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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.

Jim McNasby: Hi everyone, I'm Jim McNasby. I'm the general counsel of the Michael J. Fox Foundation. I'm also a person living with Parkinson's, having been diagnosed with Parkinson's disease 25 years ago in 2000. It's an honor to be with you here today and with our panelists. Today's conversation is about stigma and PD. We all know how it feels when an unexpected PD symptom, like a tremor, kicks in and we start to get puzzled or even concerned looks by people who don't understand what we're experiencing.

Today I'd like to talk to you or we'd like to talk to you about how to navigate those moments of stigma and even how we start to change how society perceives those moments. So we've got a lot to discuss. So let's get started and let me first introduce our panelists. First we have Omotola Thomas. Omotola was diagnosed with early onset Parkinson's in 2016 and when she was age 35. She lives in Surrey, England with her husband and her two children, aged 15 and 18. She's passionate about raising awareness of Parkinson's, and as the founder and director of Parkinson's Africa, she works to support, connect and empower Africans affected by the condition. Welcome, Omotola.

Omotola Thomas: Thank you.

Jim McNasby: Absolutely. Next we have Kat Hill. Kat was a nurse midwife and was diagnosed with early onset Parkinson's at the age of 48 in 2015, and she met that challenge by reorienting her life based on principles of gratitude and joy. She lives in Portland with her husband and she advocates for Parkinson's disease with several organizations. She co-founded the Women's Parkinson's Project and is also the host of a podcast called PD Lemonade, which I'm sure many of you're familiar with. Welcome Kat.

Kat Hill: Hi.

Jim McNasby: Third, it's my pleasure to introduce Dr. William Barbosa. Dr. Barbosa is a movement disorders specialist at the University of Rochester. He's also an Edmond J. Safra fellow from the class of 2025. Throughout his career, he's been involved in projects that address healthcare inequities and expand access care. He surely believes that patients should receive culturally competent and compassionate medical care. And thanks for joining us, Dr. Barbosa.

Dr. William Barbosa: Of course. Thank you for the introduction and I'm very glad to be a part of this conversation.

Jim McNasby: Well, we're glad you're here too. So when we think about stigma, I always think of the paradigmatic trait for me, which I started my Parkinson's journey with, which is tremor. For me, when I tremor and people observe me tremoring, there's a level of filling in the blanks that I notice other people are doing, or if they see my facial masking, for example, they think I'm not interested in what they have to say or I have no reaction, or in the worst case, that I'm angry or even disappointed. They make up their own story about what's going on from me that is inaccurate because they don't expect me to start shaking and it feels like I'm being misquoted or misunderstood. And that is especially true if their idea about me is negative. In short, it's stigmatizing.

Just with that start, can I turn to you, Dr. Barbosa, and just ask, can you give us a definition? What is stigma?

Dr. William Barbosa: So I think stigma can be a lot of things to a lot of different people just because there's different forms of stigma. But I think it's fair to say that when thinking of stigma, it comes down to what is a misperception that oftentimes gets internalized. So as you were saying, there's this assumption oftentimes that other people may make of someone's own personal experience that there's a disconnect with what's actually occurring.

So in the case that you're talking about, symptoms can oftentimes be misinterpreted. And in particular with regards to the social stigma of Parkinson's disease, it's not an uncommon occurrence that other people may perceive certain symptoms such as masked faces or decreased facial activation instead as interpreting that as a form of anger, which isn't always accurate.

Jim McNasby: Right. So Kat, how have people's reactions to your Parkinson's affected your journey with PD?

Kat Hill: Well, I'd say that it has impacted my journey pretty significantly. I was actively practicing as a nurse midwife in a full-spoke practice in a big inner city hospital. I was up all night. I worked a lot of strange hours. Babies come when they come. And as a clinician, I was having trouble with some of the multitasking functions, those executive functions, and thought it was related to perimenopause.

When I started to have tremor, however, I noticed it, my patients noticed it, my colleagues noticed it, and it impacted my ability to work. And I left my work very early, even pre-formal diagnosis because I was anxious about it. I was nervous about how I was being perceived, and the last thing that I wanted to do was have my patients feel insecure with the care that I was providing. And so it hugely impacted our finances and it also affected a lot of my self-image. I was the one that was to be caring for everybody else, and suddenly I was being diagnosed with this disease that ironically my father had, in my 40s. So it impacted a lot for me.

