

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 a cure at michaeljfox.org.

Intro/Outro: 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.

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Jim McNasby: Hi, and thanks for joining us today. I'm Jim McNasby, the General Counsel at The Michael J. Fox Foundation. I was diagnosed with Parkinson's in 2000 and I'm a member of the foundation's Patient Council and it's great to be with here with you today and our panelists. Today we're going to talk about Parkinson's taboo topics, things that are hard to talk about even with loved ones and doctors. We're going to talk about embarrassment and shame and stigma and ways to navigate awkward conversations and awkward moments where it's hard to have those conversations. We've got a lot to discuss and let's get started. First, let me introduce our panelists. Dr. Karen Jaffe is a member of MJFF's Patient Council and was diagnosed with Parkinson's in 2007. She's also a founder of InMotion, a wellness center for people with Parkinson's disease in Cleveland. Karen, it's good to have you here.

Karen Jaffe, MD: Thanks for having me, Jim.

Jim McNasby: Sure, my pleasure. We also have Marc Jaffe, Karen's husband and care partner. As you'll see, Marc is a comedian, writer and Parkinson's research advocate. Thank you for joining us, Marc.

Marc Jaffe: As you'll see, you're putting pressure on me.

Jim McNasby: I know. It's my nature. It comes from law school. Finally, we have Dr. Benzi Kluger, a movement disorder specialist, Professor of Neurology and Medicine, and director of the Palliative Care Research Center at the University of Rochester Medical Center. Welcome, Benzi.

Benzi Kluger, MD, MS: Thanks for having me.

Jim McNasby: Let's start with some basics. Parkinson's disease comes with a variety of symptoms and life changes and it's different for different people. Benzi, can you help us to level set by providing an overview of Parkinson's symptoms, including the ones that are harder to talk about?

Benzi Kluger, MD, MS: Sure. The way I usually think about them is there are motor symptoms, things like tremor, shaking, things that are visible in terms of how people move. There are what are called non-motor symptoms, and we could break those down and we'll talk about a lot of them, many of which have stigma or are difficult to talk about. Thinking and memory would fall under that, changes in mood, changes in

sleep and energy changes in what's called the autonomic nervous system or automatic nervous system. That can include things like bladder and bowels and drooling. There are things that can be side effects for medications, including on sexual function, on gambling, on certain behaviors that can be difficult to talk about. Hallucinations and illusions can be tough things to talk about because there's stigma involved and people might have the impression, "Oh, people are going to think I'm crazy if I mention these things." So it's a pretty wide range of things that come up with Parkinson's. It's much broader than the public's view of Parkinson's is just tremor.

Jim McNasby: That makes sense. Of course, a Parkinson's diagnosis can come with a lot of questions and uncertainty and change. Some symptoms are embarrassing. Others carry social stigma and create feelings of shame. They can be hard to talk about. They can affect how a person thinks about themselves, the dynamics of intimate relationships and how they interact with their community. Benzi, as somebody with a neuro-palliative care, can you explain what that means for the audience and how you are uniquely positioned to address some of these issues?

Benzi Kluger, MD, MS: Thanks for asking that. I think palliative care is something that maybe some people in this audience would've heard of, but possibly not everybody. So just to kind of set the stage, palliative care is an approach to people with serious illness, and Parkinson's is a serious illness, that's really person-centered and family-centered, so meaning that we not look at just the patient but also the family, and our goal is to improve quality of life. Another way of putting that is that we're addressing the total pain or the multi-dimensional suffering of an illness like Parkinson's. That means that we don't just look at tremor, but we also look at other physical symptoms like pain. We look at social challenges with having a serious illness like isolation, loneliness, emotional difficulties of grief and worry and guilt, spiritual and existential suffering of figuring out my identity now that I have this new serious illness, figuring out my relationships with people that are now different, and also helping people have a roadmap for what's ahead with this illness.

So as people in this audience I'm sure can resonate with that, these are all important things that people with Parkinson's face, unfortunately they're not all things that our healthcare system does a great job at acknowledging. That's part of why I got into palliative care and why I'm actually a big proponent and champion of trying to make this a new standard of care for people living with Parkinson's.

Jim McNasby: Karen, could you talk a little bit about your diagnosis with Parkinson's and especially as a practicing OBGYN, knowing the stereotypes of the disease and having a medical background?

Karen Jaffe, MD: Thanks, Jim. You would've thought that as a physician I would've had a leg up on being able to figure out what my symptoms were, but the truth is that I was no different from many other people. I didn't have any exposure to Parkinson's, I didn't see it medical school and as an OBGYN taking care of young women, I wasn't certainly going to see that many. So I didn't really know I had isolated pain in my shoulder, which led to then a tremor. But what was interesting was

that when I went to see the physician, I could tell that he knew what I had, but he didn't want to tell me. I think it was difficult from one colleague to another, two physicians, for him to be able to tell me that I had Parkinson's disease.

