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Voiceover: 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](http://michaeljfox.org).

Larry Gifford (...: I'm Larry Gifford. I am a member of the Michael J. Fox Foundation Patient Council. I host the podcast When Life Gives You Parkinson's, and I am a co-founder of the organization PD Avengers. It's great to be here with you today. Today's panelists will be discussing how to manage our emotions and navigate the early years of Parkinson's, which is not always talked about so much, but boy, it can be an emotional roller coaster. I was diagnosed in 2017. Five years in, I feel like I'm ready to get off the train.

We'll also cover the valuable role people recently diagnosed can play in research. This is really important. We've got a lot to discuss today so I want to get started. Let me first introduce our panelists. Great panel today. We have Barry Grey, he's a nonfiction TV producer and writer, book editor from Los Angeles who was diagnosed with Parkinson's in 2021. He's a participant in the foundation's landmark Parkinson's Progression Markers Initiative, also known as PPMI, and we'll talk more about that a little bit later. Barry, welcome to the webinar.

Barry Grey: Thank you, Larry. It's great to be here.

Larry Gifford (...: We also have Dr. Soania Mathur. She is the co-chair of the Michael J. Fox Foundation Patient Council, and she's been living with Parkinson's for about 24 years, and she is also a co-founder of PD Avengers. Hello, Soania.

Soania Mathur, ...: Hi, Larry. Thanks.

Larry Gifford (...: Welcome to Dr. Roseanne Dobkin. She's professor of psychology at Robert Wood Johnson Medical School at Rutgers. She's been conducting mental health research in Parkinson's disease for nearly 20 years. She's also on the PPMI Executive Steering Committee. Welcome to you, Roseanne.

Roseanne Dobkin...: Thank you so much for inviting me to join you today. Happy to be here.

Larry Gifford (...: I am really excited about this discussion today. Managing emotions can be really tough. I know even two or three years into it, my wife started to notice I had a quicker temper or I'd cry at the drop of a hat. I'm like, what's going on to me? Everyone processes Parkinson's diagnosis differently, and people may experience a range of emotions.

Barry and Soania and I will share our personal reflections on the diagnosis and the emotion in the early days, and then Dr. Dobkin can then explain to us what's going on and how we can work through those in a positive way. Barry, I'm going to start with you. When you were diagnosed, boy, what were the rush of emotions you went through?

Barry Grey:

Still the main one, which is disbelief. I never thought that something like Parkinson's was going to involve me and I suppose a lot of people probably would react the same way. I was doubting it. In the face of overwhelming evidence since then, it's absurd, I realize, that I had any moment of doubt about it because it is what it is. My reaction was disbelief and denial and hoping that it was just a mistake and that it would go away or that it was misdiagnosed. It was a common cold.

It was nothing else than that. I grabbed onto anything really, because that first moment when the doctor says the P word, it's devastating. There's just no way around it. It's just devastating. You're grasping at straws wondering, what did I do wrong? How am I going to live with this? Am I going to be a drag on my family? They're going to have to take care of me for the rest of my life. It's just a whirlwind of emotion, and I can't really tell you how did I react to it.

Because when you're in the middle of a storm, you're not thinking really clearly about, hey, maybe I should approach this a different way. My rule of thumb is at very first panic. I think that's probably as good a description as I could come up with.

Larry Gifford (...:

And you're only a year-end too, just over a year-end, so you're still processing that. You're still in the early days because I know I still go through emotional roller coasters. Soania, you've had Parkinson's for over 20 years now. Do you remember what you felt when you first were diagnosed?

Soania Mathur, ...:

Yeah, no, I do, Larry. I mean, that was a very unsettling and inconvenient time in my life to be diagnosed at 28. I just was pregnant with my first child and started medical practice and all sorts of things. My first reaction really was much like Barry's, disbelief. It's disbelief in an emotional sense.

The logical medical side means I have the diagnosis and that they were not incorrect about it, but that emotional acceptance wasn't there. That led to basically a decade of living in denial and anger and secrecy and basically busying myself with busyness of life so I didn't have to deal with it. That was my first reaction.

Larry Gifford (...:

I remember just, I was kind of like Barry, I was shocked. I denied it. Then I got angry, and then I was afraid. It's as if I had to mourn my past life and mourn what future plans we had and go through that grief process and start over. Just like if you're grieving a loved one, it's not linear. It can happen. Any of those

emotions can happen at any time. Let's bring in Dr. Dobkin. We're not weird, right? This is kind of a normal process?

Roseanne Dobkin...: 100%. Emotions are healthy, they are adaptive, and they are to be expected. Receiving a diagnosis like Parkinson's is life-changing and it takes time to come to terms with things to figure out how you feel about it. Let's be honest, people are going to feel many different emotions possibly at the same time, and that is to be expected. We want to allow ourselves to feel whatever we feel. We don't want to try to stifle those emotions or push them away because that is only going to be harmful in the long run.

