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 michaelifox.org.

Speaker 1:

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

Rebecca Gifford:

Welcome to the Michael J. Fox Foundation Parkinson's Podcast. I'm your guest host, Rebecca Gifford. I'm wife and care partner to Michael J. Fox Foundation Patient Council member, Larry Gifford. Larry was diagnosed with early-onset Parkinson's in 2017 at the age of 45. He's probably familiar to many of you, because he hosts this podcast from time to time. I'm thrilled to be hosting today. I'm a writer and workshop facilitator, and together, Larry and I host the podcast, When Life Gives You Parkinson's. The holidays are upon us, and while they are fun, they can also be stressful, even more so with Parkinson's in your life. Family gatherings, travel, shopping, indulging the excess food and drink, weather changes, not following a schedule, all things we associate with the holidays can cause stress and worsen Parkinson's symptoms. It also can be a lonely time for some as well. Maybe you've been recently diagnosed or you're experiencing depression or anxiety.

Avoiding social events can bring feelings of isolation, and all of this can have a ripple effect on care partners and the quality of interactions with your loved ones. Today, we're going to talk about our experiences and offer some tips for people living with Parkinson's, their care partners, and their friends and family, for how to have happy holidays with Parkinson's. On the podcast today is Dr. Rachel Dolhun, Senior Vice President of Medical Communications at The Michael J. Fox Foundation, Dr. Soania Mathur, a family physician who resigned her clinical practice 12 years after her diagnosis of early-onset Parkinson's disease at age 28. She is now a dedicated speaker, writer, educator, Parkinson's advocate, and member of The Michael J. Fox Foundation Patient Council. And Sarika Mathur, Soania's oldest daughter, who is a graduate student studying health sciences. Welcome everyone and happy holidays.

Dr. Rachel Dolhun: Thanks so much for having us.

Sarika Mathur: Thank you.

Dr. Soania Mathur: Thank you, Rebecca.

Rebecca Gifford: So I guess I'll start off with Rachel. I'd like for maybe some perspective, so why

are the holidays often harder for people living with Parkinson's?

Well, the holidays are hard for all of us, I think. I think that's the first thing to say out loud. We talked in the opening about how to have a happy holidays and they're not always happy. There's so much stress that goes into seeing everybody, taking time off, making sure you're away from work, making all the cookies, getting all the presents, having everything perfect. And so, I think it's stressful to begin with, and then, you add on Parkinson's on top of it. And maybe it's your first holiday with Parkinson's, maybe it's been a long time since you've seen your friends and family, maybe travel is just stressful, in and of itself, so maybe the holidays are different, because you lost somebody or you got divorced. So I think there's just so much that goes into it, that we don't talk about or think about, because we're so focused on making the holidays happy.

But with Parkinson's in particular, it might just be that it's the first time going out in public or in big spaces, as somebody with Parkinson's. It might be the first time you're seeing people for a while, and you might be worried that maybe things look different and what is everybody going to think? So maybe your symptoms, your voice is quieter, and it's harder to talk in bigger groups, or it's harder to navigate big crowded spaces, because your balance might be a little bit off. So there's so much that goes into this calculation of what a lot of us take for granted of just showing up to a big party, that goes into living with Parkinson's and celebrating the holidays.

Rebecca Gifford:

So then, as people with Parkinson's and then, the families around them, so then, we have to kind of adapt around to make sure that we're enjoying the holiday season and maintaining balance and helping and supporting our person with Parkinson's, to maintain balance. I know that Larry's Parkinson's diagnosis has changed the way that we plan for the holidays quite a bit. In the past, we've had big family gatherings, with lots of parties and activity. We live in Canada, and most of our people are in the United States, so travel was usually involved. These times could get quite stressful for Larry and, ultimately, for me and our son as well. Travel, changes in schedule, changes to habits, changes to your environment, it's required a lot of adaptation over the years, including cutting back on our activities around the holidays. But I'm curious, Soania, you've had Parkinson's for more than 20 years. Has how you handle and plan for the holidays changed over the years?