So I feel that the stigma of Parkinson's disease is so prevalent, even really in the doctor's office where he didn't want to tell me. I know lots of people who have had the same kind of experience where their symptoms just didn't jump out to them as something, but their physicians really, it didn't jump out to them either. So the stigma of Parkinson's patient being an old white guy shuffling down the street, we need to update that because the faces of Parkinson's are many, varied and much different than what we are taught in medical school.

Jim McNasby: What did you draw from that conversation or that experience and how did that make you feel?

Karen Jaffe, MD: Well, it was a chance for me to be on the other end of the stethoscope as a physician to understand that how we give a diagnosis to people matters, how we communicate with our patients matter, words matter. Because I think what I missed from that was an opportunity to engage myself with Parkinson's community, which I think is so important to reduce stigma and to not be afraid of meeting other Parkinson's patients. I mean, you get empowered when you see that people can live well with Parkinson's disease. I think that we need to change how we educate people about Parkinson's. We need to change how we think about Parkinson's because I know lots of people who didn't get diagnosed because they didn't fit the stereotype of Parkinson's disease until they were much further along.

Jim McNasby: That fits into one area of hard to discuss topics in the way I think about it, which is how PD affects the way you see yourself and your own diagnosis and your own experience. Benzi, what kind of Parkinson's topics can affect a person's self-perception, self-esteem and in turn be difficult to talk about?

Benzi Kluger, MD, MS: It's a good question. There's a lot. I mean, on the motor side, I think one of the things that can be tough to deal with, and Karen could certainly speak to this more eloquently than I am, is just your relationship with your body and having a tremor, having slowness, having stiffness, balance issues, and also your relationship with your future self and knowing that there are things that are going to be happening in the future that you might not be able to do. That's very challenging. Then on the non-motor side, cognitive function is a huge one. I think people are very afraid of dementia, and we'll talk about this more later, but changes in thinking and memory are big. Mood is a big one, and I think people are uncomfortable talking about anxiety or depression. People are also uncomfortable talking about grief and guilt and other aspects of having a normal emotional reaction to a bad illness.

In some of the studies that we've done, I think some people have felt hesitant to bring up some of these things with doctors because they felt that they would get labeled as having depression and put on a medication, whereas they're really just experiencing normal grief from being diagnosed with a crappy illness. Certainly anything around sex or around poop or around peeing, all those things I think are

embarrassing topics to bring up. Psychosis was another one that we mentioned, so hallucinations, changes in dreaming. Some of these are also tough to bring up because they're not always acknowledged. An example of that is fatigue or pain, that they're invisible symptoms and that sometimes people will bring it up and they find that they get those symptoms minimized by their doctors. Some things that are tough to bring up because they're tough internal to recognize. Sometimes things are tough to bring up because they're not really being properly acknowledged by the people around you.

Karen Jaffe, MD: Don't you think that a lot of people don't ... I mean, for me and I'm a physician, that they don't necessarily know that that symptom is from Parkinson's. Many people wouldn't know that they could have bladder and bowels dysfunctions, so they don't bring it up.

Benzi Kluger, MD, MS: No, that's a great point and there's so many gaps in care that can arise, but that's a big one, and patients don't always know who to bring things up to. Then the coordination of care is also an issue. For example, pain and Parkinson's is that neurologists don't always want to deal with that, primary care doctors don't always feel comfortable, so there's a lot of things that just fall into this netherworld and patients and families are often stuck trying to figure them out the best they can.

Jim McNasby: I know on my own side, pain has been something that I didn't even realize was Parkinson's driven. I've had a hip replacement, I've got other problems associated, and then I also have this experience, which is I got DBS surgery and my symptoms went from very advanced looking to much more well controlled. As I sit here talking to you today, I don't have conspicuously difficult symptoms since I'm still in that parentheses of feeling good after the surgery, but I worry about if I'm not manifesting symptoms, will people take my pain seriously? Do they expect me to be visibly shaking or in pain or uncomfortable or falling or tripping or being stiff in order to have a conversation? Or do I sound like a complainer? Because the pain is significant and when I finally went to the doctor about my hip, he's like, "You need a total joint replacement here. There's no cartilage left in your joint."

Anyway, it's complicated. Marc, you as a caretaker, do you notice things about Karen that she finds difficult to share with you or she's hesitant to share with you?

