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MJFF: Navigating Parkinson's disease can be challenging, but we are here to help welcome to The Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease and the Foundation's mission to speed a cure. Free resources like this podcast are always available at michaeljfox.org.

Larry Gifford: Hi, welcome to The Michael J. Fox Foundation Parkinson's podcast. I'm Larry Gifford, a proud member of The Michael J. Fox Foundation Patient Council, founder of the PD, avengers.com and host of another podcast called When Life Gives You Parkinson's. It's February, when love is in the air happy Valentine's Day, by the way, thank you for putting your heart into learning more about living with Parkinson's disease by listening to this episode of the podcast. Relationships and Parkinson's have more in common than you might think, they both require a lot of effort, both can make you act a little bit awkward at times, and both relationships and Parkinson are certainly better with a great massage. Parkinson's can and does impact relationships both physically and emotionally. It impacts intimacy, many reasons why, your mood changes, body image, physical changes, sleep changes. It's a topic that's tough for a lot of couples to discuss and tough to bring up with your doctor. And it's kind of the unspoken conversation, but we're going to speak about it today. It's important to discuss your connection and how all of this, your intimacy and your sex life is related to your own wellbeing, how much you can do. And many people who can help and it's a big part of quality of life. And here to talk about it is somebody that I'm very familiar with. My wife and my care partner, Rebecca Gifford.

Rebecca Gifford: Hi, I'm happy to be here.

Larry Gifford: Also Kat Hill, a person living with Parkinson's diagnosed in 2016 at the age of 48. She lives in Portland, Oregon. Hello, Kat.

Kat Hill: Hi, Larry. Thanks for having me.

Larry Gifford: And who's that handsome guy next to you?

Kat Hill: Well, this is my better half Ken Hill. He'll really be the star today.

Larry Gifford: Oh, great. Hi Ken.

Ken Hill: Hi, Larry. Nice to see you.

Larry Gifford: And to keep us all out of trouble. We have Dr. Maria Cristina Ospina, movement disorder specialist in private practice in Phoenix, Arizona. Hello doctor.

Dr. Ospina: Hi everybody. Thanks for having me.

Larry Gifford: Kat and Ken, let's start with you. You've had Parkinson's diagnosis since 2016. That's six years right?

Kat Hill: Actually 2015, Larry. I wish

Larry Gifford: How has Parkinson's affected your relationship and the way you relate to one another?

Kat Hill: Yeah, I think it's a really good question and I think it's a question we may not talk enough about. For me I really expected to be the caretaker. I'm a nurse by training and a nurse practitioner and midwife. And I spent my career as a caretaker. And then as a mom and as a wife, I fully intended to take that role till death do us part, if you will. We've been married, how long Ken? 30 almost 32 years.

Ken Hill: It'll be 32 years next month.

Kat Hill: Yeah, we were married as infants. I think that's the important part tonight.

Larry Gifford: An arrange marriage from birth.

Kat Hill: Exactly. But I think it really shifted how I viewed myself and therefore it really impacted how the relationship dance went. And I think it's taken a lot of time and intention to stay close and to learn how to transition from being what I thought I would be, to where I am.

Larry Gifford: So it's fair to say that Parkinson's wasn't on your bucket list?

Kat Hill: No, it wasn't on my bucket list and I'm pretty sure it wasn't on Ken's either for his wife to get Parkinson's in her forties.

Ken Hill: No.

Larry Gifford: So Ken, how do you feel the relationship has evolved since the Parkinson joined your duo and made it a trio?

Kat Hill: Yeah.