As we are taking whatever time we need to adjust to the diagnosis and to this news that was just shared with us. We also have to begin to think about, okay, how are we going to put together the best possible care team? How are we going to mobilize our supports? How are we going to arm ourselves with every tool out there so that we can be empowered and proactive and live the best life possible with this chronic medical condition?

It is possible to live a meaningful and productive and values-based life with PD. It takes some time to figure out personally how to make that happen. But people figure it out at their own rate and at their own pace.

Larry Gifford (...: A lot of that takes the accepting of the disease in order to get to that point where then you can figure out how to live your best life with it. Because as long as you're denying that you have it, you can't move forward in that direction. Soania, what was the catalyst to turn you from denial into acceptance and then sharing that with other people?

Soania Mathur, ...: Sure. Well, I call myself a slow learner because it took me a good 10 years before I really got to that acceptance. I mean, as I mentioned, the logical acceptance was there. I knew I had the disease, but that emotional acceptance, that feeling that, okay, there's nothing I can do about this. How can I frame it a different way so that I can progress with my life? That true acceptance didn't come about after some epiphany. It came about slowly. I was changing into a person that I didn't like.

I was being pessimistic about life, and it was a time in my life that I really had much to be thankful for and grateful, except for this overlying diagnosis. It wasn't one thing, one conversation, one thing I read. It was a slow evolution, but eventually I got to that point of accepting that this was a challenge I was going to have to face, and I could either face it with a glass half empty outlook or a glass half full.

And that helped me anyway and help me to move on beyond my diagnosis so that you could do the things that you're mentioning. You can deal with the diagnosis in a way that's productive and healthy for you and will lead to the best outcomes.

Larry Gifford (...: And when did you start to tell people?

Soania Mathur, ...: Oh, I'm, again, a little bit slow in that regard. I mean, my husband and a couple of close friends knew so they could help me hide the situation from the larger social group. But social group, probably I started about nine, 10 years into my diagnosis. Coworkers again and patients, it took about that much time because I didn't want to be viewed differently in my practice and so forth.

That stigma that unfortunately we all face to some degree with Parkinson's disease, which shouldn't be, but we're human. It is. But when I did disclose, I felt a weight lifted, one that I actually didn't know had existed in the first place. I regret not doing it sooner, but that's reality.

Larry Gifford (...: Thank you for sharing that. Barry, how about you? Have you found a way to embrace the diagnosis yet?

Barry Grey: Well, yeah. Just listening to the doctors, I just realized that I had a clue in 2009 that I ignored, and that is that I've become especially emotional over ridiculous things. It happened first that I recall that year, but I mean, I could start weeping at an avocado commercial. It was just ridiculous and anything, I didn't understand it. I was telling people, "Oh, the older I get, the more emotional I get. I thought it was supposed to be the other way around." I didn't understand it. I tried not to think of it as an issue, but it kept happening again and again and again.

That along with almost a dozen symptoms that are standard for Parkinson's that I recognize I had. The little light bulb went on and oh, it's real. The only person I told at first was, of course, my wife. We have a 23-year-old daughter who's extremely sensitive, and she was in her senior year of college. I said, "Anne, we do not tell Lulu until school is effectively over her or there's a logical time," because she was away at school and it would've devastated her in school. We didn't want that.

There was nothing she could do about it anyway, and she was in Illinois and I'm in California. The difficult thing about this was I was throwing my arms up, my hands up, because in the space of four months, in the space of four months, I was diagnosed with an autoimmune disease. I was found to have cancer. And then two weeks after the cancer diagnosis, oh, by the way, you have Parkinson's too. It was like a bad dream that I couldn't wake up from. It was like dominoes hitting each other, knocking each other down.

I just thought, what else can go wrong? Is this sky going to fall on me next? I was and am dealing with trying to keep all the balls in the air, which disease is the worst and which one do I have to give the most attention to?

Larry Gifford (...: Well, and Dr. Dobkin, that's unfortunately the case is once you get Parkinson's, you're still susceptible to all these other diseases too. You don't get a free pass and that's got to build up. How do you work through that?

Roseanne Dobkin...: It really is a lot, especially when you're facing one medical challenge or complication followed by the next, followed by the next. And as difficult as it is, we have to try to be in the moment and not get so far ahead of ourselves and focus on the next thing that we have to attend to, and also talk to ourselves. I mean, I think the reality is we're all talking to ourselves all of the time, but most people don't really stop and think about what they're saying to themselves unless you've got a psychologist like me saying, "Hmm, what was running through your mind right now?"

I think our self-talk is so important, reminding ourself that we don't like this and that's okay, but we can handle it. We can figure out a game plan. We can move forward one step at a time, and that we will be able to handle whatever life throws at us next. We will figure out, again, the best support team, the best partners to help us along on that journey, because we don't have to go through it alone.