Marc Jaffe: I think we have a pretty good relationship where she's pretty open with her needs. Sometimes we end up ... some of the symptoms that you have are symptoms of aging as well, so I try to compete with her with my pains and suffering so that she doesn't feel so bad that it's necessarily her Parkinson's. But one thing I would say just a little bit going back is one of the things that Karen was hesitant to talk about when she was first diagnosed was we hid the fact that she had Parkinson's for years and that's because of the stigma and issues with her career potentially. I think once she was able to come out, she realized something that was of value and that's that she was able to continue to work and perform as an OB and a surgeon and that if she hadn't presented herself as somebody with Parkinson's who was still able to do that, it just extends the stigma of it. So by being more

open with this, I think we help everybody who has it be able to talk about things more.

Jim McNasby: Yeah, that's important. Benzi, when a patient is older, it's tough to distinguish what's Parkinson's and what's normal aging. Is there a way to do that?

Benzi Kluger, MD, MS: Yeah, it does add to the challenge, and it is part of why it's important, if you can, to see a movement disorder specialist or neurologist who sees a lot of Parkinson's patients. If we take pain as an example, so about three-fourths of people with Parkinson's have pain. It's not one of the things that people first think of with Parkinson's and under the category of pain ranges all kinds of things. People have osteoarthritis and other things that you see with normal aging, but people with Parkinson's can also have dystonia or abnormal muscle contractions. They can have neuropathy or damage to the nerves related to their Parkinson's disease. So it oftentimes takes seeing somebody with that additional layer of knowledge to help to sort out whether this truly is something that's related to Parkinson's or whether it's something that's just related to old age.

That's true for memory, it's true for sleep, true for bladder, all these things. Is this Parkinson's or prostate? Is this just getting older? Those are definitely issues where it's ... and you're never going to get there unless you bring them up with your doctor. So that's always the first step, making sure that you find somebody who's really listening to you and appears to have the expertise to be able to get you the right treatment and get you the right diagnosis.

Jim McNasby: That's great. I'm looking at some of the questions here and it seems like there are a lot of questions on bladder and urinary issues. Benzi, could you talk a little bit about why this occurs and what people can do about it?

Benzi Kluger, MD, MS: With bladder, this goes back to the Parkinson's disease affecting parts of the brain as well as spinal cord nerves that are part of the autonomic nervous system or automatic nervous system. So bladder issues, constipation, blood pressure, all kind of fall under that umbrella. With the bladder, my typical approach is to kind of listen to people, hear about their symptoms. I think particularly in men, it is appropriate to get age-appropriate screening for things like prostate, which is also common in older adults. There are definitely medications that can help with the most common symptoms and most common things with Parkinson's bladder is urgency, so feeling like you have to go, you really have to go. There are medications that can help with that, but there are times where getting a urologist involved can be helpful and if symptoms are really severe or not responding to the first line of medications, there's Botox and there's other procedures that urologists can do to help people with bladder.

It can be treatable, but again, the first step is recognition, and then I think just keep pushing and asking for referrals until you get to somebody who can offer treatments or has really a high-level expertise in whatever your symptom is.

Jim McNasby: In my own experience, I've prepared for this call and 15 minutes before we started, I made sure I made a trip to the bathroom to make it through the call because it's happened to me that I've been in a presentation mode, not unlike this

one, and just out of nowhere comes this urgency and then I have to say, "Excuse me for a second, I need to step away." That's embarrassing and hard to talk about, but I think personally that one of the most important things you can do is address something once it's happening rather than ... It puts your audience at ease, it explains to others what's happening. It's important.

Karen, if I can turn to you again, there's a lot that remains unknown about Parkinson's and the way that it affects women. In a Fox Insight survey last year, 61% of women reported a change in their self-image after diagnosis. Can you talk a bit about your experience and what you've seen before you retired as an OB/GYN?

Karen Jaffe, MD:

Well, for me, I consider myself pretty lucky because I've had Parkinson's now for about 18 years, and I feel like I've had a slower progression than some of my compatriots. But that being said, I've done some looking into Parkinson's in women and there's not a lot of information about how we might differ. Certainly I have friends who had their children while they had Parkinson's disease and have done well with that. A lot of women who get diagnosed with Parkinson's are right around menopause, so the question is what are the symptoms that are from menopause and what are Parkinson's disease? There could be some interaction between some hormone replacement therapy that women might be taking and their Parkinson's, but there's not a lot of established data out there. The recommendations are to eat a healthy diet and get some exercise and I think that exercise is a really important part of our therapy that doesn't get enough credit for what it's able to do. I think that we now know that exercise can slow the progression of Parkinson's disease, and so the symptoms that we had that we might be embarrassed by might be lessened.

