

Michael J. Fox: COVID-19 is testing us all in ways we never imagined. Around the globe individuals, families, and nations are arising to this challenge with courage and grace. I'm especially grateful for the research communities quick response to this crisis. For our part, the Foundation is making this commitment. We will flex to the researcher's needs in any way we can keep to critical neuroscience moving forward with the least possible disruption. Together we will pull through this and be stronger than ever.

Larry Gifford: Today on The Michael J. Fox Foundation Parkinson's Podcast, we present an episode from our limited series on everything you need to know about navigating Parkinson's and COVID-19.

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

Larry Gifford: Hi, I'm Larry Gifford. I'm the host of the podcast "When Life Gives You Parkinson's." I was diagnosed at 45 years old like you trying to figure out everything I need to do to be healthy, well and safe during COVID-19 pandemic. That's why the Michael J. Fox Foundation for Parkinson's Research and I are teaming up to launch this limited series podcast. Each episode is designed to help people with Parkinson's disease and their care partners navigate their way through the COVID-19 pandemic and joining me each episode is the foundation's own board-certified movement disorder specialist, Dr. Rachel Dolhun. Hi Rachel.

Dr. Rachel Dolhun: Hi Larry. I live on a busy street in New York City and with social distancing we're broadcasting from my apartment so if you hear some background noise, that's what it is.

Larry Gifford: Awesome.

Dr. Rachel Dolhun: I'm really glad to be here. This limited series podcast will offer practical advice on topics including how to make the most of telemedicine appointments with your movement disorder specialist, best practices for ongoing deep brain stimulation care, tips for managing in home care during social distancing, opportunities to participate in Parkinson's research from home, and the benefits of mindfulness and physical exercise in combating depression and feelings of loneliness and isolation.

Larry Gifford: And we're not going to tackle all of this in one episode. There's going to be episode after episode every couple of weeks we'll put out another episode on a Wednesday and we're going to answer your questions too. Fire away info@michaeljfox.org just email info@michaeljfox.org. We'll begin each episode discussing some of the latest news and information that Rachel and I have come across and we're calling this segment, get this, Here's What I'm Hearing, What Are You Hearing? I'm hearing that not only is the Michael J. Fox Foundation launching this podcast, but on the website there's a whole COVID-19 resource hub.

Dr. Rachel Dolhun: That's right. We really hope people will visit michaeljfox.org and check out what we're pulling together on pretty much a daily basis. As this situation continues to evolve so quickly, it's really easy to feel worried, but we want to counter that worry by helping people stay connected to the community and to credible information. We've designed this resource hub as a one stop shop to help answer questions you have about COVID, maybe questions you don't even know you have. There's lots of different opportunities to read, listen, watch to keep yourself informed. We've got webinars including the one you hosted, Larry about making the most of a telemedicine appointment. Also a conversation we did early on with Susan Bressman, who's a world renowned movement disorder specialists at Mount Sinai who shared what she's telling her own patients with Parkinson's about COVID. There's also several of my blogs from the Foundation's "Ask the MD" series about various topics like staying active and easing mood changes and feelings of isolation. And we've got information on getting involved in Fox Insight, which is our online clinical study that you can do from home, and of course this podcast.

Larry Gifford: So what's interesting about the Fox Insight is you've got the Fox Trial Finder and you have the Fox Insight. I always thought I was signed up for Fox Insight, but I kept hearing the messages. So I went on there, I'm like, I'm not filling out questions, what are people talking about? I had not signed up for it. So I went so that's what COVID-19 has done for me, I'm now on the Fox Insight.

Dr. Rachel Dolhun: There's your silver lining.

Larry Gifford: That's right. I've been hearing mixed views on if people with Parkinson's are at a high risk of getting COVID-19. One side says, "Oh yeah, absolutely." And the other side says, "Well Parkinson's in and of itself doesn't make you a higher risk of getting the disease." Most recently I hear because most people with Parkinson's are over 70 they're automatically vulnerable and because the leading cause of death for people with Parkinson's is pneumonia and COVID-19 attacks the lungs, it's just not a great combination. What's the Foundation's position on COVID-19 and Parkinson's and how likely you are to contract it or not?

Dr. Rachel Dolhun: Well, first and foremost as a science organization, we are interested in data and evidence and because COVID is a new disease, there is little data and evidence.

Larry Gifford: I have lots of rumors for you.