Larry Gifford (...: Well, and one of the interesting notes about the symptoms of Parkinson's is that depression, anxiety, and apathy are symptoms of the disease and not just reactions to the disease. I know that I experienced all three of those, and my wife used to call it when I was really apathetic, I'd be in my little Parkinson's bubble. I wouldn't notice what the kid needed help, or I would just be in my own world. How do you escape from that apathetic state? Do you have any ticks or tricks?

Roseanne Dobkin...: I sure do. And before I even go there, I just want to really echo what you just said that these emotional complications, things like depression, anxiety, apathy, these are core symptoms, core features of Parkinson's. Parkinson's is not just about physical symptoms like tremor. They're not a sign of weakness or poor coping or character defect. These are core symptoms of the medical condition that are highly treatable.

I just want to make sure that we put that stigma off to the side in terms of, well, how do we manage these negative emotions, what do we do about them, how do we handle them, I could talk for three hours, but in about two minutes, I'll try to share some of my favorite tips and tricks. I think first and foremost, we hear a lot about exercise for managing physical health in Parkinson's. Exercise is also critically important for optimizing emotional health. It reduces stress hormones.

It boosts feel good chemicals in our brain. Exercise is so important. Some studies have shown that if an individual exercises 45 minutes three times a week, and I'm hoping that we're all out there exercising 45 minutes most days, but even a minimum 45 minutes, three times a week over six week period of time, the

emotional effects of the exercise are comparable to that of antidepressant medication. Exercise is critical.

Maintaining other healthy lifestyle habits, good nutrition, getting adequate sleep at night, connecting with the people, places, and things that enable you to experience joy and meaning and reward and satisfaction during the day. I know when apathy sets in, when depression sets in, individuals don't always feel like doing it. They may say to me, "Oh, Dr. Dobkin, I would love to go to that concert in the park, but I don't feel like it. I have to wait until I want to do it."

And then my response is typically, "Well, if we're going to wait until you want to do it, we're going to be waiting for a really long time." Because when we're feeling depressed or anxious or apathetic, that internal wants that internal zest, that internal enthusiasm might not be there. What we want to do is we want to think about our values. We want to think about our goals. Let the goal guide the behavior. Plan mini experiments for yourself. Test something out and see how you feel.

Because usually if you can get yourself to engage, to go to the concert, to return a phone call, to make plans for dinner, to go out for a walk, you'll feel better once you do it, and then it'll be easier to do it a second and a third time. We don't want to wait for the want, we want to set a goal and then let the goal guide us until that internal drive comes back and it will.

Larry Gifford (...:

No, that's great. I know oftentimes in order to prepare for an outing, I might take my walking sticks just to give me a wider berth around the crowd so I don't get as anxious, or my wife and I will have silent signals to let her know that I'm not feeling very comfortable and that we need to go.

If I can't remember somebody's name and I'm trying to introduce them, I won't say their name and she'll know that I don't know their name. She'll introduce herself and she'll ask what their name is. Just having those in advance can be very helpful. Soania, do you have any ways of dealing with some of those issues?

Soania Mathur, ...:

Yes. I mean, I think for me, accountability is a big thing. I think that works for a lot of people. So that if I plan on doing a walk every day, to have a friend come to the door, knock on my door at 8:00 in the morning to say, "Let's go," and being accountable to them in order to carry whatever task or goal I set is helpful, or having a personal trainer knock on my door three times a week and say, "Let's go. Let's do this." I mean, I find that to be very helpful for me.

Larry Gifford (...:

What about you, Barry? Have you found any personal ways that you deal with some of these issues that have pop up?

Barry Grey:

Yeah. I had heard shortly after my diagnosis that exercise was key, and my wife happened to find online something about an organization called Rock Steady

Boxing. It turns out that boxing is an ideal training for Parkinson's patients, and this program is geared specifically toward people like me. I do that once a week, which is totally inadequate and I know that. But I try to mimic a lot of the exercises. At the house here, we have a makeshift gym here. I'm doing it four or five times a week, but I now know just from today's webinar that I got to do 45 minutes, not 20 minutes or 25 minutes.

Thank you guys for that. I wish I could walk more, but my lower back hates me lately. That took one element out of a regular program. But just getting into the exercises and getting used to them and building them into my daily schedule, it gives me structure. I never understood the apathy that I was feeling ever since I got diagnosed. And now I realize it's not just mental laziness in my part, it's part of the disease, which I did not know before. I'm going to cut myself a little bit of slack.

Larry Gifford (...: Please do. Please do. You should not feel guilty or bad about the way you feel because you can't necessarily always control the emotions that are headed your way or the apathy or the depression or the anxiety even. I do want to get back to crying at avocado commercials because I was joking on that line. I love that. But Dr. Dobkin, is there a scientific reason why Parkinson's impacts our emotions so much?