For me personally, I think that one of the things that we all kind of hunch over, we seem to be stooped over and walking by a mirror or a department store window or a picture that's taken of you and you're all hunched over, we could be sitting up straighter and that we're capable of doing that. If I knew back then what I know now, I think I would've been a different Parkinson's patient. I was very fearful back then when I first got diagnosed that everything, every symptom that I had was an indication that my Parkinson's disease was worse, and that really hasn't been the case. I feel that knowledge about what to expect and what the course of Parkinson's might be is ... it's so up in the air that you shouldn't ... I'm not going to spend any time worrying about it. I'm going to take care of myself on a daily basis and hope that I can feel well every day and modify that behavior as my symptoms develop.

Jim McNasby:

That's great. You made me sit up on the chair when you said that.

Karen Jaffe, MD:

I wanted to say one thing about the bladder issue. It's funny because I got diagnosed when I was in my mid-40s, but I had 20 years of constipation and a good 10 years of bladder dysfunction that I thought was because I had vaginal deliveries for my kids. In fact, it was only recently that I realized that my urinary urgency is from my Parkinson's. So a lot of women think that that stress incontinence is the same as urgent incontinence and they really are two different things, and for urgent incontinence sometimes causes constipation. So those of us

who are prone to constipation, those medications can be difficult to balance things out with.

Jim McNasby: That makes sense. Thanks for sharing that. Well, that leads us into another area of Parkinson's hard-to-discuss topics, which is how it affects intimate relationships. Karen, can I turn to you again? How have your symptoms impacted your relationship with Marc and has it changed your roles in the relationship?

Karen Jaffe, MD: Well, we certainly have a story to tell about this. I mean, I think personally, my own personal self, that I don't have an issue with it, but we did have an issue with a drug that I was taking. I'll let Marc go into that, but how that affected our relationship. It had more to do with the medication, the treatment for the Parkinson's disease that ended up having to ... the impact of that was the side effect of my medication required that Marc take a medication that caused him side effects and it was just one big mess. But I do know that people, if they can't get their tremor under control or they have pain, those are issues that will affect their sexuality, how they feel about themselves.

So once again, I go back to education. I think that when we educate patients about a disease, how we do that is important because I think it makes them feel less ... they have a way to think about it when they have had a conversation with their physician. So I urge people not to hide those things that seem to be embarrassing because as physicians, we can handle it. I mean, we're trained to handle things that are difficult, and so I urge people not to hide those symptoms away.

Jim McNasby: Absolutely. Marc, Karen's referring to your very popular modern love essay in the New York Times, discussing what happened to your sex life when Karen went on medication that resulted in impulse control issues. Can you talk to us about that?

Marc Jaffe: Well, considering I put it in the New York Times, I think I can talk about it here. That may have a few more readers than we have current viewers, but Karen had a side effect of her medication when she was first diagnosed, from the dopamine agonist Requip in this case, that a lot of people suffer from obsessive compulsive behavior, which our doctor, he had one little throwaway line that, "Yeah, it may cause you to ... hypersexuality or something else." I was rooting for it at first and then when she got it, for a little while it was a nice change in our relationship, but eventually her continuing to have it and it continuing to ramp up started making it a little bit challenging for me to keep up with her.

It was a strange reversal of roles in our sex life and caused me to go through all kinds of questioning and what I was meant to be and do. Eventually we got it straightened out. I think one of the hard things was it also coincided with the times that we were keeping her Parkinson's a secret in general. So it took some time for us to figure out, but it's something that we couldn't have figured out without a lot of communicating and trying to understand each other's roles here.

Benzi Kluger, MD, MS: I could offer some perspectives too. Just the way I approach this is kind of always asking ... I guess taking it in terms of levels. Is this a biological issue? Is

this caused by a medication? Is this caused by Parkinson's effects on the penis or the vagina or things like that. There can be psychological issues, so how people view themselves, change in identity. Just because intimacy is such a sensitive area, that's something ... for example drooling can affect sexual performance because it's not sexy and it changes how you come into that aspect of things. Then there's relational things, and I think we're going to talk about this more as well, but how Parkinson's affects your relationship, whether you feel like you're a care partner or a caregiver, how those roles evolve over time. Those kinds of things can also affect both relationships and intimacy.

I think as in anything in medicine, the first step is finding the right diagnosis and then it's finding the right expert and that right expert could be a urologist, could be a simple change in medication, could be a couple's counselor, could be an individual's counselor. It just kind of depends on where the block happens.

Jim McNasby: All right. So let's move on and talk a little bit about care partner burnout. Benzi, could you give us a sense of what your experience is looking at care partners and the dynamic that sometimes happens with a long experience with Parkinson's?

