

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.

Speaker 1: 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.

Rebecca Gifford: Hello everyone. Welcome. I'm Rebecca Gifford. I'm a writer, activist, workshop facilitator and care partner to my husband, Larry, who was diagnosed with young onset Parkinson's in 2017. Together we hosted and produced the podcast, When Life Gives You Parkinson's. Larry is also a member of The Michael J. Fox Foundation's patient council and hosts this webinar series from time to time, so you may have seen him. It is so great to be here with you and our panelists. We have a lot to discuss. So today we'll be talking about care partnership, the many ways it can look, how it changes over time and what to do to combat stress and burnout. So let's get started.

Let me first introduce our panelists. Donny Moss is an animal rights campaigner and care partner to spouse Jim McNasby, who was diagnosed with Parkinson's in 2000 and is The Michael J. Fox Foundation's General Counsel. Thanks for being here, Donny.

Kate Harmon is also here with us. She is a senior community fundraising specialist at The Michael J. Fox Foundation and was a care partner to her father, Bob Harmon, who lived with Parkinson's. Thanks for joining us, Kate.

Kate Harmon: Yeah, I'm glad to be here.

Rebecca Gifford: And Erika Adelman is the Neurology social work Manager, movement Disorders social Worker and Center of Excellence Coordinator for the Parkinson's Foundation and Cure PSP at Columbia University Irving Medical Center. She also provides counseling for people living with Parkinson's and for caregivers through her private practice and she facilitates support groups for people with Parkinson's and their care partners. Welcome Erika.

Erika Adelman: Afternoon. It's nice to see you all and I'm grateful to be here.

Rebecca Gifford: So care partnership is such an umbrella term and it can mean a lot of different things to different people depending on symptoms, the pre-existing relationship, resources and more. Very loosely, it's anyone who takes on care roles for someone living with Parkinson's. Kate, what did being a care partner to your father look like for you?

Kate Harmon: I think that for children of people living with Parkinson's, it can look really different. I definitely saw my mother as the primary caregiver. She was living in the house with my father. They lived in Florida. My mother still lives there and I live in Pennsylvania. So my mom was dealing really with the in and outs of his

daily care and as that progressed, he had Parkinson's for 18 years and we lost him just a little under two months ago. But my role really stepped in when it come to providing that emotional support and being on the phone with them and talking to them a lot. And towards the end I was down there a lot. He got dementia in the last two years. So checking in, going down, giving my mom a break from the day-to-day life, helping her make the decisions of when to bring in someone to care for him in the home.

And towards the end really being the one to make some decisions because I think we can all say that there's a little bit of fatigue that comes from being the one who has to make all the decisions all the time, and especially if you're not used to being the one to make the decision if the person you're caring for is the one that normally does make the decision or in her case also dealt with hurricanes. And then we had a hurricane and I was the one who happened to still be stuck there. So that was nice, I got to help and deal with that. So it kind of changes a lot throughout, but whatever role it needs to be, you adapt to fill.

Rebecca Gifford: Right. It's changing all the time, this role because the person with Parkinson's is always changing and their disease continues to progress. So yeah. Donny?

Donny Moss: So as you mentioned earlier, my husband Jim is the general counsel of The Michael J. Fox Foundation. He was diagnosed in his early thirties and he's 55 now and we've been together for a little over 20 years. And so our journey has been one that's very much been in flux. The only thing predictable about our journey is how unpredictable it's been. When we met 20 years ago, he needed some sort of orthopedic help because he had pain and he needed help stretching and he needed help cracking his back. But other than that, he was okay. Over time, however, his fine motor skills began to be compromised, where I had to help him button his shirt and put in his collar stick. He made it as difficult as possible to get dressed in the morning, but we pick our battles.

And then he had DBS surgery and that sort of changed everything. He was able to be much more independent than he had been for the previous 15 years, but then his mobility was compromised by other orthopedic issues related to Parkinson's and the fact that one side of his body worked better than the other. And so my role as a caregiver has really evolved as his needs have evolved. In 2023, I went away for two weeks without him. In 2024, that was unthinkable because he was having trouble walking. Then he got a hip replacement and now he can walk again and his mobility isn't nearly as compromised. So I was away for a couple days. So it's been a journey and we're unsure about what the future will bring, but we're sort of in this together.