Jim McNasby: How about you? How has it affected your journey?

Omotola Thomas: I think very similar to Kat. It impacted me quite significantly, I think specifically because as an African, born and raised in Nigeria, an illness like Parkinson's is not necessarily something that is well understood, certainly not nine, 10 to 15 years ago when my symptoms started. And I remember, I consider myself to be a very resilient person, to be strong, and I remember when I got diagnosed, I was full of hope and I was going to take the world by storm and I wasn't going to let Parkinson's get the best of me. I wasn't going to be silent about it.

And then the first few family members, extended family members that I spoke to about coming out to talk about my disease were very reluctant. And this was particularly, I don't want to use the word confusing, but these people I know care about me, they didn't mean harm, they didn't mean to stigmatize me, that wasn't their intention, said, "Why do you want to air out your family's dirty laundry?" And that in that instance took the wind out of my sail for a moment. It made me very self-conscious. Even though I knew that they weren't trying to cause harm, harm was in fact caused, and it impacted my sense of self and sense of reality.

Jim McNasby: Wow, I can imagine. I mean, that kind of reaction from your family who you would look to for support must have been very difficult to digest. And so how did you go about the digestion process?

Omotola Thomas: It delayed slightly my coming out, for lack of a better term, but I think I was fortunate because my core family, my immediate family, understood why I was trying to do it. So I leaned more into them and their encouragement of me to go ahead and do what I felt was best. So it was basically leaning into the support that I did have and understood these people didn't mean harm and that they actually helped with my sense of purpose and direction and wanting to become an advocate to educate these people, for them to understand the impact of what they were doing, basically to raise awareness about Parkinson's.

Jim McNasby: That's great. [inaudible 00:09:37] When I talk about Parkinson's, I look for opportunities to turn negatives into positives. And so it sounds like that's what you were doing, which is a great thing.

Omotola Thomas: Exactly.

Jim McNasby: Dr. Barbosa, the literature talks about two types of stigma, social stigma and self-stigma, which is sometimes referred to as anticipatory or internalized stigma. How are those different? Can you help the audience to understand that?

Dr. William Barbosa: Certainly. So when we think about social stigma, it's what's the general public's perception of what the disease is. So when we think of how the perception of what is Parkinson's disease as it's shown in media or on TV or when you Google it, I think people have and the public have a certain idea of what Parkinson's disease is and maybe some of the negative connotations that can be associated with that.

Now, self-stigma is the thought of having maybe some sense of internalization of those misconceptions and thinking of, "Well, this is what people think of me, so then maybe is this something that I actually experience," and it starts to become internalized and a part of your own experience, when maybe it's really not. And so having that interplay between the public's perception versus your own reflection of who you think you are and what your experience is, I think those are the forms in which stigma can play out in both ways.

Jim McNasby: So Kat and Omotola, the public perception of PD is still I think in many respects that of an old white man. How does being early onset and women, and in Omotola's case being Nigerian, affect people's perception of you, do you think?

Omotola Thomas: Yeah. I think for me, the example I'm going to use underscores the importance of this question. So even the doctors at the time that I was getting diagnosed, my journey from me first noticing the first symptoms to being diagnosed took almost six years. And it wasn't until my fifth year of experiencing motor symptoms that one of the doctors said to me, he said, "I think you may have some form of Parkinsonism. I'm not sure. We typically see this disease in older white males. You're a young black African female." So even my doctors did not immediately think about Parkinson because of my demographic. If they didn't understand it at the time, how much more people that are not in the medical field?

Kat Hill: Really interesting, Omotola, and I just had kind of a light bulb go off for me. My dad was diagnosed in his mid-70s. He was also a dentist, so another clinician. And the fact that I didn't have it anywhere on my radar as a clinician, as a female clinician, I wrote off a lot of my symptoms to being perimenopausal. And so I'm a women's healthcare professional delivering babies, and it wasn't even on my radar. That was a self-stigma almost. So I didn't go in and pursue diagnosis. And when I finally did, the movement disorder specialist was pretty... It was sort of a presumptive diagnosis until I tried the Carbidopa-Levodopa, which worked, but I was in huge denial about it and really ignored symptoms for a long time.