Dr. Rachel Dolhun: Yeah, the internet is good for that. There is little data and evidence about the risks related to COVID and people with Parkinson's disease. The Foundation doesn't take a formal position on this beyond helping to share what does become known as the research moves forward. And I think it is helpful to point out as you did in your question that we're reporting what we know today. Each day we're learning more and about COVID itself, what types of neurological symptoms it may cause, how it affects people with Parkinson's. It's important to point out that this information is changing and what we say today may be different from what we'd say in a few days or a few months or a few years from now.

Dr. Rachel Dolhun: With that disclaimer out of the way, as we often discuss, Parkinson's is highly variable and I'm not an infectious disease doctor, but it appears that there also is a widely variable course of the virus itself in the general population. With older people and those who have health conditions like lung, heart or kidney problems to name a few, they seem to be more at risk of getting the virus and potentially having more severe symptoms.

Dr. Rachel Dolhun: This all means that there's likely no one size fits all experience for anyone, including people with Parkinson's who get COVID. Now for younger people with Parkinson's who are in good health, eat well, stay active, there isn't a lot of evidence to suggest that their risks of COVID are substantially different from those without Parkinson's who fit the same profile. With the exception to any infection, whether it's the common cold, urinary tract infection, contemporarily worse than Parkinson's symptoms.

Larry Gifford: Okay.

Dr. Rachel Dolhun: For those people who are older or have other health conditions or are living with other health challenges that can come with Parkinson's like limited mobility, cognitive changes, et cetera. Those could tend to create some situations that might increase the risk for contracting COVID or having a more severe course with COVID.

Larry Gifford: All right, I hear sense of smell is an early sign of coronavirus, but as some of us with Parkinson's know all too well, loss of smell is also a symptom of Parkinson's disease. What do you make of that?

Dr. Rachel Dolhun: First, I think the news about smell loss really shows how doctors, researchers, patients, and health organizations to name a few are really working together to learn about COVID and bring that information to the public in real time. We started out not even knowing that this virus existed, and then not knowing much about it. We knew that fever, cough, shortness of breath were the main symptoms. And those are still the core symptoms, but as more and more people experienced the virus, we saw these new and different symptoms including

things like smell loss, and these help doctors not only look at how best to diagnose the virus, but it also leads them to ask, why does this occur? Why is smell loss happening? Is it because the virus clogs the nasal passageways causing a stuffy nose that affects our ability to smell just like any cold or allergies would, or is it because the virus is directly affecting the smell nerves? We don't know yet. And as you pointed out, smell loss is also a common and early symptom of Parkinson's. And researchers are looking at these exact same questions for smell loss in Parkinson's. What causes it? And could it be one way to potentially diagnose the disease early on before other symptoms like movement changes, tremor, stiffness, slowness develop.

Larry Gifford: That's great. Rachel, what are you hearing?

Dr. Rachel Dolhun: So much. But a couple of things. One is important. May is Mental Health Awareness Month. And we talked about stress, anxiety, depression. These are symptoms that we don't talk about enough and these are important and real symptoms. And so it's important to recognize these and that a lot of people feel these before COVID, but they're often and really amplified now. So if you are feeling these, it's okay and there's a lot of ways to manage them and a lot of people who can help you manage them. But on the flip side, reach out and talk to people, talk to your friends, share your experiences with your family members, your community members because people who are feeling lonely or anxious or depressed, they may not want to reach out or feel like they can reach out. And, so it may be you who is the one who makes the telephone call or sets up the Zoom chat or whatever it is and extends that hand and opens that conversation that's really helpful for somebody else.

Larry Gifford: Even an instant message or a text can just-

Dr. Rachel Dolhun: Absolutely.

Larry Gifford: ... brighten somebody's day and feel like they're connected.

Dr. Rachel Dolhun: That connection is more important now than ever.

Larry Gifford: You hearing anything else?

Dr. Rachel Dolhun: April was Parkinson's Awareness Month and I feel like April was 100 years but also passed in a blur. April is such a big month for us in raising awareness about Parkinson's, the symptoms of Parkinson's. And again, for good reason it was overshadowed this year, but we did a lot of good work in talking about Parkinson's, raising awareness for it, bringing the community together and so didn't want to leave without mentioning that.

Larry Gifford: And that is what we're hearing. Now let's hear from our guest Katie Amodeo. Katie is a movement disorder specialist at the University of Rochester. Katie, thanks for taking some time with us.

Dr. Katie Amodeo: Thank you for having me.

Dr. Rachel Dolhun: Katie, we really want to dive in now into managing your Parkinson's during COVID-19 and give people some practical advice. So I'll start with telemedicine, seeing your doctor virtually. This is a really different thing for people with Parkinson's and for their doctors, and we're learning a lot during this time. Can you give people some advice on how to prepare for an appointment and how to have an appointment with their doctor during this time?