Ken Hill: The relationships with respect to intimacy, it's changed fairly substantially. We actually had a similar kind of a change in our intimacy with several years ago when our youngest son was diagnosed with type one diabetes, that was like 20 plus years ago. And I think you have these kind of changes when you have a big hit in your family around a health issue. You focus less on your own personal intimacy needs and you focus on that to other family member. And that's what happened with Kat's Parkinson's for me is that all of my energy went into

focusing on, what is this and how is it going to impact our life moving forward? And didn't even think about intimacy stuff, but subconsciously that's what goes away initially because I was just was focused on what is PD. Now, PD is not a new thing for me or Kat per se, because we've had it in our family. I've had a grandfather, we've had uncles...

Kat Hill: My father.

Ken Hill: And my father-in-law, Kat's father as well have had Parkinson's. So we're familiar with that in the family, but like everything you just don't expect it to happen to you personally. So the initial with our intimacy it was put on pause and it hasn't been until maybe a few years ago that we've actually kind of kicked it back up into what is our normal intimacy patterns has been.

Larry Gifford: That's great. Is that because you're now empty nesters?

Kat Hill: Partly for sure, but I think our comfort around discussing what Parkinson... That third party in your intimacy, we've gotten to know that third party better, understand it better as much as it can be understood and how we are wanting to stay together and stay close, stay intimate and stay around for a long time. And I think that takes intention.

Ken Hill: And I also at first Kat didn't start Parkinson's medications right away. And so her symptoms were much more visually present, compared to now because her medication has been able to basically mask those symptoms. But at first her tremor was much more prominent, visual, her feeling, just how she felt was much more visible and emotional in our lives. And as her husband, I was a little afraid to hold her with some of the physical intimacy that we used to do, and I would be worried about, am I hurting Kat? Or maybe I don't even want to, let's just put it on pause.

Larry Gifford: Rebecca. I see you nodding.

Rebecca Gifford: Yeah. How could you miss me nodding so much? Yeah, that was a big part of the evolution of our relationship with his body changing so much and so frequently with the symptoms changing and the offs and the ons. I just didn't know how to get near his body anymore. I didn't know. And of course, as you alluded to, you don't want to make anything worse and I don't want to create stress and I don't want it to be awkward or uncomfortable. This was in the early stages when we weren't as comfortable being awkward and uncomfortable about it and laughing about it and seeing kind of the ridiculousness of what we were being faced with. I didn't know how to get near his body because his body wasn't reacting the same way and it didn't function the same way.

Rebecca Gifford: And so it just became this kind of awkward dance of how do we figure this out. And until we really started talking about it, as you alluded to before. Really having those conversations of what can we do, what is important to us, how do

we adjust and work with our new reality and our new normal here to create a sense of intimacy and closeness. And ultimately that meant we had to expand our idea of what intimacy was or even more so, just rely upon the things that were not the less traditional intimacy. Everybody thinks of intimacy as being sex and whether it's penetration or not. It's of being some sort of sexual touch or sexual intimacy. And that certainly is still part of what we do, but prioritizing... We had to prioritize and make more intentional as was said before of the things that we could do and make the things that were less effort, like just nice touching and kissing, and conversations when it was a good time.

Rebecca Gifford: And really that kind of closeness making that... Expanding the idea of what our intimacy and our relationship meant, and then making those things priority. And then just understanding there's going to be more effort and intention you have to put on it. It's not as easy as it used to be. It's not as mind less as it used to be because you guys know after so many years of marriage, you don't have to think about it anymore. Things just kind of happen and there's a natural rhythm to your intimacy and your closeness and all of that shifted. So we had to rethink.

Larry Gifford: Dr. Ospina as a movement disorder specialist, you're probably always dealing with couples. What kind of issues do you find in your practice and what kind of advice do you give folks?

Dr. Ospina: So I think the most important thing is always communication, not only between the patient and the caregiver, but the patient and the doctor. So if we don't know what's going on at home or in the bedroom, then we can't address it or fix it. And remember in Parkinson's disease, there's many medicines that we use that can either make this better or worse. Many patients with Parkinson's disease, part of the pre-motor phase of that or the non-motor symptoms of PDR, things like anxiety, depression, we put you on an antidepressant.