And also, the stigma around being a young female and having Parkinson's is very confusing for a lot of providers. We don't have a lot of answers about things, about how hormones impact things. And that's partly why I helped to found the Women's Parkinson's Project was to bring together a lot of that anecdotal information and to help raise our voices that, "Hey, we're here to. We know that we're kind of outliers in terms of our numbers, but we're being really impacted by these things." And it's led me to really try to get involved to learn more about women's experiences in their lives and what led them to a Parkinson's diagnosis. We're better if we know more.

Dr. William Barbosa: I certainly agree. Unfortunate components of stigma come from are just public lack of awareness because people ultimately have this prototype of what they think Parkinson's disease is, but I'll share in my experiences in helping care for many patients, everyone's journey is different. The patient's symptoms vary very dramatically at times from patient to patient despite carrying the same diagnosis. And oftentimes, some of the symptoms that aren't visibly apparent are perhaps the ones that cause the greatest degree of stigma and uncertainties.

Jim McNasby: Yeah, that's a great point. I'm reflecting on my own experience, and I'm a lawyer. Hold your applause, by the way. And when I was in my last job before joining the Michael J. Fox Foundation, I had a really serious meeting with some government officials and there were a whole bunch of people sitting around a large table. And without me knowing it, I started to drool in an uncomfortable and embarrassing and continuous way, and I didn't feel it. And by the time I noticed, everybody in the room was thinking, "Oh my God." So I said, "I am sorry. I have Parkinson's disease. Unfortunately, sometimes this happens," which was a tough thing for me to do to kind of rise out of the meeting, address what was happening, and live with the consequences of that.

But everybody said it didn't matter and, "Don't worry about it," and, "We understand," and then I got a Botox treatment, which helped solve the problem. But from every big meeting from that point on, I felt nervous and self-conscious about doing the same thing again and embarrassing my company or myself. While that might not seem like a reasonable reaction, embarrassing my company, I just felt you don't send a lawyer in to drool in front of his negotiating partners. And drooling is not something that is an expected symptom of Parkinson's. So where tremor may be, that's not, so that kind of point is an important one to make, I think.

Kat Hill: Yeah. I'd love to also add that sometimes our own sense of self-stigma or anticipatory stigma prevents us from doing things. I know that going to the grocery store can be a very stressful thing for me. And some of you may have heard me tell this story, but I get more and more nervous as I'm trying to go through the checkout line because at the checkout line, everything happens fast. You have to get your wallet out, you have to pay, sometimes you have to bag your groceries, sometimes there's questions, sometimes there's moving a lot, and I find myself avoiding those things in anticipation of it being stressful.

And I also do sort of what you have done, Jim, is tell people ahead of time, "I'm sorry I may be a little slow. I have Parkinson's disease." And sometimes just by saying the words out loud, I feel better, like I give myself permission to be a little slower and hope that people are a little bit more understanding or compassionate. I know it helps me a lot, and I think in general it helps people to understand, like you saying what was happening with your drooling. It also I think takes attention away from our tremor or the drooling or the slowness or the shocked eyes. I tend to get real open eyes with masking and people realize that there's something going on and they move past it. I don't know if that's been your experience or not.

Jim McNasby: On my side, and Omotola, I'm curious if you've had the same experience, I find that when I address it, it's part of a conversation opener. It creates space where people can either talk about it with you or just acknowledge that you might have some things that are different from you than they are that might come up and are unexpected, but that's okay. Basically, it's a pressure reliever, I think, on the patient. So do you have a similar experience, Omotola?

Omotola Thomas: Absolutely. Almost literally every day, including today, it happens to me and it takes away the pressure. It's my number one coping mechanism, and I address it head on, and it does two things for me. Number one, it makes me not worry about if the person is wondering why I am shaking, why I'm rigid, what's wrong with this weirdo. That takes the pressure away from me. And then number two, it's almost like a script. This is what happens. I meet somebody, a contractor, or I go into a meeting or something and I'm like, "I have Parkinson's. I'm shaking, but I'm okay." And then they go, "Oh, I'm so sorry." And then I respond, "Don't worry about it. I'm used to it." I get to tell my story and what I've done with the illness and the disease and have been able to find purpose, and then they tell me how amazing and wonderful I am and everybody wins.