I will say one more thing about being a care partner, and that is it wasn't really until I was embedded in the Parkinson's community that I even thought of myself as a care partner. I was just, I had a husband who needed help. But then when I started to become more involved in the Parkinson's community, I was like, oh, right, that's me. I guess I'm a care partner.

Rebecca Gifford: And it's not a linear journey. I love that you brought that up. It's always changing. It can be one thing and then it can be another thing and then it can go back to

what it used to be. It's never this really linear journey. And then we are going to talk about DBS and your role in that a little bit later.

But just quickly, what my care partnership looks like right now. My husband Larry, is nearly eight years after diagnosis, so still relatively early but into it. My care partner role is largely emotional support at this point. So making sure he knows that we're in this together, keeping communication open, maintaining work on our relationship and making sure that that's strong. In a practical way, this role changes over time, which is very similar to what's been expressed. Because of the Parkinson's, he's less able to help with household and parenting activities. So what used to be more equal as far as responsibilities and staying on top of things have largely moved to my plate. So that was a big shift and that's always kind of changing as well. He can take on more at different times. If he's not doing well or feeling off, care partnership becomes about being flexible and adaptable. But mostly it's about having his back, really being his support during those times when Parkinson's makes life or maintaining quality of life more difficult for him.

So I'm wondering, Erika, can you give us a little bit more perspective about the many ways that care partnership can look?

Erika Adelman: Sure. I mean, as you heard from Rebecca, Donny and Kate, care partnerships can look very different from person to person. And there are many different types of care partnership models which include family caregivers, which could be family members including spouses, children or other relatives that are primary care caregivers who provide direct assistance and support. There's professional caregivers such as home health aides, nurses or respite workers that can provide assistance with various tasks, allowing family caregivers to take breaks or manage other responsibilities. And there's community-based support, which can be support groups or community programs for individuals living with Parkinson's and their families. There's also technology assisted care which isn't spoken enough about, which can enable remote monitoring communication and assistance with daily tasks. And in terms of what I see in my support groups, care partnerships can manifest as a shared space for caregivers to connect, learn, and support each other while fostering a sense of community and understanding. And this can involve sharing experiences, challenges and coping strategies as well as providing emotional and practical support.

Rebecca Gifford: So we did get a question about the difference between care partner and caregiver. And I know that some people and or at some organizations use them differently and sometimes interchangeably, but often using caregiver to indicate someone who's more actively engaged in practical care. And I'd be curious, Kate, how do you feel about the difference of being care partner and caregiver and maybe just the labels in general? What does that mean to you?

Kate Harmon: I think that traditionally you think of the giver as the one doing the work and the partners as the team around you giving you the support. But honestly, I think if you are part of the team helping someone however you feel like you're giving and however you want to call yourself in this journey, call yourself that and it is nobody's business. I think that it is so hard for all of us to be living this journey

and how the world views us and how they don't understand what is happening to a person with Parkinson's. They see the outward signs if they do happen to get dementia, which does happen in about maybe half of the people with long-term Parkinson's. Then they see that outward sign and they like to ask questions, they like to tell you what you should be doing. I mean, how many caregivers are told what they should be doing? So however you want to call yourself or refer to yourself is your business and you should feel strong about who you are and how you were caring for your loved one.

Rebecca Gifford: Self-identify confidently. Love it. In addition to potentially helping with some of the daily practicalities of living, care partners can be an important part of a person with Parkinson's care team. Parkinson's care team can be comprised of movement disorder specialists, speech therapists, pharmacists, physical therapists, you name it. But loved ones are a very important piece of that puzzle as well. And as far as my own care team, of how I'm involved with the care team, it's changing all the time depending on what Larry's needs. So my participation changes over time depending on what's going on, who he's engaged with. What I am consistently involved in is his movement disorder specialist appointments and making sure that information and perspective that I may have is included in the conversation. I also was very involved in the decision, spent a lot of time with the rest of the care team involved in Larry's deep brain stimulation surgery. And Donny, do you briefly, I know that you were involved in Jim's decision to get deep brain stimulation surgery. Can you briefly talk about your role in that process?

Donny Moss: Sure. So Jim and I were obviously well aware of what deep brain stimulation surgery is, but both of us were afraid of it. And then I was at a focus group for care partners in 2019 and when I told Jim's story about young onset and about what his symptoms were, virtually everyone in the room was stunned to hear that he hadn't already received deep brain stimulation surgery. So I called him during a break and I said, "Everyone here thinks he should have deep brain stimulation surgery." And it was like an aha moment for us. And with that he contacted a neurosurgeon and he had the surgery scheduled within the next couple of months. And what a game changer it was and what a testament to the power of speaking to other people and other care partners with Parkinson's 'cause I don't know if we would've ever done it had we not had that experience.