Dr. Ospina: Many of those antidepressants, the SSRIs, cause anorgasmia. And so not only do we put you on Prozac or something like that, but then we also give you things like dopamine agonist, those are medicines like Pramipexole, Ropinirole and Neupro, and those increase your libido. So now we've increased your libido but none of the plumbing works and now we've just frustrated you and your care partner. But if we don't know about that, then we can't address it.

Dr. Ospina: So if you tell me, hey, I'm having trouble reaching an orgasm, maybe we should switch your Prozac to Wellbutrin or another drug. Or, I have a lot of impulse control or hypersexuality. That's dose dependent. I can lower the dose of your dopamine agonist and not make you as compulsive. So I think communication is key, not only between the patient and the caregiver and the family, because remember PD is a disease that affects all of the family, not just the Parkinson's patient. It's like the type one diabetes. It affects all of the family.

Dr. Ospina: And then between you and your doctor, because if we don't know what's causing distress at home, we can't address it and fix it. And then remember that PD, many patients are young onset, below the age of 50 like Kat, but as we grow

older our body changes and those changes make intercourse more difficult. Patients become postmenopausal, have lower levels of estrogen, erectile dysfunction also comes with lower levels of testosterone. And we can address those if the doctor knows about it.

Larry Gifford: Kat, you had a question.

Kat Hill: Well, I had a thought. Pre-dating Parkinson's I was in fact diagnosed with depression and was on an SSRI for many years. And looking back, was that Parkinson's, was it something else? But it definitely impacted my ability to enjoy sex, or anorgasmia. I enjoyed it, but it wasn't quite as enjoyable as I would like it to be.

Kat Hill: And so for me it was hard to sift out, going through the diagnosis process. I was perimenopausal, I was working long hours. I was away from home a lot. We had a child with a chronic illness. There were a lot of factors that were contributing to me not feeling very well. It was very difficult to sift out. I was definitely guilty as a patient of not bringing that up with my provider, but I think there's some area for growth in the exam rooms.

Kat Hill: I think that just like we feel awkward maybe talking about sex and intimacy and all of those pieces, I think some of our providers are not as comfortable either. And I think we can grow in that realm by A, bringing it up as a patient. Physicians and providers cannot read our minds.

Kat Hill: And second to that, I'd like this to be an invitation to clinicians to bring it up and ask the questions. Sexual health is really a part of our integral health, and many of us are cautious, embarrassed, forget, getting nervous in the exam room, and don't bring it up. So I'd love to see it be a more routine part of the dialogue.

Kat Hill: And I get that I'm a little biased. I was a clinician and a nurse practitioner for many years, and a midwife, talking about reproductive health. So I gained comfort with it. And even I didn't bring it up. So if I'm not bringing it up and I talked about it professionally, I imagine there's at least a couple of listeners out there that feel the same way. So we have to own that as people with Parkinson's.

Larry Gifford: I was going to follow up with Dr. Ospina on that. I was going to ask, whose responsibility is it? Because I've never been asked in the office about it, except for on the survey that I get every time I go to the office, but then they don't do anything with the survey as far as following up. If I say my sexual desire's a one out of five, nobody asks me about that.

Dr. Ospina: And I think that's a bad point that happens in the clinic, that we just focus on the motor symptoms of Parkinson's disease. And Parkinson's encompasses so many other things other than your primary motor symptoms, tremor, rigidity,

slowness of movement, trouble with gait and balance. There's a whole host of non-motor symptoms. And of course, we need to think of the whole patient.

Dr. Ospina: If I give you Levodopa and get rid of your tremor, but you're too depressed to get out of bed, or you're not discussing things with your spouse. You're not having intercourse anymore. And I think Rebecca's really good. We need to expand our idea of what is intimacy and expand that to just not sexual intercourse, it's just not penetration. We should really call it outer-course, so that it includes everything from handholding, to massage, to using sex toys or oral stimulation, those sorts of things.