Roseanne Dobkin...: Yes, there is. Our brain is amazing, and the areas of the brain that control movement are also involved in the regulation of emotion, how we feel, how we think about things. Even in the earliest stages and phases of Parkinson's, individuals are experiencing changes not only with respect to the availability of those feel good neurotransmitters like dopamine and serotonin, but there's some changes taking place in the amount of activity that's occurring in certain neighborhoods in the brain and in the highways that connect, the networks that connect the different areas of the brain. All of those changes can lead to changes in emotion, as well as movement and thought and cognition.

Larry Gifford (...: Great. I also want to tell you about PPMI. Foundation's landmark study, the Parkinson's Progression Markers Initiative, also known as PPMI, is recruiting volunteers. That could be you. The PPMI follows participants, collects data over time. The information helps researchers better understand, because it's hard to understand some days, most days, and could lead to new ways we treat or even prevent the disease from onsetting.

People recently diagnosed with Parkinson's and not yet taking medication are prime candidates. They can play a critical role. Let's talk about why some studies like PPMI especially need people recently diagnosed with Parkinson's. I know, Soania, you've been involved in research for a long time. Why is it critical that people early on are involved in some of this research?

Soania Mathur, ...: Yeah, thanks, Larry. I think being involved with research is important for everybody at every stage of Parkinson's disease, because without us there can

be no clinical trials. We need to have people with the disease in order to study potential treatments or learn more about this disease and its pathology. That's the first thing. Early in the disease, it's important because especially when you're trying to get a longitudinal look at how the disease is progressing, what factors might be influencing that progression, for instance, demographically or otherwise.

Also, a lot of interventional trials perhaps may be preventative or disease modifying, and they often involve earlier onset patients that maybe aren't on any medications and are drug naive, what we call, in order to test potential treatments that would slow down the progression of the disease. There are many reasons to participate and those are some specific ones for early participation.

Larry Gifford (...: Great, thank you. I'm going to bring in Dr. Dobkin here who's on the steering committee for PPMI. What do you find most rewarding so far about the PPMI study, and how can people participate even if they don't have Parkinson's?

Roseanne Dobkin...: There's so much to talk about. I want to further highlight a point that Soania just made and really focus on something called the golden year or in some cases the golden years. This is a period of time after an individual is diagnosed with Parkinson's, but before they begin taking medication to help treat the symptoms of PD. This is the absolute critical time for individuals to enroll in studies like PPMI or other early stage or other clinical trials that are looking at the development of novel therapeutics.

It's so important in order to advance the field, in order to develop better treatments for Parkinson's and ultimately figure out how to stop it, how to prevent it altogether, we really need to understand the complex biology of PD and on the biological level. How is the disease starting? How is it changing over time? Once we can really begin to better understand what's happening, we're going to be able to have better tools that assist with diagnosis, treatment, and ultimate prevention.

Once an individual starts taking Parkinson's medication, it muddies the water a little bit and it makes it more difficult to study these biological processes as they naturally unfold. That's why it's so important if individuals are able to participate in studies like PPMI before you start taking medication so we can really learn what's happening on the biological level in order to develop better treatments and ultimately slow or stop the disease from even beginning in the first place.

The other point I really want to make about research is everybody talks about Parkinson's being progressive, which it is, but we really need to focus on the fact that science is progressive. We can be empowered. We can be agents of change. We can influence the rate and the pace of scientific progress and discovery by participating in research. It is a critical opportunity to not only be empowered in



one's own self-care, but to really play an instrumental role in advancing the field.

Larry Gifford (...: That's great. Barry, I know you're only a year past your diagnosis, but you're already enrolled in PPMI. How did you make that decision?

Barry Grey: It was really pretty easy. I mean, shortly after I got diagnosed, I looked up the foundation online and saw a pitch for it. I thought, why would I not? Why would I not sign up for this program, the study, because it can only help people, it can only help me maybe in some direct or indirect way? I don't see any reason why I wouldn't. I have not started any medications. I asked my neurologist, can I stay off of them as long as possible? He sort of said yes, but he looked like he was holding back something.

In fact, I'm going to see him I think a week or two now from now, and so I'm going to ask him again. I had heard so many stories about how miraculous L-DOPA is, but it also has lots of side effects, and I was hoping to avoid those side effects as long as possible. What I need to know for sure is whether I'm harming myself by delaying it, because my symptoms are really pretty mild right now. The worst that I have is that I have very poor balance and I tend to tip over like a poorly built Tower of Pisa.

And that happens a lot. I fell three times in a couple of months after I was diagnosed, and one of them I face planted and broke two of my front teeth. It was really horrible because you go down really fast, but it feels like slow motion. It's like you're seeing it happen and you can't stop it. In a way, that's almost an analogy for Parkinson's. God-willing, there will be something to stop it maybe from this research, the program that I joined.

Larry Gifford (...: For sure. Real quick lesson on falling, once you've fallen, just stay there for a second and catch your breath because the worst part's over. And then try to feel for your body to make sure nothing's broken. If you've broken your teeth, then you know that too. But the other thing is afterwards make sure you go see a physical therapist because they can realign you so you don't keep falling. Because once you fall once, it's easier to fall twice, then third time. Just to get off the main topic for a second, you brought that up. I had falling issues too, so I understand how that goes.