Benzi Kluger, MD, MS: Sure. So care partners, and it changes throughout the course of illness. The things that are tough at the beginning of Parkinson's will change. Things that contribute to burnout are multifold. In terms of some of the symptoms that we're talking about, certainly paranoia, so people with later stage Parkinson's, that can be a big one. Communication difficulties, I would say, is something that we hear a lot in our clinic, is that if people are speaking in a soft voice, having problems annunciating, that that can be a cause of caregiver strain. Change in emotion and in perceived emotion, and I think we're going to talk about this a little bit, but sometimes if a person with Parkinson's doesn't have the same facial expressions or change in voice that they used to, that their care partner maybe feels that they don't care as much. So there can be kind of involuntary changes that happen with Parkinson's that affect the fabric of that relationship.

I guess just a few off the top of my head that I think come into this very complex dynamic. The changes in roles, I would say, is one not to be under-emphasized, but as Parkinson's can progress, if people are needing more help with certain things, that definitely can change people's feeling of being a partner to being a caregiver. That creates, I think, a sense of isolation for both the patient and for the carer.

Jim McNasby: That makes sense. Another symptom that I've had to deal with, which I find particularly embarrassing to talk about, is REM sleep disorder or RBD. Unless I take medication, I have really significant horrible nightmares and I act them out while I sleep. I've intentionally hurt my husband by hitting him during the night and it's to the point where there are phases when I know they're going to come on in bunches that I sleep in a sleeping bag on top of the covers to protect my arms so they can't flail around, and that doesn't help anything except it protects him. It's embarrassing because you walk with your care partner into a doctor's office and you say, "This person is here to help me, they get me through my life, and I punched him in the face last night by accident." You take some responsibility for that, but you almost feel like the victim too. It's hard to justify.

But anyway, part of the reason that we focus on RBD at the Fox Foundation is it can be an early sign of Parkinson's disease appearing years before an actual diagnosis. Mine has come on later, but that's the you've seen one case of Parkinson's, you've seen one phenomenon, and ongoing smell loss besides the early onset. I mean, RBD can be another early indicator of Parkinson's. The Michael J. Fox Foundation has a landmark research study called the Parkinson's Progression Markers Initiative, which is known as PPMI, and that examines risk factors and planning for Parkinson's prevention. People of all backgrounds with or without Parkinson's disease can participate in the study and so we urge people in general at the Fox Foundation to join the study that's changing everything.

Marc Jaffe:

Jim, if I can just jump in and say that I have been a member of PPMI for 13 years and it's been great. Very exciting. When we came up with the finding of the biomarker, that made those of us who've been in the study feel like we've done something extra. Just to bring it back to our conversation earlier, it's also for care partners something that is a way of stepping in further and making yourself feel good, a different way of caring for your loved one.

Jim McNasby:

Sometimes when we talk about it, my husband says, "I wish I could take your Parkinson's for a while to give you a rest from it", and that really ... I find that very touching and it plays exactly the same dynamic, Marc, that you just mentioned, which is you really make a valid contribution when you participate in research, both as a patient and as a spouse, and it's terrific.

Let me move along to another topic, which is misinterpreting visible signals. For example, I was on a business trip once to Taiwan and I didn't know any of the people I was meeting with and they served dinner on a lazy Susan on a round table, so it was far away from me and they handed me some chopsticks and I was like, "You've got to be kidding me. This is like a Parkinson's nightmare come true." I would try, I couldn't maneuver the chopstick, my hand was back and forth. I couldn't reach far away from my body. It was just a disaster. So I said, "No. Can I have the table's attention please? I have Parkinson's disease, it's going to be very difficult for me to eat."

The next thing you know, the dynamic which had been uncomfortable around my shaking and people looking at me, everyone stopped talking about it, they got me a fork, they moved the food closer to me and it was delicious. So there's that kind of moving through the world when you have an issue and you address it, it relieves tension around you, it makes people develop an understanding of you, and empathy is more available, which I think is very nice. Karen, have you had any experiences like that where you've been struggling with visible symptoms of some sort?

Karen Jaffe, MD:

[inaudible 00:31:03] Parkinson's Congress four years ago, which was in Japan, all of these Parkinson's patients were there and we all go to the first lunch and it's just chopsticks. I was like, "Are you kidding me?" We're at a Parkinson's Congress and they were giving us chopsticks. We all got a kick out of that. I thought that was pretty funny.