Dr. Soania Mathur:

Yes, it has. It definitely has. Over the past 25 years, I would say that, as the disease has progressed, my ability to adapt has had to increase as well. That adaptability has to be there when you're dealing with a disease like this, which is chronically progressive. So in sort of material ways that it's changed, it first actually triggered my disclosure to my social circle, the Parkinson's disease, trying to be at large gatherings like they have at the holidays and not being able to hide my symptoms anymore and having to recruit a couple of closer relatives to sort of get my food for me or hold my drink for me, it just became very difficult to hide.

So it actually triggered the disclosure of my diagnosis probably about a decade after I was told I had Parkinson's disease. And then, over the years, now that people know, I've had to prioritize my commitments, that's changed. Maybe I not going to eight holiday parties during the season, I might only be going to four choices instead. I've also had to accept the fact that things take longer. So whether it's cooking or wrapping or decorating, I have to give myself the time, be kind to myself, and not leave things until the last minute.

Rebecca Gifford:

And then, more specifically, when it comes to your symptoms, because your schedule is changing and maybe what you're eating and drinking is changing, then does that require you to change how you manage your medication and deal with your symptoms on a regular basis?

Dr. Soania Mathur:

Yes, absolutely. I think what's really important to remember is that, as Parkinson's patients, schedule is everything. You have to try and maintain your routine as much as possible, and that comes when we're talking about your diet, which is very difficult during the holidays, particularly with all the protein that floats around, and your exercise and your sleep. These are things that we really have to be conscious of trying to incorporate into the holiday schedule, because if those are thrown off, then I find, for myself, my symptoms increase exponentially. And it becomes harder and harder to recover from that in the long run. So schedule, I try and manage my commitments, taking into consideration my schedule.

Rebecca Gifford:

Well, and you mentioned sleep, that's a big one for Larry in particular, if we're traveling, which we'll talk about in a minute. So when schedules change, when you're in a different place or in a different home or maybe in a hotel, sleep can become really difficult, but we know it's important to everybody's quality of life, but for people with Parkinson's, if that gets thrown off, that can throw everything off for a period of time. So what do you do to help make sure that you keep a sleep schedule that matches you and that you're getting enough rest during the holidays or maybe during travel?

Dr. Soania Mathur:

That doesn't always happen, I must admit, but I try and do things like take a pillowcase that I like or take a throw blanket that I like, just something familiar to me that would allow me to sort of create an environment for sleep. I don't sleep very well anyway, so jet lag usually isn't too much of a problem, because my sleep is very fragmented at any rate. But certainly taking that downtime, taking familiar things with you, if you're going to a family member's house, sort of planning ahead with them, in terms of where you're going to be sleeping, is it a cool quiet place that you can find rest there? I think these are things that you have to, again, plan ahead and look to whatever environment you're going to be traveling to, but it becomes more complicated. And Rachel, maybe you could help us with this, in terms of managing medications, because that always, if you're going to a different time zone, can throw you off as well.

Absolutely. And I was going to say, on your last point about sleep, and Soania, you mentioned diet is off during the holidays, exercise may be more limited. Those impact your sleep as well. So if we can be thinking ahead about how we want eat the holidays and eat the cookie we get once a year, but how can we still... Maybe you have the same breakfast that you know gets your fiber and your fruit in, and that's the thing you can control outside of all the other parties and restaurants you're going to be going to. Or maybe you're the person who brings the fruit plate or the veggie side as your contribution, so that you know you've got some healthy choices there.

But really just thinking about how can you still bring in those things that we know are so important to feeling well, sleeping well. Exercise too. Maybe you're not going to get in your daily exercise, but suggest that your family goes for a walk after dinner to look at the holiday lights around the neighborhood. Just making sure that you're getting in these things where you can, giving yourself grace and knowing that you're not going to be on your regular schedule.