Barry Grey: Thank you.

Larry Gifford (...: Yeah, for sure. Also, PPMI Online is available to anybody in the United States over the age of 18. Other studies are also recruiting family members and they can join in to show their support as well. If you are interested, please visit the PPMI Study Online and we would love to have you participate. All right, seeking support over time. As Parkinson's progresses and advances and you go into your one year if you're Barry, your five years if you're Larry, and yr 20 some years if

you're Soania, it changes and evolves over time. How, Soania, has your care and your disease progressed over the years?

Soania Mathur, ...: Well, Larry, as we all know, it's a progressive disease, and it has progressed over the years. What it started off as an intermittent tremor and my pinky finger, then evolved into the hand and then the foot and then the other side and so on and so forth. And then came the onslaught of more noticeable non-motor symptoms like sleep disorder and pain and balance issues, and now more off periods. It's an ever evolving disease. There's no shortage of challenges that will face you, but at each point you have to realign how you're thinking about the disease as well.

At one time, it used to really frustrate me that I couldn't get my to-do list done, and then I had to realign and say, "Well, maybe my to-do list is just a little too much right now," so reduce it, or who can I rely on to help me get things done? How can I delegate more? And that sort of thing. It does progress physically and your emotional state also progresses. There are days where I feel pessimistic, I feel down about the future. But then again, I have to talk to myself, as Roseanne said, and realign my thinking to deal with whatever's facing me at that moment.

Larry Gifford (...: In addition to your movement disorder specialist and your GP, who are some of the other carers that you rely on, therapists or whatever?

Soania Mathur, ...: As far as allied health professionals go, I have a massage therapist that I use quite frequently. I also have an exercise specialist who I use to help me with my exercise routine. I've seen a speech and language pathologist as well because I had issues with swallowing and potential aspirations. I've seen a speech and language pathologist. Those are the current ones, but I mean, there's so many available to us. That whole team building, gathering people, surrounding yourself with people that have your ultimate quality of life in mind is really, really important for anyone that's dealing with this disease.

Larry Gifford (...: One of the great things as you move along in the disease is you get to know these professionals better because you see them more and more. I see my pharmacist more than I see my wife sometimes. I walk into the pharmacy, I feel like Norm from Cheers. But also I have a mental health counselor. I've got occupational therapist, a physical therapist, a speech therapist. I don't see them all at the same time, but these are all people that are now part of my support. I think it's really important.

Sometimes you need to just like you go in for a regular physical with your GP, oftentimes before the symptoms start to onset, it can be very valuable for you to learn how to speak strongly and with intention before you need to so you can develop those muscles. The occupational therapist for me was one of the... Just blew my mind. She walked me through my day and I realized where I was losing my energy because I'd get so tired. You started with like when you wake up in the morning and get in the shower.

She's like, "So you're standing in the shower, you've got your eyes closed, your back to the water. Your head's tilted back. You've got Parkinson's, so you have balance issues. She goes, "What kind of energy do you think you're wasting before you even have breakfast?" I bought a shower chair and it changed my life. Just those little things can make a huge difference and these professionals can really help you. Dr. Dobkin, talk about the support folks can get from somebody like you.

Roseanne Dobkin...: Oh, I would be happy to. I am a clinical psychologist and I provide both one-on-one, as well as group talk therapy to help individuals deal as effectively as possible with the non-motor symptoms, with the emotional concerns that go hand-in-hand with living day in and day out with Parkinson's.

I think working with a mental health professional, psychologist, a counselor, a social worker at some point, even if it's for prevention, can be really beneficial to really arm yourself with coping skills with all the different tools that one can utilize to manage the understandable emotional reactions that arise in response to daily challenges and stressors that people experience. There are so many different tools that can help an individual to manage anxiety, to manage depression, to feel more connected, to work on acceptance of the diagnosis. There's no reason to struggle or to suffer alone.

There are many, many people out there that can provide support and structure and skills and guidance to help you along the way. Oftentimes I will see individuals maybe for three or four months when they're going through a more difficult period of time, and then we just touch base a couple times a year to make sure things are going well and to catch up and review all of the tips and tricks and coping skills that an individual can utilize to help themselves deal as effectively as possible with challenging life circumstances.

An analogy that I like to use is that if you're living with Parkinson's and you're also dealing with poorly treated depression or anxiety, you're going through your day with an extra 25 pounds of potatoes on your back and we don't need to do that. Let's get rid of the sack of potatoes.

Larry Gifford (...: Please. I think I may have a couple. I also think it's important that people understand the power that they do have and how they react to things that come their way, and that can change your entire day. If you wake up with a new pain, you can either be really angry about it, or you can go, okay, well, so what are we going to do today to work around this or to work with this? I think my life changed when I stopped resisting the disease and I embraced it. Oftentimes when you resist something, it becomes stronger because you're putting more energy towards it.