Jim McNasby: That's a good outcome.

Dr. William Barbosa: I guess one thing I wanted to add in hearing your stories, it's very inspiring to think of having your diagnosis be a form of empowerment when you disclose that. There was a study out of the University of Utah that actually showed that about 50% of people with Parkinson's disease chose not to disclose diagnosis. And I just wonder if encouraging others to consider that as an option of a form of empowerment to disclose your diagnosis, I think can go a long way in helping address some of the social, as well personal stigma.

Jim McNasby: Yeah, that makes sense. Dr. Barbosa, is there a relationship do you think, between keeping the stigma inside and stress?

Dr. William Barbosa: So certainly. I think that coming to, again, down to the internalization of some of these negative reactions, the way that that internalization can then manifest, people can be more stressed, more anxious, depression being another concern that we frequently have to screen for, but there are consequences to internalized stigma, and I think it's important that we acknowledge that because there are ways that we can help treat it.

Jim McNasby: Do you think if you succumb to the pressures of stigma, do you think that there can be medical consequences to that in terms of more negative outcomes or what does the research say about that?

Dr. William Barbosa: Certainly. So stigma oftentimes when internalized can lead to forms of isolation. And what we see is that those people who aren't staying social, they're isolating, they're not exercising as much, they're not engaging cognitively as much, and they can have decline overall, the motor and non-motor features of artisans. So it's something that we certainly want to try to recognize and address sooner rather than later so that we don't go down that path.

Jim McNasby: Good advice. So Kat, how has stigma impacted your mental health and relationships?

Kat Hill: That's a good question. And I think as my Parkinson's has progressed, it has impacted me more, which is not surprising. I took great pride in taking care of everything. I'm the clinician. I know about my meds, I know what I'm doing. I felt this sort of sense of control over something that's not controllable, classic sort of type A, right? I can do this, I'm staying ahead of it, like Omotola. This is not going to get to me. I'm going to live positively. But so much so that I wasn't really communicating very well with my family about really what was going on.

And I pride myself in being a good communicator, and so I've been trying to learn to be more honest. My husband and I have some time set aside to talk about the diagnosis and how it's going. We don't really fight, but not in the middle of an argument, not in the heat of the moment do we want to talk about it, but we set aside time to talk about pain. And I've had a lot of dystonia and cervical dystonia, which has led to some pretty intense migraine headaches consistently. So I've been down and out more, and that's a very noticeable thing to my family.

Prior to that, there wasn't a real thing that people could point to when I was hurting, and so therefore I didn't communicate it. I was limiting myself. I was doing some of these things like not joining in things and not talking about it because I didn't want to focus on the negative. So we are trying to set aside more time and check in with each other and use words like, "How much energy do you have on a scale of one to 10? How's your pain?" And those are sort of neutral words, rather than me feeling like I have to complain about what's happening with my neck and shoulders.

Jim McNasby: Omotola, let me ask you how stigma has impacted your mental health and relationships?

Omotola Thomas: For me, it has at certain points in time, it has made me feel very inadequate. Particularly when I got diagnosed, my children were much younger. They were nine and seven, and when my symptoms started, were even younger. They were like three, two, and five or something like that. It's caused me to be withdrawn. At least the early stages. I withdrew from a lot of family functions. I withdrew from going to their games and activities. I didn't want people to look at me and wonder what was wrong with me. And I also didn't want that pressure on the children themselves. I didn't want them to have to explain to their friends, and kids can be cruel sometimes. "Why is your mom shaking? Why does she look like that?" I think the biggest impact it had on me was the feeling of inadequacy and then having to withdraw because I didn't know how to deal with the stigma at the time.

Jim McNasby: Okay. So I want to make a little bit of a pivot here and talk about navigating stigma. So let me go back to you, Kat, if I may. Could you give the listeners a short reflection on one technique that you use to navigate stigma when you're experiencing it?

