Secret is out. It's okay.

Yvonne Jackson: It's okay.

Dr. Soania Mathur: It's okay. Dr. Marsh, you said something about bundling the less desirable, something that's desirable. Could you explain what you meant?

Dr. Laura Marsh: This is another cognitive behavior therapy tip, so that you bundle. If you are exercising every day, but you want to watch Netflix. I had to do this myself. I put the bike where the TV was, or I had my daughter come over and do something. So she would talk to me or I call someone up on the phone who I want to talk to, who I've maybe not been paying attention to, and I would like to, and I'll get on the stationary bike. So all these things, I don't really want to get on that bike and I don't run marathons or triathlons, but I will want to talk to my friend. So I add them together and then my friend encourages me while I'm on the bike talking to them. So these kinds of things, if you find those little things, it's always great.

Dr. Soania Mathur: So in the last couple of minutes that we have, I'd like to ask each of our panelists that have PD to answer in one sentence what's the best advice you've received that you'd like to pass on to the audience? Bret?

Bret Parker: That one's an easy one for me. So I was running the Chicago Marathon and towards the end of the race I saw a woman standing above on a barrier and she was wearing a shirt and it said, "Do epic." The shirt said something that [inaudible 01:14:21]. And so for me, that's the best advice I've gotten. And that means do epic for you, whatever that means at that day or that time. So having goals [inaudible 01:14:30], do epic, and a stretch, to me, that's the best advice.

Dr. Soania Mathur: Perfect. Fiona?

Fiona Davis: Yeah, I think there are so many symptoms to Parkinson's. There are so many things that you might get and so many things that other people might have but you don't or you do when they don't. For me, the best advice was just stay in your lane, keep focused on what you have to deal with and don't feel like you have to have the whole bundle of Parkinson's in your body. It's just what you're going through right now.

Dr. Soania Mathur: Excellent. Jim?

Jim Hurtsellers: Yeah. The best advice I got came from my wife. She said, "Why don't you just be you? You do you every day. Whatever that day looks like, you do you that day." And I realized that she was right because I don't know what the next day is going to look like, but I can deal with what I have on any given day.

Dr. Soania Mathur: Absolutely. Yvonne?

Yvonne Jackson: Set goals and they can be short, long, 12 months, 6 months, 3 months.

Dr. Soania Mathur: Great advice.

Yvonne Jackson: On whatever kinds of things you want to do. Exercising is important. It may include once a week call one of your old friends that you haven't talked to.

Dr. Soania Mathur: So thank you kindly, everyone for joining us today. I hope you feel that your time was well spent and that you found the discussion informative and valuable, and a special thank you to all our esteemed panelists for sharing your expertise and experience. So thank you again everyone. And remember, those of us with Parkinson's really have no choice in our diagnosis, but how we face the challenges is really ours to determine to empower yourself by educating yourself as much as you can about this disease and learn from each other. So until next time, thank you.

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