When I just realized I breathe through it and I found a way to say, "Okay, well, this is going to be part of our life now. How are we going to move forward together with this?" My wife and I, I think it's really important, communication

is so important, to share with your loved one or your partner exactly what you're feeling and thinking and how it's affecting you because nobody can understand what's happening inside your body, even other people with Parkinson's. Everybody's Parkinson's is so different.

All right, so we've been through a lot here. You've got all support. On your screen you can see, for example, the Buddy Network, that's a great place to go, faith-based groups, support groups, online communities. I mean, COVID brought the world together online, and so there's so many opportunities out there. You can even build your own custom. There's like 10 couples in Vancouver where I live, where we go out to dinner once a quarter just as a group and have a great time.

We know we can call on each other at any time. It's nice to have that. But I do want to get to some of the Q&A because there's a lot of interest in this topic. I've got some here that I'll start with. We'll go from here. I'll either direct them or I'll keep open-ended and any of you can chime in. Any suggestions for helping balance the emotions between the person with Parkinson's and those of a spouse who is also a primary caregiver?

Roseanne Dobkin...: People living with PD, as well as their family members are going on this journey together, and friends, family, spouses are also feeling as though they are on an emotional rollercoaster from time to time trying to make meaning and make sense of things. It is so important if you're a loved one, a spouse, a care partner of a person living with PD, especially around the time of diagnosis, to get some extra support for yourself as well, to potentially reach out to a mental health professional, or join a group that is geared towards family members of people living with PD.

Because everybody is going through this together and support needs may be very different if you're a care partner or if you are a person that's actually been diagnosed with the medical condition personally. We want to make sure that everybody seeks out the personalized help that is going to be most beneficial.

Larry Gifford (...: Soania, it looks like you want to chime in there.

Soania Mathur, ...: I'm kind of chuckling to myself because I can chuckle looking back at what our and who you know and myself went through at the beginning. As I was coming to terms with my diagnosis, so was he, but he was specifically coming to terms with how to deal with my coping with my diagnosis. For instance, if I was trying to open a pickle jar and I was having trouble, some days he could... If he said, "Can I help you with that pickle jar," it was kind of like he'd get snapped at, "Well, what do you think? I'm disabled, I can't open this pickle jar?"

Or if he didn't ask, then it would be like, "Well, can't you see I'm struggling? Can't you help?" To navigate that whole situation is very difficult for care partners. I began to recognize that unless I was open and honest about my

communication, about what my needs were and not be ashamed to express those needs, it would've been very difficult. Coming to that realization that your partner is there to support you, I think, is very important to maintain that communication.

Larry Gifford (...:

My wife and I, we host the podcast When Life Gives You Parkinson's, and earlier this year we did a three episode arc on the talk. It was just us talking about the communication changes. We were both communicators by trade, and for the first 20 years of our life, we had shorthand. We knew exactly what each other were thinking. There was no question about how we were communicating. And then Parkinson's came along and upended everything. We had to relearn how to communicate, how to be intimate and everything.

I think it's really important that you have that open discussion and that open dialogue. I think that's a critical piece of the Parkinson's. Sometimes that can't happen until each side has dealt with it. But as far as getting support for everybody, my son, my wife and I, we each have our own therapist because we're all dealing with it in a different way. I think that's really powerful. Barry, do you have any thoughts on this topic?

Barry Grey:

Yeah. I hate to strike the same note again, but for me it's been my wife who has been the go-getter on all of this stuff. She's the one that found the boxing program. She's the one that insists that we have to remodel the bathroom because the way it's configured now, you have to step down into the tub to take a shower and it's easy to trip. It's really easy to fall and hit your head. She's saying, "We got to do this. We got to do that. We got to replace the shower." I'm thinking, I don't have any terrible, horrible things to justify that, but I really kind of do.

My wife's always been... By the way, her name is Anne. She's always been really proactive in a lot of ways and it's really come into play, especially about emotionally being... I have sensed probably incorrectly that I'm being treated differently and maybe people are trying to see what happened. I've got brain fog now.

Larry Gifford (...:

It's all right. Let me just say this, Barr, Anne and Erin and my wife Rebecca, we are so fortunate to have them to support us. But Dr. Dobkin, what if you were alone? What if you don't have a partner? Do you have any advice for folks on navigating these emotional journeys when they're by themselves?

Roseanne Dobkin...:

Yeah, it presents a whole separate set of challenges for sure. The first recommendation I would make would be to think about the social circle that does exist. Are there a couple of close friends or family members that you might feel most comfortable reaching out to, connecting with? Maybe it doesn't feel comfortable to discuss your innermost thoughts and feelings about the diagnosis, but just having people to connect with, to spend time with, so that you don't feel as alone or as isolated.