Dr. Katie Amodeo: Yeah. Thanks, Rachel. It's an excellent question that is definitely very relevant right now. Make sure you call ahead, call the staff ahead. Most of the staff are doing teaching and making sure there's no issues with connection. They almost do like a practice run. And I think what's important about doing a dry run before your encounter with your provider is making sure that the camera is positioned well. Sometimes this can take up a bit of your appointment if we're trying to position the camera. Make sure we can see you know as much of you as we can so we can do a thorough exam. So I think those are things to keep in mind.

Larry Gifford: What are some of the benefits of telemedicine?

Dr. Katie Amodeo: The benefits are that you can A, connect with your provider during a time like this where we want to try to limit exposure the best we can. And so, it's a safe way where you can see your provider from the comfort of your home. We know that there are just inherent with the office visit, we're only capturing a piece of what's going on in individual's lives. So when we check blood pressure, that's just a piece in time. And often sometimes they can be elevated or falsely elevated, things like that, because of just anxiety of coming to the appointment or maybe the rush of getting to the appointment. So I think by having individuals in their home, it's a really comfortable environment for patients. And my patients have really enjoyed it.

Dr. Katie Amodeo: I enjoy it because I can see a glimpse into what their lives are like at home. Maybe there's a dog there, or something like that, that I can see how they operate in their home life. So, I think there's a lot of benefits. Particularly also, as a movement specialist at a tertiary hospital, we often have individuals coming from maybe two, three hours away and now they don't have to travel that far. We can see them, like I said, in their homes.

Dr. Rachel Dolhun: There are a lot of people who need in home care, people thinking about what's the exposure risk of having somebody come in my home. What have you talked with people about as far as getting in home care during this time?

Dr. Katie Amodeo: Yeah, so I think there are a couple options. So certainly for individuals who have assistance coming into their home, I think as long as they're limiting who is coming into the home and those that are coming into the home are practicing safe hygiene, I think it's okay. Now in terms of - I've had some situations come up where I've seen a patient over tele-home and I've really felt like they would

benefit from either occupational therapy or physical therapy. And that's another beautiful thing that's going on right now is we are able to do that virtually as well. So some of the physical therapists that I work with are able to offer these services via tele-home as well.

Larry Gifford: What if your doctor wants you to have a blood or a urine test? Is it safe to go to the lab?

Dr. Katie Amodeo: Yeah, that's a great question. That does come up. You're right. So thanks for bringing it up. I think overall as a field, we're trying to really make sure that we are only getting tests that we feel are urgent and trying to just again limit if they can wait to maybe when things hopefully become less acute right now. But obviously we don't know when that will be. So there's going to be times where people need to go get blood work or maybe get imaging done. And I don't want people to be afraid of going to the doctor's office because, or to even the emergency room, because the thing is everyone's doing a really good job in terms of being safe. So there'll be screening questions asked to make sure that there's no concerns for infection.

Dr. Katie Amodeo: Everyone's doing universal masking to make sure that that's taking away a risk and everyone's practicing six feet apart. So even just coming into the waiting room, people will be sat six feet apart. Or another option is actually to stay in the car and just you'll be called when it's time to come in, when it's your time. So, that's another way. But everyone's really practicing disinfecting. And generally I have to say, I have to go into the office at times to do Botox, and people feel safe. I wouldn't be afraid of going to get blood work. It's okay.

Dr. Rachel Dolhun: You mentioned the word, Katie, being afraid, and there's so much fear right now and so much stress and anxiety, and for people with and without Parkinson's, I'm feeling a lot of this, and so what can people do to lessen some of this anxiety and stress just around their symptoms, around being afraid to go to the doctor?

Dr. Katie Amodeo: I think first and foremost is just being in-tuned with yourself. I like that you just said that, Rachel, I myself am anxious, and me too. We have to be, I think, attuned to that and practice techniques to help with anxiety. So deep breathing, mindfulness, meditation, yoga, make sure you're getting that in every day as well. Just because this is a time you really have to focus on self-care too because it is a time of high anxiety, so I think doing things that are good for you and good for your mental health are so important.

Dr. Katie Amodeo: This can include painting, adult coloring, things like that to really help. But in terms of how to mitigate fears, definitely I think talk to your providers, try to get accurate information from your doctor. I have had my patients call me and just ask questions. What happens if I get coronavirus? The questions you're asking me, Larry, and I think when you can hear it from your providers and be reassured that that can really help.