Dr. Ospina: So I think what happens in the clinic is that the provider's very focused on your motor symptoms, that UPDRS. Are you getting up and walking. Are you falling. How's the swallowing, how's the speech. And we're forgetting about the rest of the person. And so I think both the healthcare team and the patient need to put that more front-and-center and think of you more as an integrative, that mind-body connection, so that we can think of your overall health.

Dr. Ospina: But of course, I always want patients to write down all your questions so that way you don't forget your questions. And that don't be afraid to add the sex part in there because there's many things that we can do. We know that you can have anorgasmia with SSRIs. We can fix that. We know that we make you hyper-sexual with high doses of dopamine agonist. We can fix that. But you just need to bring it up.

Dr. Ospina: If your provider doesn't have enough time in their 20-minute visit, advocate for yourself and say, hey, I know my tremor is a lot better and I haven't had any falls in the last three months, but I can't reach orgasm. Maybe I should shed Prozac to Wellbutrin. What do you think?

Larry Gifford: Kat, you're right. It's hard to bring it up in the office. And I like my neurologist. We have a great relationship, but I couldn't bring it up. So I actually emailed him after my appointment said, hey, can I get some Viagra? And he's like, sure, I'll phone it in. So that's one way you can do it.

Larry Gifford: But Rebecca and Kat and Ken and Dr. Ospina, the people that I admire the most are the people that are still dating and have Parkinson's disease, the single folk. We're so lucky that we have partners that we've been with for decades, but I just think, I don't know how they do it.

Larry Gifford: Do you have any thoughts on how they go about having a sex life and dating and all that stuff with Parkinson's and when do you tell the person you're dating you have something? And it's hard. Thoughts on that?

Dr. Ospina: Before Kat started medications, her PD was very visible, lots of tremor. And remember that mind-body connection, the more stress or arousal your body has, the more the tremor, dyskinesia, dystonia is to come out. And so that,

especially if you haven't known your partner for 10, 20, 30 years, you're out there dating, that can be quite inhibiting that you've got these body issues. You're worried about your tremor. You're worried about the cramping in the foot. You're worried about drooling maybe, or the skin changes.

Dr. Ospina: And so, again, it's always communication. I would lead right off the bat, I have Parkinson's disease, so it's just not this thing that you're hiding in the corner, that sort of thing. Our goal and our job is to get you out there and living a full life. And so just because you have a chronic disease like Parkinson's disease, doesn't mean that you have to stop dating and not go on any dates anymore.

Dr. Ospina: And one thing, just as a doctor I like to plug, is that remember that you can still get STIs. Even if you're postmenopausal, you don't have to worry about pregnancy anymore, those infections are still out there. And so you want to have safe sex, especially if you don't know your partner that well, it's not a monogamous relationship.

Larry Gifford: Kat, do you want to add to that?

Kat Hill: Well, I want to come back to the foundation of communication, I think. Yes, I feel so blessed that I have Ken in my life, and I really do have a lot of respect and care and love for those that are out in the dating scene, whether they have Parkinson's or not right now in this world. But I think as you develop intimacy, communication is such a key part of that. And I think that developing a relationship is a process of developing intimacy on many levels, the physical being one of those.

Kat Hill: And so I think that being able to gain confidence in the body that is changing, everybody's body's changing, everybody's body's aging, right? We're never going to be as young as we are right this second, aren't I sunshine, right?

Dr. Ospina: But we get wiser.

Kat Hill: Yeah. So that's going to happen with who you're dating as well. And so maybe my, I like to call it my quirkiness or my bounciness is what I would call my a tremor a lot, that I'm just showing a lot of my emotion on the outside. And maybe that's a good thing for a partner. They know when I'm a little nervous or when I'm excited. But it's about getting comfortable with who you are as a human being and then a human being with Parkinson's.