That can be really helpful. Many people find great companionship and understanding in support groups, although support groups are not for everybody. Some people really love to attend and share, other people rather not, but they're an option for consideration. Joining exercise programs. There's Rock Steady. There are dance for PD programs. Becoming more involved in non-Parkinson's related community activities in order to strengthen those social ties and connections.

That can be really beneficial. Starting even earlier with regards to building that multidisciplinary healthcare team. Even if you feel like you don't necessarily need all the professionals right now, maybe go for a PT consult, meet with a speech therapist, really get ahead of the curve, learn what you can learn now. Empower yourself so that you can pull all the levers that you're able to reach in order to take control to the extent possible of what you're learning, what you're doing, how you're coping, how you're feeling, how you're responding.

Larry Gifford (...:

Thank you. I think that's really powerful. There's all sorts of great classes out there that folks with Parkinson's and folks without Parkinson's take, whether it's a writing seminar where you get to meet people or writing class. I do improvisation theater and take classes with that. There's all sorts of great activities out there, and Parkinson's actually gives you permission to do the things that you've always wanted to do, but never did.

Now you've got a reason to go, well, I got Parkinson's. Now I can do this. At least that's the case for me. That's my reason for doing crazy things now. Soania, there's some questions from the audience about when you're diagnosed with Parkinson's as a young mother. Do you have any advice?

Soania Mathur, ...:

Sure, Larry. I mean, that was my life in the beginning because all three of my daughters were born after my diagnosis. I was expecting my first when I was diagnosed. I think we're all struck, especially in this day and age, of trying to be the super mom, trying to do everything. I really had to, first of all, redefine what that meant to me. Was it that I had to keep up with all the other moms? Did I have to go to all the soccer games? Did I have to do all the art stuff with them?

Or is parenting or being good parent mean raising well-adjusted, independent, compassionate individuals while providing them with a safe, loving home so that they can go out and make themselves a positive force in the world? It was just that shift in thinking that that was my main goal, not keeping up with the bake sales and the soccer games and that sort of thing.

I also had to reevaluate how I did things because I wanted to do everything myself, but I had to recognize that I had to accept help, had to create my own village to help raise my children, and that was a big help to me as well. The other thing that was helpful was not allowing guilt to impact my parenting, because it's very easy to feel guilty about maybe missed games or them having

to watch TV a little bit more while my meds kicked in and that sort of thing. But I think that we can't allow that guilt to impact our parenting.

We're still parents after all. For us and our family, we recognized that this was a life experience that was there, and we use it as a teaching moment for my kids. I was afraid when I had them that they would really be burdened with my diagnosis, and I was very upset by that. But I recognize now that what they've learned from this experience is actually that life's not perfect and life not being perfect means that you have to face it in a certain way and how you face those challenges is really going to define you as a person.

My children are now 24, 22, and 17. They've really learned a lot in terms of charity and empathy, and again, that we're going to be faced with challenges and they'll have to face it in a positive way.

Barry Grey:

I feel like I'm walking a tightrope between not wanting to be a burden to anybody, especially the other two people in my family, but knowing that I'm going to need help and not knowing how to ask for it. And also sometimes I feel like people are being a little bit simple with me because, well, maybe Barry's got some brain fog. I say things like I'm stupid, but I'm not dumb and all kinds of ridiculous malaprops.

But I mean, the point is I don't really know where to ask for help, where that ends, and trying to go it alone, which I realize, of course, realistically I can't do, but I want to do it as long as I can. I don't want to be a burden to my family.

Larry Gifford (...:

I think that's really common. I know I've been through that as well. Dr. Dobkin, I think there's two things here. There's the family members that don't know how to help, and then there's the people with Parkinson's who aren't sure how much help they should ask for. Do you have any advice on how to balance that out?

Roseanne Dobkin...:

Let's try to address those two points because they're so important separately. As far as the family members maybe not knowing how to help, what's going to be perceived as beneficial versus maybe off-putting, there's no substitute for having a conversation in your own way so that the words come out naturally. They don't sound like they're coming from your psychologist. Speak with your loved one. What would be helpful for you? How can I support you? What would you like me to do?

What do you really want me to stay away from and not go near and not approach? Oftentimes loving, caring, best intention family members don't have the conversation. They try to figure it out on their own. They guess and they guess wrong. It's okay to ask and it's okay for the conversation to be ongoing, and the answer's going to change. The needs are going to change over time, and that's okay too. In the context of marriages, in the context of a family, we're always, whether we recognize it or not, at one point in time, we're wearing the hat of the supporter.

In other times, we're wearing the hat of the support recipient. It's a two-way street and it goes both ways. Relationships are never 50/50. It's always 60/40, 70/30. But whoever's holding the 60% or the 40%, it shifts back and forth. We're playing both of those roles in a creative way all of the time in a dynamic way in the context of our relationship. I think it's important to remember that. As far as knowing when to ask for help and when to try to do things independently, you have to feel your way.