- Dr. Katie Amodeo: Try to make sure you're getting accurate information. I honestly, I'm just going to say this. I would say limit your news watching, because I think if we watch news all day long, you're going to get anxious because, of course, you're going to be hearing about some extreme cases, things like that. And I would say try to limit as much as you can. Obviously, it's important to stay informed, but just make sure that you're also taking time for not hearing about coronavirus too.
- Larry Gifford: Well the anxiety and the stress can actually exacerbate your Parkinson's symptoms. So not consuming too much news could actually help you a lot down the road. We need to take our meds on time, we need to exercise, we need to do all those things.
- Larry Gifford: Let's talk about DBS for a minute. DBS, deep brain stimulation. If you've had DBS; my friend had it a while back. His battery lasts three to five years and two weeks into Covid-19, and just at the three-year mark it ran out of juice. Battery, dead. He ended up having pretty much emergency surgery to get that battery replaced. Can you talk people through what they should do if they notice their batteries getting low or if their battery drains?
- Dr. Katie Amodeo: We do ask our patients always, but particularly during this time, make sure you're checking your batteries, particularly if you're not able, as we're just encouraging office visits. So if you're not able to actually get in front of your provider who will check your battery, it's really on our patients to be checking their batteries regularly, which depending on where their juice is, as you say, it could be monthly, it could be weekly depending on where it is.
- Dr. Katie Amodeo: So I think if there's any questions about that, certainly call your providers or some practices have DBS nurses who specialize and can help with those instructions, but make sure you know how regularly you should be checking. And what often happens is, when it's time to get it checked, you'll get this little warning. Some devices will say ER1 or something. And some people will be like, "What does that mean?"
- Dr. Katie Amodeo: But what that means is, yes, you should be calling your provider to get scheduled. When you get that warning, there's usually time, there's usually a few months built in to get you calling your provider, be scheduled for your procedure so that it's not so urgent.
- Dr. Rachel Dolhun: Katie, you specialize not only in movement disorders like Parkinson's, but also memory changes, thinking problems or processing changes that can happen in Parkinson's as well. And this can be a particularly hard time for people who don't understand what's going on, in addition to being such a time of uncertainty but also such a time of us not understanding what's happening for people who have cognitive problems or trouble understanding ... having thinking changes or problems with memory. For care partners of people who might have thinking changes or memory changes, do you have tips to help with this time?

Dr. Katie Amodeo: This is a time that is tough particularly for the care partner because they're having to explain why to their loved ones that they're not going out. Explain why they need to be safe right now or what's even just going on in the world. They're finding that they're having to repeat that. Things like that. Things that come along sometimes with cognitive impairment. And so my advice to the care partners is A, be kind to yourself. So the first thing I say is, "How are you doing? Give yourself a big hug for doing all that you're doing. Check in with yourself. Are you feeling burnt out at all? Overwhelmed? That's the time to call your providers too so that we can be addressing your needs or talk with your own doctors about what's going on."

Dr. Katie Amodeo: If you do need help, ask for it. Try to be patient. If you ever get overwhelmed, just step out of the room for a minute, give yourself some time and just know that your loved one with Parkinson's and cognitive impairment, they don't mean it. It's part of the ... it can be part of the disease. And so just being patient and if there's anxiety in your loved one with Parkinson's and cognitive impairment and not understanding what's going on, you can limit the news. Try to do tasks that are good for cognitive function, which that brings me to another point.

Dr. Katie Amodeo: A lot of what I usually talk about is how to preserve cognitive function, to stimulate cognitive function, and a big piece of that is socialization, which is a whole different beast right now. We're not able to socialize in ways that we used to. But I say, get on FaceTime with your grandkids, make sure you're calling friends, do novel things together, puzzling, planting, baking, trying to do things that stimulate cognition in a different way.

Larry Gifford: I know some people have their grandparents or their loved ones in a care center or a nursing home and they're not allowed to visit now, and because of the cognitive issues, the person with Parkinson's or the person with Alzheimer's or whatever, they don't understand why they're not getting any visitors anymore. And I don't know how you can make that easy for them.

Dr. Katie Amodeo: Yeah. No, my heart breaks for everyone, but particularly our loved ones and our patients in nursing homes. I think it's a very difficult time for everyone. But like I said, more so for them because they really are being restricted on who can visit. Some are restricted to where they can't even go in the nursing home, and I think it's very difficult. But ways that we can help; I have heard of some nursing homes allowing people to kind of visit outside the window. So if your loved one that has that opportunity, I think that's important to just maybe ... Or plant something outside their window. Say hi. There are ways to communicate again via TeleHome. I have been seeing some of my patients via TeleHome, and if you're able to talk to your grandparent via Zoom or Skype or something, please do it because they really need that support right now.