Rebecca Gifford: Well, in communication, and I love that that's come up so much because of course it's important to relationships and to this particular topic, and keeping that open communication, honest communication, talking, having the tough talks. But we all know that communications is challenged with Parkinson's in the relationship for anybody with Parkinson's, anybody speaking to a person or trying to communicate on all levels with a person with Parkinson's.

Rebecca Gifford: And our communication style has had to change. It was so effortless and easy and really how we built our relationship initially, because we were long distance for a while in our early relationship. And so it was so easy to rely upon that. And then the Parkinson's comes in and everything has to become more intentional, everything has to become more mindful and require more effort and thought, and all the things that come with Parkinson's. Having these kinds of conversations about intimacy become that much harder, right? You have to find the right time. They have to be on. It can't be too late in the day. Everybody needs to be in a good mood. You've got space to have a nice private conversation where nobody's coming into the room and you don't have other meetings that you have to get to and all of that stuff. It just becomes the window for communication, intimate or not. It becomes smaller all the time.

Larry Gifford: Well, and part of that is... We're not sleeping in the same bed anymore because of some of my symptoms and I have active dreaming, and I don't want to elbow you in the back anymore. There's fewer opportunities.

Rebecca Gifford: It's only happened once.

Larry Gifford: Yeah, well, but there's fewer opportunities for those conversations. We used to have that sort of the going to the sleep conversations and we don't have those anymore, so we have to find other times to do that.

Ken Hill: Speak of timing of it all, that made me think of one... I've been working from home since this pandemic started. I'm one of the fortunate people that able to work from home and continue working, but it's also freed up our time for our best time of day for physical intimacy and intercourse is in the middle of the day. In some ways, that's opened a door for us to be more physically intimate when we want to and we don't have that, oh, we're both at the office, or we're both in different parts of the city.

Ken Hill: Also, I wanted to share that in some ways, this has been... Kat's Parkinson's and our adjustment for our intimacy, it's given me an opportunity and I think Kat also to focus on some of our more emotional intimacy needs and getting a lot more enjoyment out of that than we used to because we were so busy with other parts of our lives. In some ways, Parkinson's has given us an opportunity to focus on that and really work on identifying the emotional, intimate parts of our lives that we used to enjoy and now that we're able to spend more time doing some of those things.

Rebecca Gifford: Like embracing the evolution of it, right? It's different now, so let's grieve the loss of what we can't do anymore, or the things become a lot more effortful and move forward and as you're alluding to, there are some new ways to connect and that's exciting, right? It makes the losses more palatable, but also it's about embracing the new and moving forward.

Larry Gifford: Yeah. Then there's the unknown, which is once you find your balance and then something else happens and you got to re-find your balance.

Rebecca Gifford: Let's embrace the uncertainty. Easier said than done.

Larry Gifford: Dr. Ospina, I brought it up earlier. There is a lot of sleep problems with folks with PD. What are some of the different ways Parkinson's can affect sleep?

Dr. Ospina: Yeah. Sleep is part of what we put in the non-motor bucket and as you were talking about those active dreaming or REM sleep behavior disorder, many times that's present many years and sometimes decades before your diagnosis of Parkinson's disease. What that is, when you go to sleep and you go to REM sleep, which it's your dream sleep, usually you're paralyzed during REM. You're atonic so that you don't act out your dreams, but in Parkinson's disease, that atonia doesn't take place. You're no longer paralyzed during REM and so you can act out your dreams. You can talk, yell, scream, kick, and punch. It turns out that during REM that's, when your brain is practicing getting away from a threat, and so that's why these dreams tend to be very active, lots of screaming and kicking and punching because you're trying to get away from a threat. You're practicing that in your sleep.