Rebecca Gifford:

For Larry, it's really important that he still gets his nap time. His naps have become kind of a ritual and a rest that he gives himself during the day. And so, I love what you said about thinking ahead about where you might have a quiet space, where, if you're going to someone's home or if you're going to an event, can you just kind of scope out a place where you can get some rest time, and ideally, he could still have his power nap, his 45 minute power nap, and then, keep up with the rest of the schedule. That could make a world of difference to his quality of life. So we mentioned travel a few times, and often, travel comes with the holidays. I'm wondering, Rachel, if you have some other tips for helping to maintain a balance and manage symptoms as we're traveling during a very busy time of the year.

Dr. Rachel Dolhun:

It's a big question. Soania mentioned medication before. I think that's a big one on everybody's mind, especially as you're traveling, especially if you go across different time zones, and this is where that preparation, thinking ahead, comes into play again. So if you know you're taking a trip for a couple weeks, it's making sure you have medication for more than a couple weeks, in case you've got delays or you need to take more. It's also talking with your doctor ahead of time and saying, "Hey, I'm going to a different time zone. Say I'm going from east to west, and I have a longer day. What do I do with my medication then? Do I take a little bit extra? Do I keep on my every three hours, when, normally, I'd be sleeping? What about the next day, when my morning comes earlier than I thought? Do I start from that moment?" So it's really about making sure you're talking with your doctor and you're planning ahead and thinking through these scenarios.

That's the other really big thing. Think through the scenarios. I like to, when I'm even packing for a vacation, I mentally rehearse my day and I go, "Okay, I brush my teeth in the morning. Do I have my toothbrush? But then, I take a shower. Do I have my shampoo and conditioner?" So it's really going through like, "I'm

going to the airport. I'm going to have to check my bag. I'm going to then... Do I need a wheelchair? Do I want assistance? What about, is an aisle seat better than a window seat?" So it's like taking yourself planning for every step of the trip and kind of going through, either in your mind or with your care partner or family member, so that you're thinking through all those steps and planning ahead to limit, knowing things will go wrong as they always do with travel, but thinking through and planning and controlling what you can ahead of time.

Dr. Soania Mathur:

There's one thing I wanted to add to that, and very practical tip as Sarika will be able to attest to, don't put half your medication in your checked-in baggage. I've always put two supplies of medication. And on a recent trip to Barcelona, I ended up being the only one whose luggage didn't arrive, and half my medications were in there. So we were kind of in limbo for a few days.

Rebecca Gifford:

Well, and speaking of air travel, I like that you mentioned thinking about where you're going to sit and how you're going to get on the airplane and planning ahead. Because there is all kinds of help involved and available to you, assistance available. Larry likes to think about, whatever help has been offered to him, he will take advantage of it. Whatever is available to him, he'll take advantage of, and he may not even need it when it arrives, but he's planned ahead. So he's been thinking about, "How are we going to get from that gate to that gate? Am I going to need some help, because there's not enough time for me to walk it? Where is going to be the most comfortable place for me to sit? And am I going to take advantage of the pre-boarding? Who do I talk to make sure of that?"

I think all of those things, preparing as much as possible, and then, letting it go. Because when we go with air travel especially, things can go wrong, and flexibility is required and all of that in a sense of humor. A signature of the holidays is big family gatherings, and they can be overwhelming and maybe even stressful. So I'm curious, to the panel, what are some ways to navigate that, if you are living with Parkinson's?

Dr. Soania Mathur:

Well, if you heard the saying, "We give advice by the bucket, but take it by the grain," that's probably the situation I'm in, so I know what to say and what I should be doing, it's not necessarily something I follow. But I think, again, prioritizing your commitments, accepting the fact that some things are going to either need to be done differently or may take more time. For instance, delegating, learning to delegate and give other people responsibility that you may have assumed as your own in past years, I think, is important. Being kind to yourself, when you do that. Don't look at it as a failure. Look at it as a way in which to achieve your goal, which is to have a nice holiday season with family and friends. And be honest about your limitations. People are willing to step up, as my daughter, Sarika, can, again, speak to. Family is very much available to step up and help out. And take advantage of that.

Rebecca Gifford:

So Sarika, then when you see that your mom is doing a lot and she's very busy and she's maybe taken on some responsibilities and managing a house full of people and other things, how do you go in to that situation with an eye towards her needs and supporting her?