Kat Hill: I know that I have, especially when I'm tremoring, I have a strong internal tremor that feels a lot like anxiety. And when I am in a situation where either I am feeling very aware of that and starting to beat up on myself, I try really hard to close my eyes for a second and take a big deep breath. And if I'm home alone and struggling with that anxious feeling, I try to think about one or two things that I feel grateful for. So I'm trying to shift what my brain is doing, and sometimes it's just that I can turn lights on or that my toilet is flushing or that our garbage is going to be picked up at the end of the week. I feel grateful for those things.

If I'm with other people, sometimes I will ask if I'm with my family or just even say... I have another word, a teapot moment, where I'm feeling overwhelmed by anxiety, like the steam coming out of the teapot that screams. That's how I've explained it a little bit to my family, like I feel paralyzed by that moment. And if I say I'm having a teapot moment, I don't have to explain a lot. They kind of understand and it gives myself permission to be what I'm doing.

If I'm out in public, I try to stop what I'm doing and go sit down somewhere, outside on a bench, take a moment because what I find is I don't power through very well anymore. The symptoms just get worse. And it often happens when I'm out in public, but usually, even if I go sit down in my car for a minute, taking a minute, taking a pause really helps me.

Jim McNasby: That makes sense. Omotola, same question to you. What technique do you use most frequently to navigate a moment where you're experiencing stigma?

Omotola Thomas: I think for me, it goes back to one of the things that I said earlier, which is addressing my symptoms head on, addressing the fact that I have Parkinson's. That way it takes away the pressure. The person may still stigmatize, but it doesn't impact me anymore because I've explained why what is happening to me is happening, and that way it doesn't bother me. So for me, addressing it head on from the beginning when you meet somebody to say, "Hey, I have Parkinson's and I shake," or, "I drool," or whatever the most troubling symptom is, that's how I try to navigate stigma.

Jim McNasby: And one of the things that I do is I try to use humor when I can to kind of open the conversation. So for example, with me, I was in the airport a few weeks ago and I went to a Starbucks and my right hand was shaking as I went to pick up my drink and I said, "I like my latte shaken and not stirred," or one time, I was a lawyer, as I mentioned, hold your applause, and I was sitting on a panel discussion in front of a group of lawyers and I fell off the stool I was sitting on, and it was kind of a dramatic moment and all of these people were looking at me and I kind of brushed myself off and I said, "Is there a good lawyer in the house?" Because when you use humor, you give people permission to ask and engage about what's actually happening to you.

People make jokes about dispensing Parmesan cheese off spoons on the pasta or the shake and stir thing, or I sometimes when I walk with a droop in my step and I'm scuffing my feet, I say, "I'm like a cat with a bell around its neck. You always hear me coming." And so those kinds of things are helpful because they allow people to give them permission to engage with you on something which otherwise might seem personal without being so heavy-handed about it.

How about stigma in the workplace? Do either of you feel like you've experienced that in the workplace and how have you wrestled with that or how have you addressed that?

Kat Hill: I work predominantly now at home in an advocacy. For me, it was my own self-stigma that had me step away.

Omotola Thomas: I stopped working about four months ago in December, but I worked for about three years. And what Kat said is so key and it's so true, is that I think generally speaking, most people are nice and understanding and empathetic. That certainly was my experience for the almost three years that I worked. And I realized that the issue was my own perception of what their perception of me was, and I had to deal with that, because my boss, my colleagues for the most part were all very understanding. They gave me allowances, flexibility, but I was the one struggling. I was my own worst enemy in that instance. So I didn't experience that in the workplace.

Jim McNasby: Yeah, that's good to hear. Dr. Barbosa, when experiencing stigma results in clinical mood symptoms or really starts impacting life, what can the doctors do to help? What medical options are available and how does someone know it's time for professional help?

Dr. William Barbosa: So that's a great question. And to start off from when is the appropriate time, I would say it's never too early. So sometimes people can have this rationalization of, "Oh, it's not so bad. I can take care of this myself." Keeping your doctors informed, even when you're starting to have those perhaps initial feelings, can go a long way in preventing things from worsening.

We're talking about toolbox of strategies to help stigmatizing moments, and when those ultimately lead to symptoms of anxiety, depression, there are medications that can be offered to help alleviate some of those symptoms. In addition to medications, we can think about therapy and counseling as being another part of the toolbox that can be very effective as well. And so keeping your doctor informed along the way, knowing that there are options to help, I think can go a long way in helping make sure that you live the best quality of life that you can.