Before the surgery, Jim really had some severe tremor and he had rigidity, he had lots of classic Parkinson's symptoms and when they activated that device, a month or two after the electrodes were implanted and the batteries were implanted, it was shocking. I mean, so much changed in that moment and what a gift that he was able to do that, what a gift to him and to me as a care partner.

Rebecca Gifford: And how great that you were involved in that process. And I do find that with DBS, that's actually really helpful for the care partner, caregivers to be involved in that process and be working with the dial-ins and all of that. It requires a lot of feedback and sometimes our perspective can be really valuable in that process.

I'm wondering how do you, it's kind of a balance, I know that Michael J. Fox Foundation get questions about this a lot, how do you not treat your loved one

like a child while simultaneously helping them or protecting them? So helping them to think about what they need to be thinking about while also treating them like the full-grown adults that they are and not becoming naggy or irritating in that way.

Erika Adelman:

It's important really to validate your loved one's experiences instead of dismissing what they're experiencing and acknowledging that what they're going through is also their reality. And in terms of not nagging somebody, one thing I tell my caregivers is to eliminate the words "you need to," "you should" or "you have to," because if you do take this approach, you're going to be met with resistance as people do not like to be told what to do, especially if you're not their mother or father.

Instead, maybe you can approach situations such as exercise by saying things like, "I know that you're not a big fan of exercise, but I think it could really help make you feel better physically and mentally and maybe we could try a new activity together or something that you might enjoy more," which is a better approach.

Then there's other things you can do such as maybe help your loved ones set up a routine for themselves, incorporating exercise within that routine, which is definitely a good approach for those who are apathetic, depressed, and just need the extra push to get motivated. You can actually work out with them by attending an exercise class or maybe have a monthly contest where whomever exercises the most gets their favorite dessert, dinner or a small gift as a reward. You could say, "Hey, why don't we go for a walk together," and make it more about quality time instead of about exercising. You can engage other family members and I heard that kids and grandkids can be very motivating at times. And if all else fails, you can go back to the care team and have them emphasize the importance of exercise so that you don't have to be the bad guy.

Kate Harmon:

I would like to echo if I can for just a second, as the primary caregiver partner, however you deem yourself, you don't have to do everything alone. I know my mother for the longest time said, "I said, in sickness and in health. I said I would do this." And it took a lot for her to let my sister and I behind the curtain to see just how bad things were. And then that's when I'm a little bit of a fixer. I came down and I said, "This is what we're going to do now." And I think that there can be a little bit of denial or apprehension on both sides, the patient and the caregiver when there's time to make some changes. And I think trying to make it as much of a team effort as possible so it doesn't have to just be the caregiver saying, this is what we're going to do.

For me, when we brought in a home health aide, it was really me saying to my mom, we're not doing this anymore. We're bringing in a home health aide. But for my father it was maybe we should try this out for mom. And then he realized he liked it and then I said, "How about we do three days? And then how about every day?" And just kind of working together? And if you're not the right person to maybe have that conversation where they're arguing with you or you can't, I mean none of us have the patience of a saint, there's always something that's going to push you over the edge, so if you can't get that point across, if you can't

make that change, pull in somebody on your team to help you make that change happen. It can't just be you against the world at all times.

Rebecca Gifford:

I love that. Get creative and figure out and then also be aware of the messenger. I think that's great advice. And maybe pulling in a different messenger if there's baggage attached with that topic or whatever, getting creative and thinking about their needs. And I also love that you acknowledged your own needs as well.

So just a quick note here. Family and friends of people with Parkinson's often search for ways to support their loved ones. So one unique way to show support is to get involved in Parkinson's research. The foundation's landmark study, the Parkinson's Progression Markers Initiative, also known as PPMI, is recruiting volunteers. So people from all backgrounds with and without Parkinson's can help move research forward. So we encourage you to join the study that's changing everything.

So every Parkinson's journey is different. That's as true for care partners as it is for the people diagnosed and for many care partners, significant parts of that journey can be stressful and even isolating.