Dr. Ospina: That happens many years, sometimes decades before your diagnosis of Parkinson's disease, but as the disease advances, like you said, it leads to couples either moving to separate beds or sometimes to separate rooms. Then that can affect the intimacy. As you said, you're no longer in the same room in the same bed to talk about what happened during your day, what you're thinking about to give you that if you both wake up at two in the morning, something could happen. RBD is one of the most common things that happens during sleep or interrupt sleep and Parkinson's disease. There's many other things like sleep apnea. Sleep apnea is very common in Parkinson's disease. Many times, patients have to use a CPAP machine. Again, people feel like, oh, I have this octopus stuck to my head. It's not very sexy. That doesn't lead to a lot of intimacy, but as Kat said, maybe you can find times for intimacy. One of the silver linings of this pandemic is that now you could work from home and then have intimacy in the middle of the day instead of at night.

Dr. Ospina: Then I just want to put a plug for sleep because sleep is really, really important, especially in Parkinson's disease. Why do we spend a third of our life asleep? It must be doing something super important for our bodies. Sleep is when we our learning and memory take place. Your short-term memory encodes into long-term memory, and then it's the house cleaning part of the brain. That's when your brain does all of its house clean. It cleans up all that cellular debris that happens in the brain. It cleans it all out.

Dr. Ospina: We know in Parkinson's disease, that's one of the problems that lead to cell death. You have this misfolded protein called alpha-synuclein that clogs up the cell and it causes the Lewy bodies and then the cell dies. But if we get more stage three and four deep sleep, then there's more of an opportunity for that

house cleaning to take place. Many times, you'll have sleep fragmentation. Many PD patients get distressed like, oh, I can't sleep eight hours in a row anymore. That's okay. We can sleep a chunk at night, and then you can take a nap in the day. That's fine. We just want to get enough sleep throughout the 24 hour period.

Larry Gifford: Well, speaking of REM sleep behavior disorder, the Foundation's landmark study, the Parkinson's Progression Markers Initiative, PPMI, is recruiting people with RBD. Now, the study aims to better understand and measure Parkinson's disease, including before movement symptoms begin. This information could lead to new treatments and through PPMI, scientists also could learn more about the biology in experience of REM sleep behavior disorder. Learn more at michaeljfox.org/dreams.

Dr. Ospina: We know that many patients with RBD go on to progress to a Parkinson's disease or an alpha-synucleinopathy. We want to pick up these patients early on so that we can stop the progression of PD when it's just constipation, anosmia, losing your sense of smell and acting out your dreams. That you never develop the neurologic point, the motor symptoms of PD and all of the disability that comes with the on and off. Many patients say, "Well, what's the cure for PD? Are we going to replace these cells?" The cure for PD is going to come that we're going to stop the progression of PD in the pre-motor stage. Just like you get a colonoscopy and a mammogram when you're 50 years old, patients who are at risk have RBD, like Kat, a first degree relative with Parkinson's disease, constipation, anosmia, history of anxiety, depression, gets a DAT scan and then we'll use compound X, whatever it turns out to be, to stop the per aggression of that alpha-synuclein migrating up into the brain.

Larry Gifford: Let's talk up on that complex X or whatever.

Dr. Ospina: Right now, the only thing we know is that exercise is the closest thing we have to that compound X.

Larry Gifford: Right. Hey, Kat, I don't know about you, but Parkinson's makes me moody at times. It makes me angrier at times. It makes me apathetic at times, which none of those things really are too sexy for my wife.

Kat Hill: I wish I could say that. I don't have a single one of those Larry, but that would be absolutely not true and my husband's right here, so... I think that the intensity of emotions that we have swing more. I will say that since being diagnosed and since leaving my very intense sleep interrupting job, I'm able to take care of myself more and therefore, my emotions feel more regulated. I realize that that's a real privilege and a loss. I really miss catching babies at the hospital, but I have realized that so much of that lifestyle contributed to probably the exacerbation of my symptoms. That by getting better sleep, by exercising regularly, by eating more healthy, by being an empty nester, there's hope you guys. Just in terms of being able to regulate what helps me feel good, that helps but definitely, my emotions run high. I get anxious very quickly. To add to the

sexy factor, I have severe sleep apnea, so I may be shaky, emotional, angry, cranky, and wear my Darth Vader mask at night. I'm the [crosstalk 00:31:47].