I think it's important to maintain as much independence as one can, but it's also important to be able to mobilize supports when you need to as you need to and not take unnecessary chances that could compromise one's safety. I think it's about experimenting, trying to do some things independently and asking for help and trying to figure out where that sweet spot lies, because it's not all or none. It's a little bit of both.

Larry Gifford (...:

I find just asking, how can I help you, or do you need some help, is efficient. Because sometimes I'm trying to button my shirt and I can't get it, but I want to keep trying, or trying to open the pickle jar, or whatever it is. I may ultimately go, I can't do it, but I'd like to at least give it a shot. Now, another example is if I'm cooking and I'm flailing the knife all around recklessly with dyskinesia, my wife will just take the knife and go, "Yeah, I'm going to take over that duty right now."

It's not even going to be a question. I think that when it becomes an issue of safety, the care partners and the friends or whoever is around can really oftentimes see things more clearly than we can. Because if we're going through a dyskinetic phase, we're off our meds and we're not quite clear thinking as maybe we should be when we're doing those things. Let's ask a few more questions. We've got five more minutes here. Do antidepressants interfere with Parkinson's medications?

Roseanne Dobkin...:

I'll jump in and offer a response. In general, no. However, it's very important to have the conversation with your personal healthcare team about medications that you're on, medications that you may like to try, what the advantages are, and what the potential interaction effects may be. There have been some concerns that have been raised in the past with the use of antidepressants with some of the Parkinson's medications, particularly the MAOB inhibitors, some concern about interaction effects and serotonin syndrome.

More recent research suggests that for most people, taking an antidepressant with an MAOB that you're taking for Parkinson's is likely to be okay, but it's something that needs to be reviewed by your doctor and your pharmacist to make sure that the dosages are correct and that you know how to monitor for side effects that could potentially arise.

Larry Gifford (...:

After 14 years, I'm still asking, why me? Is this normal? Will I ever get past this and accept my PD?



Barry Grey: I hope so.

Larry Gifford (...: I hope so. Yeah, I think that you have to work at it. It's not going to happen without you putting some time and effort into it and working on yourself, and that takes time with a counselor or meditation practice or yoga or whatever it is for you to get to that place where you can be accepting of what has come your way.

Soania Mathur, ...: Yes, you'll get there. I mean, I went through a long period of why me, but I got to the point where the question was more like, why not me? Better me than maybe someone that didn't have the ability to cope with the disease. May be better me than a loved one that has the disease, because I have a lot of respect for care partners. I think it's much easier to deal with the effects of the disease than to witness it in someone that you love. You get eventually to the point I'd say where it changes to why not me.

Roseanne Dobkin...: And then I also wanted to add that the process is not linear. Some days are definitely easier, some days are definitely harder. If you find that you are continuing to have difficulties for a prolonged period of time, I definitely want to echo the importance of maybe reaching out and speaking with a counselor for a couple of sessions or maybe longer to try to work through some of those thoughts and feelings.

Because while all emotions are understandable and all reactions are to be expected, when the reaction is prolonged and when it's associated with significant distress and it's starting to really get in the way and make life harder, I think that those are good signs, those are good signals to maybe reach out for some short-term professional guidance.

Larry Gifford (...: We have about two minutes left, so I'm going to ask one question. We all get to answer it. What's the most important things to do or what are the most important things to do after being diagnosed with Parkinson's? Soania, I'll start with you.

Soania Mathur, ...: First, educate yourself. Educate yourself about the disease, the potential treatments, what is a side effect versus a symptom, and then set yourself up with a team of experts that are all motivated to help you with your quality of life and optimize your quality of life.

Larry Gifford (...: Barry?

Barry Grey: I would say take your apathy and throw it out the window. Get rid of it and get going. That's the biggest lesson I learned from my wife who was way faster to react to all this than I was. Apathy, it really sucks. Get rid of it.

Larry Gifford (...: Doctor?

Roseanne Dobkin...: Do not allow yourself to be defined by the diagnosis. You have Parkinson's, but you are not Parkinson's. It is possible to live a meaningful, happy, productive life with a chronic medical condition. We want to focus on taking control, being proactive, and being empowered.

Larry Gifford (...: I would say one of the first things you should do when you get diagnosed is begin to tell your close friends and family or your close family so they can help begin to support you and figure out what is causing you the most trouble in your everyday life, so you can tell your doctors what it is about the Parkinson's that's giving you the most trouble so they can address that first. This is a lifelong progressive disease, so you need to make sure that you really focus on the things that are disrupting the best life you can live and address those.

And laugh a lot. We laugh a lot in our house. Every glass we break, we just laugh. I want to thank the panel for being here. I want to thank the folks who tuned in online, and I want to thank the Michael J. Fox Foundation for Parkinson's Research. This was a great webinar. I enjoyed being here. Hope you learned a lot. I know I certainly did. I think we could probably talk for a couple of hours on this topic, but thanks so much.

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