So for me, the practical considerations, the changing and increased responsibilities within the family, especially when it comes to parenting in our family, is stressful. It's that magic we all have to do to juggle all the information and appointments and considerations that come with the diagnosis. But even more so are the emotional stressors, the uncertainty of the Parkinson's journey that's already come up, the cyclical grieving process as you kind of face loss, it's a progressive disease, so there's loss of things over time and kind of continuously. So loss of freedoms, loss of social circles, changes in priorities, changes in my husband and in our relationship because of the Parkinson's. So it's hard to ignore that even with the gifts that Parkinson's has brought to our family, there are significant stressors to be aware of and to manage.

And Erika, when you are in your support groups, what do people bring up as their main sources of stress and is it maybe different for where they are in their Parkinson's journey?

Erika Adelman:

So in Parkinson's, caregiver support groups that I facilitate, people often discuss topics related to stress and burnout, which might include mental stress in terms of constantly worrying about the person with Parkinson's including their safety. Maybe there's a perceived loss of the relationship where the caregiver might be feeling like they've lost their relationship with a person with Parkinson's, there's isolation discussions where someone might feel isolated or like they're losing their entire sense of self. There's frustrations that are brought up where caregivers might be feeling like they can't do anything right or that things just don't go as planned. There might be guilt over not having done enough or feeling impatient or not loving or liking the care receiver. There might be moments where people express that they're depressed and feeling hopeless, where they're having trouble sleeping and just really want to cry and scream. And there really are significant differences in the main stressors experienced by care partners of people who are

newly diagnosed compared to those caring for a loved one who's further along on their journey.

To sum it up and make it more simple, some people in the initial phases of the disease and the caregiving, they are often marked by secrecy and uncertainty and their care partner and the person with Parkinson's might struggle with disclosing the diagnosis to others, leading to feelings of isolation and lack of support. The diagnosis can come as a shock, leading to emotional turmoil and fear of the unknown. The care partner might be grappling with the potential impact of the illness on their loved one's health and wellbeing as well as their own way. And the early stages usually involve a barrage of information about Parkinson's treatment options and potential outcomes, which can be very overwhelming and confusing for care partners, adding to their stress and anxiety. The caregiver might experience guilt or self-blame, questioning if they could have prevented the illness or done something differently. And their care partner needs to adjust to a new reality where their loved one's health is in jeopardy and their life's maybe impacted by the disease. This can be really emotionally challenging and require significant adaptation.

Whereas care partners whose loved ones are further along on their journey have different stressors because the care partner role, as it was mentioned before, evolves over time and the care partner might become responsible for a wide range of tasks, from managing meds to appointments to providing personal care and emotional support. And this increased responsibilities can lead to strain and burnout. The care partner might experience fatigue, sleep deprivation and increased levels of stress when they're providing long-term care, which can be physically and emotionally demanding. And Parkinson's at the later stages can impact the care partner's relationships with other family members, friends and colleagues where they might face isolation as mentioned before, and a reduction in social activities due to increased caregiving responsibilities.

And there's also a financial strain because of the costs associated with managing the disease, including maybe medical expenses, medications, and home modifications, which can place a significant financial burden on the care partner. And as the disease progresses, the person with Parkinson's might lose some degree of independence, require more assistance and support from their care partner, which can lead to feelings of helplessness and frustration that you feel.

Rebecca Gifford:

Erika, yeah, that's a lot and very helpful. You did mention early in your answer about patients and the need for patience and also understanding the need for patience, but not always being able to be patient. And that's something that I know I've experienced and I know partners that I speak with have experienced of wanting to be and having an intention of being patient when things don't go well, when you need to be flexible, when they're struggling to understand something, when they're having a reaction that maybe isn't convenient or comfortable and wanting to have that beautiful, compassionate patient response to that, but not always being able to. So I'm wondering to the panel and maybe even Kate and Donny, what would your response be to a care partner asking about, "I don't feel like I have very much patience. How do I handle that? What do I do with that?"

Kate Harmon:

I have to say, the further along you get in this journey, you probably shouldn't have patience left. And if you do, you are an amazing human being and I feel like we should clone you and I would love to learn more, because being alive in this world is already exhausting and everyone is already full of anxiety. And then throw on top of it what you're going through, caring for this person that you love so much and who is changing and your relationship is changing and the anticipatory grief of that, you're grieving the diagnosis, the change of that person, the change of the relationship, and then how things progress towards the end, and how can you be patient?