Kat Hill: I'd like to just add, if I may, that I had an anxiety diagnosis 10 years before I started having Parkinson's symptoms. And I've talked to a lot of folks with young onset or early onset Parkinson's disease that have also experienced that. And I have realized that even though I took medication and did counseling for many, many years while I was working and raising our kids, that it really wasn't adequately treated until I was diagnosed with Parkinson's disease and started medicine for Parkinson's disease.

There seems to be an awful lot of crossover. And I don't think we fully know, I'm hoping that that's a fair statement, Dr. Barbosa, that we don't totally know sort of the pre-prodromal Parkinson's symptoms. But I often wonder, was that really the beginning of my low dopamine levels or fluctuating dopamine levels and I was treating with medicine the serotonin parts that were diagnosed for anxiety and depression? I don't know that we know.

But I think having an open conversation about what kind of tools we all have. Mental health effects so many of us with Parkinson's and those that don't have Parkinson's. And so normalizing a dialogue around that is so important. We need to be talking about it with each other, we need to be talking with our providers about it. And it's a hard conversation to have and really it impacts us hugely. So there's ways and there's tools, and not just medicine. There's friendships, there's making friends across the country and visiting with each other even when you're not on a webinar and those kinds of things.

Dr. William Barbosa: I think that was very well said. I think that I agree with everything you were saying.

Jim McNasby: Me too. So just in terms of destigmatizing Parkinson's disease more generally, Omotola, you founded an organization to increase awareness of Parkinson's. Can you tell us a little bit more about it and how it's helped you?

Omotola Thomas: I will try to answer that question in a little time as I can, but I just wanted to go back real quickly, because I'm not sure if my answer to stigma in the workplace was helpful. It was like, "Oh, I don't suffer from stigma in the workplace." Well, people are like, "How is that helpful to me?" But I think if you're experiencing it, I think there must be at least one person that you can talk to, hopefully somebody senior level. I think honesty would be the person's best bet. Just talk to people. Most people are not horrible and will be empathetic. There may be one or two, but my advice would be to find somebody to speak to candidly and honestly. I think silence breeds misunderstanding and when we're honest, we control the narrative, and then what that does is that it invites compassion as opposed to confusion and fear. So that's the response that I wanted to give for that.

Back to Parkinson's Africa, when I got diagnosed, I couldn't find anyone who looked like me. I felt very isolated and alone as an African, and I wanted to create an organization that would provide the support and empowerment that I didn't find when I got diagnosed. And so Parkinson's Africa was established to just do that, to provide support, empowerment, to raise awareness, to improve education, improve access to research for Africans living with Parkinson's disease.

And I think I'll say one more thing real quickly. I think we all may have similar symptoms, but our cultural backgrounds and our cultural experiences impact the way that these symptoms affect us. So Kat has just talked about anxiety and how she took medication from it. And in hearing her speak, I have had debilitating anxiety for a very long time. I don't think I've ever really seriously considered getting it treated because to me, and this is me, I'm an advocate, I am very well involved and immersed in the Parkinson's committee, I'm educated, I understand that this is the neurochemical imbalance or whatnot, but I still see it... I'm self-stigmatizing, and I still see it as a character flaw. I still see it as something that if I just learn the right tools [inaudible 00:37:43] myself, or I still see it as me being irrational. And that is incredible when I sit back and I look at how far I've come in my journey with Parkinson's to still 10 years, 15 years into this journey, be stigmatizing myself about anxiety.

So these are the things that we are trying to address with Parkinson's Africa, for Africans impacted by the disease.

Jim McNasby: Yeah, that's a great comment, Omotola. The other thing that I think is difficult to reconcile is that I think there's different stigmas associated with different symptoms. Even among people with Parkinson's, the motor symptoms are more acceptable than the non-motor symptoms. People I find are afraid to say, "I'm having trouble with executive function," or, "I'm having trouble with hallucination from my medication," because that's crossing away from Parkinson's, which is seen as a movement-dominated disease, into an Alzheimer's-like realm. And people are afraid of that. When they talk to their doctors and when they talk to others with Parkinson's, they prioritize the motor symptoms because that's easier to listen to. And you have to talk to your doctor to get help. And so you need to recognize that even though those symptoms are more difficult to handle or to talk about, that you need to get your arms around them and confront them. And that's what I've learned after 25 years of dealing with this, that you got to be open with your doctor.