Jim McNasby: For me, sometimes when I shuffle, I notice people are staring at me and sometimes I feel like saying "I have Parkinson's disease, I'm sorry I'm shuffling." Other times, though, I think they fill in the blanks if I don't. They think I'm drunk or that kind of thing, which can be stigmatizing. We mentioned this before, another thing that is important for me actually is when I'm communicating, sometimes my mask is very pronounced and so I go to say hello to somebody and it sounds like my voice is low and my mask is significant. I sometimes tell people, "I am excited to see you, I'm just sorry that I'm presenting this way."

Marc, do you notice Karen ever doing that kind of thing with suffering from the mask and miscommunicating or ...

Marc Jaffe: Yeah. Well, I've told her that for me, the hardest part of the Parkinson's has been her facial masking. Communicating, when someone doesn't have it, a little movement in your face, a little quarter smile or a raised eyebrow or something, those kinds of things can mean so much. To not get that has been difficult for me because I miss it. Now, lately we started playing ping pong and we have these lights over at the ping pong table that the ping pong ball hits and makes a boing. It just cracks us up for some of our feebleness and trying to hit the ball and we laugh and it's in those moments, Karen's huge smile comes back and really reminds me of not only what we had before, but it's a real treat of now to get that and is extra special to see those things.

I wish there was something I could do about it. I'm sure she wishes there was something she could do about it, but just knowing that it's still there makes us feel good. It makes it harder when I tell jokes and nah, she never laughed at anything I said anyway, so that doesn't matter.

Jim McNasby: That's great. Oh gosh. Karen, what do you do when you're having an embarrassing moment of some sort?

Karen Jaffe, MD: You have to have a sense of humor about things. I remember it was years ago, but my husband and my daughter are both really into baseball and when it's a tight game, their legs are bouncing up and down like this and I said to my daughter, "it looks like you have got Parkinson's", and she said, "That's not funny, Mom."

Jim McNasby: Right. Oh my gosh.

Karen Jaffe, MD: I try to keep a sense of humor about things and keep it light. Obviously I let Marc do this whole play. I mean, there's an entire play about the side effects of the medication and I think that we've got to be able to talk about this kind sort of stuff because if we don't, it just eats at you. InMotion is a place that I co-founded in Cleveland and one of the things that's great about there is that it allows for people who've had Parkinson's for many, many years to come into a community where they can talk about Parkinson's or they don't have to talk about Parkinson's, but if they fall down, we'll pick them up. It's just community is so important. The Parkinson's community, the people that you meet are so amazing. I mean, they're willing to put the gloves on and get down and do the dirty work. They really are advocates.

There's so many patient advocates in the Parkinson's community to get to know, and it makes you feel not alone at all and it normalizes lots of the disease because you can see that people can live a long time and they can be healthy.

Jim McNasby: Absolutely. One of the things I used to do when my tremor was pronounced and it was conspicuous to people and I could tell they're being uncomfortable is I said, "Did anybody see where I left my tambourine?" Usually that would trigger a smile at least.

Marc Jaffe: How many tambourines do you have now because of it?

Jim McNasby: It's the same number that I've always had. 11, of course. Benzi, what are some of the Parkinson's taboos topic involving other people's perceptions that people struggle to talk to you about? How do you approach those conversations? What do you see from your patients that you can tell us about?

Benzi Kluger, MD, MS: Just so I'm clear, are you asking what issues do people feel hesitation bringing up with me or bringing up with doctors?

Jim McNasby: Yes, that was better said.

Benzi Kluger, MD, MS: Just wanted make sure. One of the things, and this maybe ties into our next segment of tips and tricks that you can do to get the most out of your doctor visits. I have a checklist that I go through and part of the reason I have this checklist is I really want to normalize the questions that I'm asking. So I tell people that these are things that I ask every person with Parkinson's, and they include asking about anxiety and depression, which can be tough things to bring up, sexual function, bladder and constipation, pain. Also ask people about the emotional and spiritual side of things. I think two of the most telling questions that I ask people, one is "What's the toughest part of this for you?"

Being a Parkinson's care partner can be a lonely place and so sometimes people have never been asked that question, and usually it's not the tremor. Usually the toughest Parkinson's is "I'm not able to do the things I enjoy the way I used to", or "I can't be the type of grandmother that I wanted to be" or for a care partner, "Not being able to or knowing how to help my partner when I see that she's struggling." So it's oftentimes these deeper things, and it's part of why on our team we have a chaplain and counselor and social worker is that we really want to break through the surface of everything that's going on with having a serious illness like Parkinson's to create a safe space where we could talk about that side of things.

The flip side, which I think is also kind of taboo in our society, is to talk about joy and to talk about love and to talk about meaning and to put that on the table as our clinic is a safe place to talk about things and to really encourage people "What are your opportunities right now for fun and for joy and meaning, and how can we magnify those despite the fact that you have Parkinson's?"