So for us, it was a lot of my mom didn't want to call on friends for help because what if she needs them later? And I'm like, "No, they're here to help because they love you and they're your friends. So if you need so-and-so to come over and sit with dad and watch golf so you can just drive around in circles so you're not yelling at him because he doesn't get it, then do it." And I did it too. I spent two weeks taking care of my father before he got the Duopa pump, and it was probably two of the hardest weeks of my life. I would call my husband just saying, "This is not manageable." And then I also felt so guilty because on the same vein, my mother was doing this every day and I knew I got to leave at the end of the two weeks.

So it's just to realize I'm about to be a person I don't want to be, I need to step away from this really quickly. And then having the ability to have someone else step in for you or putting that person into a safe environment so that you have the ability to step away really quickly and gather yourself so that you don't freak out or say the wrong thing or go too far.

Rebecca Gifford:

Well, a lot of what you said leads into a conversation about burnout. So because you're stepping away and all those things and having patience with yourself, even though not necessarily having patience with the other person, those things can ratchet up and the stress can start to spiral and can start to lead to burnout. So Erika, maybe you can give us a little bit of perspective about what is burnout and what are the symptoms of burnout?

Erika Adelman:

So caregiver burnout is definitely something you need to look out for and it's a state of physical, emotional and mental exhaustion that can occur when someone is caring for a loved one with Parkinson's. And this can happen when a care partner doesn't get the help that they need, maybe tries to do more than they can, maybe they don't practice self-care or have too many demands on their energy, strength and resources. Maybe they have conflicting demands from the person they're caring for, their family members and other people or if they are unclear about their role or responsibilities, this can also lead to burn out as well.

And some of the symptoms of burnout can include things like feeling tired, stressed, withdrawn, anxious or depressed, maybe having a change in attitude from positive and caring to negative and unconcerned. Maybe they're experiencing physical signs like body aches and pains, frequent headaches, fatigue, unusual changes in weight, insomnia or weakened immune systems. Maybe the caregiver might be feeling like you can never be alone or be by yourself even for a brief break. You might feel incompetent or like you've

reduced your sense of achievement. They might be using substances like alcohol or drugs or prescription drugs to feel better or they could have even suicidal thoughts. And if you're unable to keep yourself safe, this is a mental health emergency. But burnout is really different from stress in the notion that burnout exhaustion doesn't improve with normal recovery tactics like time off. So I would say that it's really important to be mindful of the signs of burnout and to seek help as needed because taking breaks and practicing self-care can help caregivers recharge and better care for their loved one's needs.

Rebecca Gifford: Very helpful. Thank you for that perspective. Donny or Kate, have you ever gotten to that place of burnout where it crosses over from I'm having stressful day or week or month into some of these symptoms of burnout?

Donny Moss: I have not experienced the kind of burnout that Erika described, but I will say this, I mean on a day-to-day basis, there are stressors that really affect me. As Erika mentioned, safety, I worry about Jim's safety. Jim is at times a falling risk and when I'm not with him, and if I'm not with him and he's walking down the street, I worry is he going to fall? When we are together and we're walking down the street and he puts his hands in his pockets, I'm there to remind him that he can't walk with his hands in his pockets 'cause they need to be available if he falls down or for whatever reason he wants to keep his hands in his pockets, then I know that I'm going to hold onto him while we're walking down the street. It's a silly thing, but it's something that's with me all the time.

Another sort of daily stressor is the fact that Jim, like so many other patients or people living with Parkinson's, is that he's a low talker and I often can't hear him and frequently have to ask him to repeat himself. And that's frustrating for him because he thinks he's speaking loudly and it's frustrating for me because I can't hear him and I don't want to consistently ask him to repeat himself. And so it's just finding a balance. Sometimes he's saying something that I don't think he even cares if I hear. He's just saying something and I'll note it, sort of, I don't have to follow up on that. It's always there. It's always in the background.

And then I would say the biggest stressor and something that's really affected me and us in our relationship is that Jim has REM behavior sleep disorder. And so he has nightmares and he acts them out and that could be thrashing in bed, falling out of bed, which is scary because he has these electrodes in his head from the deep brain stimulation surgery, he has two hip replacements and so it's the fear that he's going to fall out of bed, the fear that he's going to harm himself, the fear that he's going to harm me during these dreams has created anxiety. But we're working with a neuropsychiatrist and he's on treatment and most of the time it's under control. But these things, they do affect us, but they haven't really quite led to burnout.