Sarika Mathur:

Yeah, she mentioned at the beginning of what she was saying about how she can give all the advice in the world, but it's very difficult to take it yourself. I think there's a very difficult balance that has to be struck by someone who is a family member or a caretaker with someone with Parkinson's and someone who has Parkinson's, because, and my mother can definitely attest to this, while it might not always be physically the most comfortable thing for them to be wanting to do all those things, there's obviously a lot of emotional or psychological benefit to being able to still involve yourself properly with your family over the holidays, accomplish the tasks that you set out to do at the beginning.

So I think it's difficult, because on our side, as much as we want to step in and help all the time and handle things, because why have people in your family who are able to help you out, if we're not helping you out? As much as we do want to do that, we also should remember why it's important to let them try and let them do the things that they want to do. At the same time, I should really hope that at least, again, I can only speak to my own personal experience, but in cases like my mother's case, I think the balance does also have to be struck, where she's more willing to accept help, because it's not always a matter of, "I have to do this, I have to do this."

Sometimes, it's nicer to spend time with your family and give back to your family in other ways, which is keeping yourself well and keeping yourself as happy and healthy as possible. So yeah, I think it's difficult to say what can we do to assist in these situations, because it's constantly evolving and it's on such a personal basis between you and the person with Parkinson's. So I think it's difficult to give kind of overarching advice.

Dr. Rachel Dolhun:

I think, on that note, I would say, you're so good at anticipating your mom's needs and delicately walking that fine line on where she wants to do things herself and where you can help. And so, I think it's having that safe person, that secure person with you too. So if it's your first time going to a party or going to a big gathering, and Rebecca, you've talked about this with Larry, again, back to that plan, but having a plan ahead of time, "Hey, I'd really love to... These are the three people I really want to talk to, and I want to get a glass of that eggnog that I only get once a year. And then, I'm probably going to be good to go in about two to three hours, but let's cut out early if things aren't going well."

And also, having that person by your side to help you flex. So having maybe your talking points and your go-to, like if people are trying to make it about Parkinson's or your Parkinson's and that's not really what you're there to talk about, and somebody says, "Well, how are you? How's your Parkinson's?" "I'm

really good. How are you?" Or whatever. "I've been doing a lot of fundraising. Oh, I just guest hosted a podcast." So just having your go-to, so that, if you're put in that position, you kind of have your out or your ways to move the conversation in the direction that you want to go.

Sarika Mathur:

Yeah, I think, definitely, what you said about that open dialogue is the most important thing, because as people supporting people with Parkinson's, we obviously do not have any idea what the experience is like, not just in a physical sense, but also, in an emotional and psychological sense. So I think, being able to have that dialogue is imperative and being able to ask ahead of time, "Do you want me to push a little more? Do you want me to step in a little more?" Or if that's a really important thing to be doing for them for their sake, or whether they're a little more relaxed, they're like, "Yeah, I can use the help right now." I just think that open dialogue at all times, especially during such a busy season, is important, so that we know also where our boundaries are.

Rebecca Gifford:

Great advice. And along those lines, when you are stepping into a social situation, where maybe you haven't seen people for quite a long time, they haven't seen how your Parkinson's may have progressed or how your family dynamic is changing or they may not understand what needs you have, as related to the Parkinson's, and maybe they haven't seen you since the last holidays or a couple holidays ago, there are ways, I suppose, to kind of prepare the family or the social group for that situation and have that open communication that you spoke about, Sarika, with them, and maybe so that they can anticipate and have an idea of what you may be walking into and what your needs may be, as a person with Parkinson's, as a care partner, as the family around to support. Are there tips along those lines for family gatherings or social gatherings, that people can keep in mind as they anticipate maybe seeing a big group of people they haven't seen for a year? Rachel?