Dr. Barbosa, let me ask you, what do you think is the role of the clinician in shaping the social conversation around PD?

Dr. William Barbosa: Well, I think we're doing it in part right now, in creating awareness for perhaps the unrecognized components of PD. You're talking about many times people are aware of more of the motor symptoms, but these non-motor symptoms that are very much part of PD can also significantly impact quality of life and lead to stigma. And so as a clinician, my role is to help raise awareness, but also to meet people where they're at, because as I was talking about before, everyone's journey is very different and you can't have a one-size-fits-all approach.

And so my role in really helping guide people navigate through stigma is to see where they're at, see what is their perception, what are the misperceptions that are going on, and how best can I treat perhaps some of the other symptoms that may come of that. So my role really is to be an active listener and really adapt treatment plans according to what makes the most sense in that particular individual's case.

Jim McNasby: I want to now transition to our question and answer. We give the audience a chance to have their questions grouped and answered together. But before I do that, I want to take a moment and call out that the Michael J. Foundation's landmark study, the Parkinson Progressive Markers Initiative, known as PPMI, is recruiting for volunteers. People from all backgrounds with and without Parkinson's can help move research forward. And we're asking people to join the study that's changing everything by clicking the link in the resource list, which should be available on your screen.

So the first question we have is this one. How do patient partner or spouses support them with stigma? Kat, why don't we start with you on that one?

Kat Hill: I would say in my household, the biggest obstacle of dealing with stigma is me. And so I need to be bringing it up and talking about how I'm feeling about it and trying to be honest and straightforward when I need some help with things so that my husband is not guessing all the time about how to help.

And I think talking about it recently, we tend to talk, I go in for Botox every three months and we set aside time the day before I go to talk about Parkinson's, and that helps us. I know some people that circle a day on a calendar and they do it once a month or so. I need to realize that I'm my own worst enemy, and being honest. Being honest, again, it's that pressure release. It's the pressure release.

Jim McNasby: It's educational too, isn't it? Because-

Kat Hill: It is. And coming out here and talking, baring my soul is getting more comfortable because I tend to do it a lot. But what I find is people are struggling with all these same issues and we're all human and we all have egos, and we've got to be honest with ourselves and each other about it.

Jim McNasby: Yeah, that makes sense. Omotola, if I could ask you a different question, which is do you ever deal with a different kind of stigma? And that is a stigma that on good days that people don't believe your diagnosis or the seriousness of it?

Omotola Thomas: Tremor-dominant Parkinson's, it's very difficult for people not to believe my diagnosis. If I could pivot, maybe I would say what I do experience is people believe in that, like Nigerians, Nigeria is a largely spiritual and religious country. I think many parts of Africa are as well. And so what I do experience is people feeling that I'm not spiritual enough or I'm not Christian enough or I'm not praying enough, and that is why I have this illness and that is why it hasn't gone away. And that's really, really tough for me.

Jim McNasby: I can imagine. That's what I deal with sometimes because my symptoms are relatively well controlled, but I got deep brain stimulation six years ago, and that took my symptoms from year 19 back to year two. And when people realize that I had to get a brain surgery to address my symptoms, that really underscored for people how challenging it is, it can be to navigate the symptoms, but then when your symptoms are early and they're not that visible, you may be seeing a darker future than you're telegraphing through your symptoms. And so that kind of complexity, and then for me, turning the clock back and doing that again, it gets to be complicated.

So there's a couple of folks who've made observations about finding the courage to come out at work. Let me actually start with you, Dr. Barbosa. Have your patients shared with you stories or do you have advice about whether people should be out at work, as it were?