Larry Gifford: Rebecca, you know about the sexy Darth Vader mask. It's a turn on, right?

Rebecca Gifford: I do. I'm just used to it now. It's just your nighttime Larry self, as an extra component.

Larry Gifford: How do you think my mood swings... Because I was a kind of even keeled guy before Parkinson's.

Rebecca Gifford: Yes. You were not an anxious person. You didn't have a lot of mood swings. You were pretty even keel. Your moods were weeks long and that's quite different now. Another thing to consider when you're considering communication and all the things that are necessary to maintain that close sense of closeness and it took a bit. We're only what five years into our journey after diagnosis? So we're early, but it took a little bit. We're still working on it. We will continue to have to work on it, learning to manage that. I had to adjust my reactions because I was not used to that. I was not used to angry Larry. I was not used to anxious Larry and didn't know how to take it at first, even though I understood it was part of the Parkinson's. It just didn't compute, so I had to build that muscle of patience and recognizing what's happening, and what are the ways that we have? What are the tools we have to manage that? What tools do I have to make sure that I don't overreact? All of that. How about you, Ken?

Ken Hill: Yeah. That's really interesting; this topic was brought up because I have seen a change in Kat becoming more quick to change in her personality and getting angry quicker, mood swings more rapidly. If you were to look at us 10, 15 years ago, we would be the opposite. I was the one having the drastic mood changes and mood swings, and now, it's reversed. And so there are times where I just have to go, "Okay. Let me just back off a little bit; let the situation calm down." And I've had to be able to; when I've seen some of these mood changes, I have to take a breath and take a pause and wait and see where this thing is going to go.

Dr. Ospina: So I mean, let's explain why that happens in Parkinson's disease. So I think both patients and providers are still stuck in PD as a motor symptom. It's just the tremor, the rigidity. But Parkinson's has all these non-motor symptoms. And part of that is the anxiety and depression that come with those mood swings. So as your levels of dopamine fluctuate throughout the day, when your dopamine level is low, and the tremor and rigidity is coming back, many times, the very first sign of an off or your low level of dopamine is not a motor symptom like tremor or rigidity, it's a non-motor symptom like anxiety. Some people have a frank panic attack. And so that anxiety comes up, and that's your first symptom of off, and then the tremor comes. And so, if you recognize that these are fluctuations of the levodopa throughout the day, then we can add longer-acting forms of dopamine during the day.

Dr. Ospina: And then remember, when you have low levels of dopamine, that leads to low levels of norepinephrine and serotonin, which causes anxiety and depression and the lack of emotional resilience. So if you have low levels of serotonin, you're less likely to bounce back from a stressor. You're more irritable. That fuse is really short, so you get angry right away. So it's the reason we add in an SSRI, something that's going to increase serotonin or norepinephrine until we increase that fuse, make you more emotionally resilient like you felt five years ago so that if airlines cancel your flight or the realtor didn't show up, it doesn't seem like such a big deal. And then, we need to recognize that anxiety may be the very first sign of wearing off before the tremor comes.

Dr. Ospina: And that's why there could be lots of fluctuations throughout the day in the sort of mood symptoms of a PD patient. And once you understand that, then the caregiver doesn't take it as personally. You're like, oh my gosh; they're always snapping at me; she was never like that before. And then you understand the content of the disease, and then you can come in and tell your healthcare team about it, and then they can change your medicines to make those fluctuations less throughout the day. So you're more even-keeled, both motor-wise and non-motor-wise emotionally as well.