Jim McNasby: That's great advice. Karen, do you have any tips for care partners on opening a space for you and your loved one to talk about difficult issues?

Karen Jaffe, MD: Well, so it's interesting because as a type A personality to have my husband in one fell swoop become all of a sudden a care partner, I'm like, "Well, wait a minute. Isn't he just my husband and why does he need an extra title?" So just to me, he's my husband and he married me for better, for worse, for richer, for poorer, for sickness and in health, and so I feel like he doesn't necessarily need it. So we've had to adjust a little bit because he wants to ... as a care partner, he's got this title, he wants to be in there and sometimes helping me. I don't always let him come to my doctor's appointments because I want to be in control of the situation and not the other way around. It's a little bit of a challenge for us because I don't really feel like ... I don't want to feel like I need that person.

But one of the other things that I tell my students in my PD 101 class that I teach is that they should read the care partner books themselves. They should see what their care partner has to do to help with them so they have an understanding. On the other side of the coin, we can all try to pretend that a care partner can ... they can't really pretend to have Parkinson's disease, so they can't really step in my shoes, but I think that care partners get a rough ride with the Parkinson's patient sometimes, and I think that they should know that the Parkinson's patient should know what's being asked of their care partner, which I don't think happens very much.

Jim McNasby: Then just more in general, Karen, what has helped you to reduce shame and stigma in your life? I mean, I admire you so much for your continuing to work and for founding InMotion, but what ... I mean, you're in a position to tell all of us about what to do to reduce shame and stigma.

Karen Jaffe, MD: Well, as Marc was alluding to before, I'd been hiding my diagnosis for several years and I finally realized that I was perpetuating the stigma because if I waited until I couldn't hide it anymore, I would become the instant Parkinson's patient who was symptomatic versus the person who had just worked five more years as an OB/GYN surgeon and doing it well. So I decided that we've got to realize that people with Parkinson's, some are older, but there's plenty of young onset Parkinson's patients who are going to live for many years and be completely capable. We have to make sure that people understand that, that Parkinson's is not something that's just going to make you cognitively impaired from the minute you get the diagnosis or make you be falling down the street a week later, that people can live healthy lives with this.

That comes from the community and bringing people together who have ... and there's so many people who are passionate about Parkinson's disease. When I was growing up, I don't ever remember anybody having Parkinson's disease, but now I turn the corner and everybody's got somebody else, their friend or their family member themselves with Parkinson's disease. It's amazing how many people do have it. That gives people an opportunity to find in their own community a group of people who can be supportive and help you get rid of the stigma, because the more you see Parkinson's patients who are living well, you can understand that the stigma doesn't apply to everybody.

Jim McNasby: That makes sense. Benzi, can I do a radical subject change on you and just throw in a quick second on mental health and issues. Is there any advice you have for our audience about how they can reduce the stigma or the fear associated with the mental health aspects of Parkinson's?

Benzi Kluger, MD, MS: Yeah, a few things. One which I think is important for people to recognize is that if you compare people with Parkinson's to, say, rheumatoid arthritis at the same level of disability, people with Parkinson's have twice the rates of anxiety and depression. I bring that up because I think it's important to know that part of changes in mood is chemical. So just like people take dopamine for their tremor, people can take serotonin or other medications for changes in their mood, and so what it is is just recognizing that this is not a personal weakness, just like having Parkinson's isn't a personal weakness or tremor is a personal weakness, that those kinds of things have to do with biochemistry. So that, I think, is an important thing for people to recognize.

I also think it's important to recognize, as I hinted at before, is that not all sadness and worries is psychiatric or chemical, that when people are worried about the future or when they feel a loss of things that they can no longer do, feeling guilty about maybe being a burden to their care partner, there's a lot of things that I would say fall under normal emotional reactions to having a difficult illness. I think knowing that, and it's something that I really work hard on is trying to distinguish between what's depression as a psychiatric thing and what's grief and sadness as a normal part of it. Oftentimes those things go together, but it changes our approach to it, it changes the right kind of treatment, and I think it also changes the way that care partners and family can support you in those challenges.

Jim McNasby: That's great. That's really helpful. As I think about the conversation we've just had and I look back on it, there's a couple of themes that I think are really important. One is that if you are experiencing a Parkinson's symptom, know that you're not alone, that there are other people out there who are experiencing the same exact thing, maybe to a greater or lesser degree, and there's comfort that comes from sharing. There's strengths, there's helpful hints, there's camaraderie, there's empathy, and all of those things are things that Parkinson's patients should strive to participate in because it's important. The other thing is, I think as Karen said repeatedly, and so have you, Benzi too, is to educate yourself, to make sure you understand or try to understand what's happening and what you can do about it. Because when you're empowered, you wind up being in a better situation.