Dr. William Barbosa: Certainly this is a common question that comes up as symptom burden starts to increase. There can be a bit more of a challenge to meet job expectations. And there's also, as we're talking about, the stigma and the worry about what are other people going to say. So my advice, in my practice, we are very much a multidisciplinary team and a big part of our team is social work. So if there's need for workplace accommodations, our social worker can help navigate the next steps in going forward with that and what are other resources to think of that maybe me as a clinician I'm not fully aware of, but they may have better insight into. So having social work being a part of the toolbox of ways and strategies we can help with that transition point I think is a bit advice I think can go a long way for a lot of people.

Jim McNasby: We have a question from the audience and it says, "I tend not to bring up my PD diagnosis because it makes me feel like I'm looking for their sympathy. Can anyone relate?"

Kat Hill: I felt that way early on, like, "Am I making excuses for myself or am I looking for pity?" I've tried to shift that, and part of what I tell myself in my head, and some of this comes from now having young adult and middle adult children, what other people think of me is really none of my business. And I do that because I feel like I'm constantly trying to please everybody else and do the right thing.

What I'm trying to learn is to stay honestly and in an iMessage what I'm dealing with. "I have Parkinson's disease. I might be a little slower at the checkout. Forgive me, I have Parkinson's disease. I'm walking a little slow through this turnstile." And what it does for me, again, is relieves that pressure and not judging, trying to stay out of my head about how other people are going to receive that. And it really has helped me, probably mostly parenting young adult children as they're launching, but also with my own Parkinson's disease and trying to model that even for my children, because they're going to age. Hopefully with any luck, they'll live to a ripe old age, and how are they going to navigate that? So I hope that answered the question.

Omotola Thomas: My first response when I saw this question was, honey, you have Parkinson's. You deserve all the sympathy you can get for it.

Jim McNasby: I think it's incumbent on every person with Parkinson's to make the burden as light as they can on the people who support them. But at the same time, this is not an easy disease. This is not something that you take lightly. This is something where you have to make a decision that you're going to take care of it and you're going need a group of people to help you. And if you're not honest with them and you're worried about them giving you sympathy, you need to think about the people in that network.

And so maybe Dr. Barbosa, you can help us with this one too, which is how do we address memory issues when they arise during conversations with people who aren't familiar with PD or don't know that it can impact memory? First of all, the medical perspective, and then second from our panelists, do we have a go-to or humorous response that you might use or something like that? But let me start with you, Dr. Barbosa.

Dr. William Barbosa: Yeah, so I'll share that memory difficulties do coincide with Parkinson's disease. It's a common occurrence, so whoever put that question in the chat, you're not alone. And I would say that everyone has different coping strategies, but in talking with some of my patients, if they're having a hard time remembering things, to try and just unapologetically ask for a question to be repeated. If they have a care partner or someone to support, that's someone that they can lean on to sort of repeat a question without them having to always ask. So I think using your supports, finding out what coping mechanisms work best for you, whether it's humor or other strategies, I think figuring out an individualized plan.

Jim McNasby: And Kat or Omotola, do you ever handle this? Do you ever have memory issues that you do address? And do you have any advice for the audience?

Omotola Thomas: Yes. I'll say mine real quick. For me, I just tell people, "I'm having a PD moment, so just bear with me." I remember the last webinar that I was on, I was asked a question and I completely blanked out, and I was mortified and embarrassed, and I actually started crying during the webinar. Kat was there and she was extreme... It was Kat, Sonia, and think Rochelle, and they all huddled around me virtually. But since then, I have decided to take it upon myself. If that happens again, I'm not going to be embarrassed about it because it's not something that I'm controlling. So I just have this line where I tell them, "I'm sorry I'm having a PD moment. Can we circle back to this question later or never?"

Kat Hill: That's right.

Jim McNasby: We need a real moderator.

Omotola Thomas: Exactly. What's wrong with you, moderator?

Jim McNasby: [inaudible 00:50:59] on the moderator. We're coming to the end of our hour together. I just wanted to thank you all very much for your honesty, for your courage, and for your willingness to help on the patient side. And Dr. Barbosa, we have so much confidence in you, and thank you for bringing a well-rounded perspective to our sharing of stories. And we wish you the best going forward, and your patients are lucky to have you on their care team. So thanks to all of you. And sign up for PPMI, contribute to research and get out there and educate people because the more we do it, the more Michael J. Fox is our beacon with his publicity about himself, we're going to move the conversation in the right direction. So thank you very much and we will see you soon.

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