Dr. Rachel Dolhun:

I think it's back to that conversation, it's back to that planning. So I think, depending on your relationship with the people you're going to see, I find it very helpful for families to connect ahead of time, for example. We've heard a lot over the years from people who maybe haven't seen their loved one for six months or a year, and they see them and they're very concerned or they're very worried about the changes that they see. Whereas the person who's been with them day to day has seen things evolve and change, and so, they've been there through this change, so it's perhaps not as right in your face or as concerning at the first impression.

So oftentimes, what I tell people is, if you can, try to connect ahead of time, and maybe that's directly with the person who has Parkinson's. Again, depending on your relationship, maybe it's with their care partner or spouse, maybe it's with one of your siblings who's nearby and can kind of update you on things, just so that you sort of know, where do things stand? And then, it also gives you an opportunity to talk to them about what they want the holidays to look like, how you can make them easier for them. And again, it's just back to that open

conversation, that planning ahead, so that you get the most out of the visit together and you're not confronted by this big change perhaps that you weren't prepared for.

Rebecca Gifford:

Well, Rachel, don't you have a guide on this topic, that's specific for family and loved ones of folks with Parkinson's, if you haven't seen them in a while?

Dr. Rachel Dolhun:

Yeah, we have a guide for this exact reason, because again, we had these conversations so many times throughout the years, where just helping people think ahead. And this is for the family members of the people with Parkinson's, for the loved ones who maybe are going to be visiting together, and how you can best prepare yourself to help and get the most out of your visit with your loved one who has Parkinson's.

Dr. Soania Mathur:

That's great advice. I think the only thing I would add is that, sometimes, it can be awkward to have those conversations, as someone living with the disease. You don't necessarily know what to say or how to explain your boundaries that you may have in mind. And so, sometimes, having a proxy, be it, in my case, it's my husband, talk with people on your behalf ahead of time, as Rachel said, to let them know maybe what my boundaries are, my limitations are, in terms of length of stay and circumstances around the event, I think, is a good way to sort of get that communication across as well.

Dr. Rachel Dolhun:

Can I ask you, Soania, if somebody were to approach you, what would you want them to say? Or how would it feel less awkward if somebody wanted to ask you ahead of time? How best could we approach somebody, whether it's a loved one or a friend?

Dr. Soania Mathur:

Again, it's such a personal journey that everyone's going to have a different answer for that question. For me personally, I'm fine with people asking me direct questions about it, and I am more than happy to discuss. I'm very open about it, but I'm not the type that would volunteer though that information necessarily. I won't go up to somebody and talk about my challenges with Parkinson's, but if they were to ask me, then, certainly, I would answer the question. So it depends on the individual, how comfortable they are, how much they've accepted their diagnosis, what emotional state they're in, what the relationship is like between the person asking the question and you answering it as well.

Rebecca Gifford:

So for care partners, the holidays can quickly become quite complicated, as we navigate the busyness of it all, in addition to supporting and caring for our person with Parkinson's. And I know that where a person with Parkinson's is in their progression can affect this quite a lot, but I know that also burnout is for real, and especially at this time of increased expectations and activity. So I'm wondering what tips we have for care partners. What are some things that care partners can keep in mind to help manage the increased needs and activity of the person with Parkinson's during a busy time like this? Rachel?

I was going to say, you should start, because you're the care partner who navigates this, but I can certainly begin. But you're the one who has the real world firsthand experience and advice. I think, as you said, it's just acknowledging and being open about the fact that this is a stressful time for everybody and this is a time when care partners and family members might be taking on even more. You're making the cookies or organizing the party or planning the travel, in addition to helping your loved one along on all of that. So I think us, as other people, who are part of the family, part of the friend circle, we can look for ways where we can take the burden. And just like with how we support care partners throughout the year, thinking about those same ways we can support. So it's not about just throwing out like, "Well, how can I help?"

It's, "Hey, let me bring over the casserole. We're having dinner. Let me bring the main dish. Or you know what? We're making cookies. I'll bring all the cookie dough, or instead of making dough from scratch, let's take a shortcut and buy the cookie dough pre-made, so that we can still have this experience." So it's about taking out extra steps, where you maybe don't need them, that you're going to have to look at processes and things. But it's also about us offering specific help and care partners asking specifically for help, where they can use help. And then, the other thing I would say, which, Rebecca, you can speak much more to this, but it's just about caring for yourself as much as you can. So whether that's trying to get five minutes alone, while you're drinking your coffee in the morning, or doing a meditation in the afternoon, while your loved one's taking a nap, or those sorts of things, but taking care of yourself where you can, especially taking care of yourself more than ever during this time, where there's so much pressure put on you.