So that's great. We've received a lot of questions, and one of the things we can talk about is drooling. We didn't really do that. I had first-hand experience with this. I was in a meeting. Before I worked at the Fox Foundation, I worked at a big publicly-traded company as their general counsel, and I was meeting with a state government official who was very senior and well-known, and I was sitting across from him and I started to drool and I couldn't feel it. I drooled a big puddle on the table in front of me, and I tried to wipe it off, but I had to address it because it was so conspicuous or whatever. But I was so embarrassed and then I told him I had Parkinson's and he reacted very nicely to it, but it's embarrassing.

I found out that there are treatments. For me, there was two. One is you can get Botox to help control your drooling and the second is I had my DPS surgery, which returned some of the strength to the musculature around my mouth, so it wasn't sliding down as much as possible. But are there innovations since my experience, Benzi, in terms of the way to treat drooling as an issue?

Benzi Kluger, MD, MS: Yeah, those are the main ones still. Botox, I mean, you started actually, particularly if it's not severe, is sometimes having a lollipop or gum or something like that that just reminds people to swallow can sometimes help with more minor drooling. There are some oral medications, atropine drops and glycopyrrolate can help. Sometimes working with a speech therapist can be helpful. But I think the basic treatments are there and I would say for all of these things, probably the number one reason why people aren't getting cured of these symptoms is that they just aren't being talked about or brought up. But for almost everything we talked about, whether it's depression or drooling or pain, there are often things that can be brought into bear that can help make you feel better.

Jim McNasby: That's great. Marc, a question from the audience from you. The person says, "I find I always have to be the one up or the one who's positive. It seems very hard to share with my wife when I feel down about her situation." Do you also find this difficult?

Marc Jaffe: Yeah, I guess it can be, but I have shared with Karen or sometimes there will be an emotional moment where I'm down and you shouldn't feel bad that it affects you. Obviously your partner knows that you're going through it with him or her and that you can have feelings too. I would express those and not feel like that they are putting a burden on your care partner. I think they're well aware of it and they're concerned about you at the same time. I've had many Parkinson's tell me, "I feel so bad about what my partner has to go through because of this." So like anything, I think having an open communication. The other thing in general I would say about when you face issues like this from either side is it's good to have the discussion not necessarily in the moment, but be able to bring it up in a quieter moment when it's not an issue at that time, and then it makes it a little easier to discuss.

Jim McNasby: That's great advice. Karen, a question from the audience for you. "How do I support my loved one when they forget their train of thought, retell a story a couple of times, or become frustrated if they're caught out having forgotten something and are embarrassed?"

Karen Jaffe, MD: Are we talking about Marc doing that or me doing that?

Jim McNasby: I mean the person [inaudible 00:48:31].

Karen Jaffe, MD: I think that we might be equal on the occurrence. The thing is that I would say here is that if by some chance you thought you were having some cognitive issues, you really need to be evaluated and seen and bring that up with your physician, because there are things that can be done about it and I think it's one of those things that people really worry about with Parkinson's is cognitive impairment. As an OB, I used to tell people who were worried about it. I'd say it's

one thing to forget where you put your keys, but it's another thing to forget what your keys are for. If you've got confusion and things like that, then you should really be having a medical evaluation of that. We know that they've got a million cognitive tests because anybody who's in the PPMI has to do this every six months. They can certainly tell you whether they think that there's something going on and what you can do about it.

Jim McNasby: Benzi, another question for you very quickly. Erectile dysfunction has come up a lot. Any hints for discussing that?

Benzi Kluger, MD, MS: Yeah, a few things, and one is just ways to get these kinds of things on the table. Sometimes it could be emailing your doctor through the MyChart or something like that to put it up there. Coming into your visit with a list of things that you want to make sure you talk about can be strategies. Recognizing that sometimes your doctor may not ask about it because they're not totally comfortable with it, but maybe even [inaudible 00:49:58], bring an ally with you if that would be helpful. Those would be ways to get the topic on the table. Once it's out there, there definitely are treatments. Sometimes it can be a side effect of medications or certain antidepressants. Medications like Viagra and Salus can also work for some people with Parkinson's, and sometimes it may go beyond the skill set of your neurologist and may end up getting you to see a urologist, but it's definitely something that's worth bringing up and it is, to that question, a difficult thing to bring up.

Jim McNasby: I really appreciated the conversation and it was nice to talk to you all.

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