Larry Gifford: This is a fascinating topic. If folks want to learn more about how mood changes are happening in Parkinson's, you can check out the replay of a webinar on mood changes and aging and Parkinson's on February 17th at Michaeljfox.org/webinars. All right, we're going to do around Robin here. Everybody gets a chance to contribute. First, we'll start with Ken, Kat, and Rebecca. And then I have a different question for you, Dr. Ospina, how do you continue to nurture the connection, closeness, and intimacy as Parkinson's changes?

Ken Hill: For me, and I think for us, it's carving the time out. It's actually making this a priority in our lives and making sure we have at least sometime during the week we can do something intimate and drop everything else that's going on around our lives. And focus on us; we don't have to have a specific plan. It's not like a date night in the calendar, but it's just making sure we make that a priority is our intimacy.

Kat Hill: And I would say I like how before I get Botox for dystonia in my hands every 12 weeks. And before that appointment, check-in about where I am with symptoms, how we feel it's going, and that helps us because we know it's coming up; it's not in the moment. Like, gosh, you're angry more often, or your medicine isn't working or whatever, but we're able to connect about it. And we know that we have a set-aside time to talk about how is the progression.

Larry Gifford: Rebecca.

Rebecca Gifford: Along with enthusiastically agreeing with what's already been said, I think that part of those conversations for you and me, Larry, are also just kind of renewing that intention. And we have that trust that we want to work on it. Kind of

renewing the vows in a way and renewing that commitment because things are changing so fast and just checking in with each other; as part of that check-in, you mentioned it's saying we're still in this, right. Okay, so let's talk about how to move forward. What needs to shift? All of that. So, of course, communication, and then kind of having that trust that you're in it together. And that you don't need to worry about that piece of it, and then you can move forward, and you can say the awkward things and be brutally honest about something or write and express your needs and then make a plan.

Larry Gifford: Yeah. And I think for me, one of the things that's really helped is I don't notice when I'm not contributing at the level I should at the house with the kid, with the dinners, with the stuff. And so we have a whiteboard now in the kitchen so that we have a list. So I can look at that to see if anything's going on. Rebecca's really good at saying, Hey, can you help out here? Can you do this? Can you do this? Often times she has to ask me three times because I forget, but it's that communication, and it's not nagging. I need that, whether it's a visual reminder or an audio reminder, because I can get lost quickly, especially towards the end of the day. And I don't want to escape the family after having worked all day; actually, I'm working so I can be with the family. So we have to make those things a priority, like Ken said. Dr. Ospina, what kind of advice would you give people to consider as they're trying to nurture their relationships?

Dr. Ospina: So, as Rebecca said, this is a disease that's changing from day to day, from hour to hour; as the disease advances, it's a new person. And the better you communicate about that, the better you understand the disease, the medicines and how they work, and how you fit into that context. The easier it is to sort of roll with it and go with the punches. So I think communication between you and the care partner is key and between you and your healthcare team.

Larry Gifford: I want to thank you all. This is an amazing conversation. We could probably go on for another three hours, Kat and Ken and Beck and Dr. Ospina; thank you for being here.

Kat Hill: Thank you.

Dr. Ospina: Thank you for having us.

Ken Hill: Yeah, thank you for having us, Larry.

Rebecca Gifford: Pleasure.

Larry Gifford: I want to remind you that there are many resources available for you to find out more about how Parkinson's can affect relationships. There's the Ask the MD videos; there's blogs, Third Thursday Webinars, all of these topics, and more at michaeljfox.org. Our landmark Parkinson's Progression Markers Initiative is open to anyone over the age of 18 in the U.S. Join the study that could change everything at michaeljfox.org/podcast-PPMI. There will be a link in the show

notes; please rate and review the podcast. It's really a great way to spread the word about Parkinson's disease, raise the awareness and share it with your friends. Personal recommendations are always the best. Thank you for listening on behalf of our guests today and everyone at The Michael J. Fox Foundation, who is here until Parkinson's isn't. I'm Larry Gifford; we'll talk to you next time.

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