Rebecca Gifford:

I really like what you said about asking for help if you need it. And part of that is also accepting the help when it's offered. As care partners, we're not always good at accepting the help. "No, we can handle it." We're just used to handling things. Well, during these busy times, taking on more things, taking on more responsibility, more things to juggle, that's when you need the help. And if it's offered, accept it, and that can make a world of difference, to even a day that can be really busy, "Do you need a ride somewhere? Do you need to pick up your son?" Just little things like that can really take the pressure off of the day. And part of that is managing your expectations for yourself and being easy with yourself and forgiving yourself when things don't go well. As we like to say, be as prepared as possible and then, be prepared to be flexible and adaptable, when things don't go as planned. Can plan and plan and plan, but things will not always go that way.

So leaning into that mentality of flexibility, adaptability, a sense of humor, about when things don't go well. Larry and I like to say, when things don't go well or plans get pivoted in a big way, "Look, we're just making memories." So it's just a way to... And then, we know that that's a chuckle that we know will bring some levity to that moment and some perspective into it. I think also part of it is just, and this is just advice that everyone could use around the holidays, just leaning

into the joy of it, rather than the responsibility of it and the practical needs of it, but enjoying, allowing yourself to enjoy the holidays, to enjoy that time with people maybe you haven't seen, enjoy the food, enjoy the atmosphere, enjoy the support that's offered to you, and really kind of leaning into that holiday mentality in that way.

Dr. Rachel Dolhun:

I love that. And I think, if you get back to, what do you enjoy out of the holidays? So it'll be different for different people. Maybe it's being with family, maybe it's decorating the tree, maybe it's making the cookies your grandma made, but getting back to, "What is going to give me the most joy? How do I want to celebrate? What's most important to me in this holiday?" Then that helps you prioritize, like Soania was talking about. That 15th Christmas party maybe isn't going to be the way I want to celebrate. So it just gets you back in that mindset of, and expectations, as you said, I think, is such a good way to say it. "What do I want out of the holiday? What do I expect?" And then, that helps you focus on, what are the most important things and people you want to bring into your holiday?

Rebecca Gifford:

So if someone is newly diagnosed or maybe has decided that being in a social situation is too much, maybe you have depression or anxiety, what are some ways that you can still make your holidays happy?

Dr. Rachel Dolhun:

Or even if somebody's Parkinson's is changing and it's not as comfortable for them to be in gatherings, I think the first thing is to acknowledge it. And this is how we started too. It's like we're running around saying, "Happy holidays," and signing all our emails with that, and maybe the holidays aren't happy for everybody. Maybe people are navigating these kinds of things. So I think one is for the person who is experiencing that to acknowledge that, give themselves grace and say, "that's okay. They aren't happy for everybody. Things are different." It's also on us too to be aware when we're asking people or we have a neighbor who we know might be lonely, just checking on people. I can't tell you how much a simple text message or phone call, just to say, "Hey, how are you?" goes, that person feels seen and cared about.

But then, for the person who is thinking about the holidays looking different, I would say, it's your holiday. You can bring in whatever makes you happy. You want to have a movie marathon, you want to order takeout, you want to sing Christmas carols from the top of your lungs alone, whatever it is that again is your holiday is okay. But remember that connection is really important too. Now, I caveat that with saying, I don't want people to then feel badly saying, "I want to be alone," or, "I feel like I have to be alone," or those sorts of things. Then you don't want to make people feel worse by saying, "But you really should be connecting. Loneliness is bad for us too," which it is. But the point being, there are ways that you can connect still without having to go out and go to big Christmas parties or holiday parties or be in big groups.