Larry Gifford: So this is going to be the final question, and this is for all of us. Anytime we're faced with adversity in life, we hope that there are lessons learned. So what lessons are you personally learning through this, and what in general do you think the Parkinson's community will learn from this?

Dr. Rachel Dolhun: When we are faced with any, like you said, any tough time or, what it's taught me is that, to really focus on the good and what we're grateful for. And that's been really helpful to me. Another thing that I'm, I think, realizing during this time for myself, it's something I actually have talked about with patients during other times.

Dr. Rachel Dolhun: So say for example, in the setting of a patient having this discussion with me about giving up or no longer working in the setting of Parkinson's and how tough that was, that decision is when you think you're defined by your job. And we talk about how you're not, that's not who you are. You are a father, a husband, those are, that's who you are.

Dr. Rachel Dolhun: And so I think times like this where we're having furloughs or layoffs or we're not working in the same way we used to, it helps me to think about how those things are just things we do, but they're not who we are. So I guess that's what I would do.

Dr. Katie Amodeo: That's great.

Dr. Rachel Dolhun: I've learned or am learning several lessons in this time. And I think one of the biggest ones is to really focus on the present. You know, if I get caught up in my worry spiral about what, what may or may not happen in the next couple of days or the next couple of months, it can really send me on a downward turn. And so it really helps me to stay in this present moment.

Dr. Rachel Dolhun: Katie, you mentioned gratitude and that really helps me stay grounded, but I know that at least I have this guise of control, but I know that I think I can control this moment. That's about all I can stay in control of. And so that's been a really big one for me. I think it's also been a real big get back to the basics. Eating healthy, staying active, keeping a routine, sleeping eight hours a night and we're about there.

Dr. Larry Gifford: What is that like?

Dr. Rachel Dolhun: So also I don't have kids so you know, it's these sorts of things and the big one there is staying connected. You know, I've talked to my family and my friends who I've lost touch with more in these past six weeks than I probably have over the past year. And those connections and reconnections are really fueling me in this time. And that's something we talk about in the Parkinson's community all the time, is how these connections really fuel us and build this framework that builds us up and supports us at a time when we need support more than ever. Those are the huge learnings that will hopefully carry us forward.

Larry Gifford: Those are great. You know, I'm taking improv classes online right now because we can't do in person. Part of that is being in the present, you have to be in the moment. And so the way to get, one of the easy ways to get there is to just notice five things around you. Right now I see my cell phone, I see a pen, I see a

piece of paper, I see Rachel and I see a speaker. So suddenly I'm here, I'm in the moment.

Larry Gifford: And so that's just an easy way that people, you don't have to do the frou-frou stuff if you don't want to, but I love to meditate for half hour a day or whatever I can get in before my 10 year old jumps on my lap. And then finding that time to spend with my wife and my 10 year old and playing Lego for a half hour and just being there with him and in his imagination. That for me is just so rewarding.

Larry Gifford: And to your point about the job, like I worked full time in an office usually, but I haven't been. And I realize because I'm not commuting, I'm not on public transportation, I'm not in big crowds downtown. I'm not eating crap for lunch at the restaurants. My symptoms have improved. And so now I'm rethinking how I move forward after COVID, so it's really a huge lesson to be learned. All right. Well Katie, thank you so much for joining us.

Dr. Katie Amodeo: Thank you. I thank you both. I always enjoy talking with you guys. Thank you.

Larry Gifford: That's Katie Amodeo, MD at the University of Rochester where she completed the Edmond J Safra Fellowship in movement disorders. That's a prestigious fellowship offered by the Michael J. Fox Foundation to train the next generation of clinician researchers in Parkinson's disease. Rachel, our time has done. This was great. I look forward to doing this again.

Dr. Rachel Dolhun: Me too. That was a great conversation.

Larry Gifford: Rachel Dolhun, MD as Vice President of Medical Communications for the Michael J. Fox Foundation and a board-certified movement disorder specialist, neurologist, and I'm Larry Gifford, just a regular guy who has Parkinson's disease. You can connect with me on social media at @Parkinsonspod, on Facebook, Twitter, and Instagram. You can email us at info@MichaelJFox.org.

Dr. Rachel Dolhun: Thank you so much for joining us. Be sure to check out the MichaelJFox.org website for more resources, webinars, blog posts, and all sorts of resources for living a better life with Parkinson's. Click on "Understanding Parkinson's" and look down the column on the far right.

Larry Gifford: Stay safe, connect with your Parkinson's community. Keep exercising and we'll get through this together.

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