So connecting one-on-one with people, making sure you talk to somebody you trust, making sure you connect on online forums. You can just chat. You don't even have to be on camera, but you connect with other people who live with Parkinson's or have similar experiences. And then, you could schedule short, simple virtual visits. So if I can't be with my family on the holidays, oftentimes, we'll set a time to do a quick FaceTime or Zoom, when they may all be together and I'm joining remotely. But there are many, many different ways to connect with people, even if you maybe don't, like I said, want to go to that kind of standard big gathering.

Dr. Soania Mathur:

Yeah, I just want to reiterate what you said, Rachel, in that our Parkinson's community is very tight. We have a lot of care for the others that are living through similar life experiences. So I think, as a member of that community, being aware of those people that are vulnerable, that are alone, that may be going through some change in their symptoms, that really is isolating them, to reach out. The holiday season is all about giving. So just giving even of your time and yourself, and as Rachel said, just reaching out and expressing that care for that person can go a long way, in terms of making it a better season for them as well.

Rebecca Gifford:

Very well said. So any final thoughts, last bits of wisdom to share?

Dr. Soania Mathur:

So I think that the holiday season is a season of kindness, and that means being kind to those around you, allowing them to help you, if they really want to, because that gives them a sense of joy as well. Being kind to those in your community, your Parkinson's community, in terms of reaching out to those that are vulnerable. And most importantly, being kind to yourself as someone living with the disease. Plan ahead, delegate, if necessary, but just understand that this is a season to enjoy with other people, and that's really the most important thing to keep in mind.

Rebecca Gifford:

Sarika, any final words?

Sarika Mathur:

Sure. I can't remember who said it earlier, but the notion of centering the joy of the holidays versus the responsibility of the holidays, I think, is really, really important. I know, for example, for my mom, it's been really important, as we get older, to really value, because I have two other sisters, but none of us live at home, but to really value those few weeks we have together every year and to let yourself get rid of that responsibility that you constantly have to be the one baking the cookies or putting up the tree. And sometimes, it's just nice to be and be with the people who love you and be with the people who want to help you out. I hope that people with Parkinson's can make sure to give themselves that grace this holiday season.

Rebecca Gifford:

Rachel, any final words?

It's hard to follow that. It was such a good conversation and such good advice. I think it's also an opportunity. Parkinson's never goes away, of course, right? It's always there with us, but it is a little bit of a chance to kind of experiment and be open to new experiences. And maybe this is a time where, as life changes for all of us, but especially changes with Parkinson's, you have a chance to look at creating your own new traditions, making your own new memories, like you said, Rebecca, maybe not ones that are a surprise sometimes, but I think, again, all of us, as we get older, as life changes, people come in and out of our lives, disease comes into our lives, it's an opportunity really to look at, "What's important to us? How do we want to celebrate? Who do we want to be around?"

And then, we can make that happen. So it's less about, again, having to have all the gifts under the tree or make everything from scratch or do maybe the traditions that you've held onto throughout your life, but now, you get a chance to look at, "What are the traditions that I want to establish and that mean the most to me and my loved ones?"

Rebecca Gifford:

Beautifully said. And from a care partner perspective, be sure you're taking care of yourself. We take care of others all year round, and here's a time when you can lean into the joy and the celebration of family time and rest, if you can get it, and celebration and joy and activity, if that's what you want. But don't forget to take care of yourself. Take a rest, if you need to. Be easy with yourself, be forgiving with yourself, and don't forget that sense of humor. We have more information and resources on this topic at the Michael J. Fox Foundation website, including Ask the MD blogs, a video and a guide on visiting with family members who have Parkinson's co-authored by Dr. Rachel Dolhun. The guide was last updated in 2020 with a section on the COVID-19 pandemic. Visit michaeljfox.org to learn more, and please rate and review this podcast. Feel free to share it with friends and family, and be sure to check out the links in the show notes for resources. Happy holidays to you all. Thanks for listening, and until next time, I'm Rebecca Gifford.

Speaker 1:

Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about The Michael J. Fox Foundation at michaeljfox.org. Thanks for listening.

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.