Rebecca Gifford: Great. Thank you for sharing that. I think that the stressors that you explained and that we're all describing are going to resonate with the care partners watching very much, very identifiable. So I really appreciate you sharing that.

So I'd like to turn to maybe preventing, I'd love to start to talk about preventing burnout. How do we do that? So one of the hats that I wear is Writing Workshop

Facilitator. In one of my regular workshop sessions, I talk about burnout and using writing to break the stress response cycle before it spirals into burnout. So dealing with the stress before it gets to the burnout stage. And this workshop is informed and inspired by research presented in a great book that I discovered during the stress of the pandemic, appropriately, that has been really helpful to me. It's called Burnout by Emily and Amelia Nagoski, and that's Nagoski, and they are twin sisters, believe it or not.

And in it they talk about what research tells us are several very simple ways to effectively break the stress response cycle to prevent burnout. I found this information so impactful and comforting because as you can see on the slide, there are several effective, very accessible ways to do this that many of us already have in our toolboxes. So even a good cry, giving yourself the luxury of a good cry, having a laugh with friends, getting a hug from someone, even simply taking a moment to ourselves for one or two mindful breaths can help bring us back from the brink of burnout.

But Erika, what do you recommend in your support groups when care partners start to feel overwhelmed by stress?

Erika Adelman:

So I encourage our caregivers to speak up about what's attributing to their stress so that the group members can provide tips that have worked for them and I can also provide resources that might be helpful.

Secondly, I usually like to normalize their feelings and encourage them to take one day at a time, and I might also ask them to think about what coping mechanisms they've used in the past that have worked for them in difficult situations and encourage them to implement those same coping mechanisms to help them through the challenges that they might be facing now.

Then I might typically recommend that they find time to practice daily self-care, which we speak a lot about, and this could be while their loved one's at physical therapy or at an exercise class, maybe a support group. And if they aren't involved with any of the above, then I might say that it might be helpful for their loved one to get involved in these types of activities.

I also encourage them to ask for help, which is sometimes very difficult as mentioned before, in order for them to get a break, whether it's from a family member, aid or respite provider or even sending their loved one to a day program.

And this is a big one, that if they don't know how someone else can help, I might encourage them to make a list of things that they need to do and let people actually pick one or two things off that list that they can help with or possibly bring it to the doctors and speak with the social worker to see if there are resources for whatever needs to be done.

Depending on the situation, I might also recommend that they hire a case manager or a geriatric care manager if everything is becoming overwhelming.

And I've also told them, which caregivers have said this is really how helpful, that sometimes they don't really have to do anything. Just being there and being present is sometimes enough because active listening is an intervention in itself.

And lastly, I like to remind my folks that they're doing the best that they can, so it's important that they give themselves some grace and compassion as there's no loophole to care giving.

Rebecca Gifford: Great advice. I love that. I wish it should just be running on a loop in all of our homes, right? You're doing the best that you can. Have some grace for yourself. I love that.

Donny, I'm curious as to what you do when you start to feel... What do you do to manage your stress as a care partner?

Donny Moss: A few things. For me, the biggest thing is walking. We live in New York City, which is walking city to begin with, and we have a lot of parks. Walking, speed walking in parks for whatever reason is my go-to for when I'm feeling stress. Also, other exercise sort of more intensive cardiovascular strength training exercise, I think that's probably good for all of us who can do it.

And I would say lastly, eating healthfully, which I don't think was mentioned here. We both feel better about ourselves and probably less stressed, who knows if it's placebo effect, when we're eating fresh fruits and vegetables instead of french fries. About 20 years ago we both made the switch to a plant-based diet and it's tough to say if that's slowed his disease progression or how it's affected him physically, but we stick to that because we think that it's helping both of us emotionally and physically.

Rebecca Gifford: Great. Great advice. Thank you. I think that something that also comes up a lot for care partners caregivers is, okay, so I should be taking care of myself. I've been given the advice for how to go about that. I'm recognizing that I'm stressed out, I'm reaching burnout. How do I make time for that and how do I address that? Erika, if you have any response to that.

Erika Adelman: Sure. I mean, I mentioned some of these before, but it's really important to use time when your loved one is maybe at therapy, at an exercise class or support group to do what you need to do. Or maybe when they're napping, that's a good time. 15 minutes, 20 minutes may not feel like enough, but a little bit each day would be helpful. You can maybe send your loved one to a day program so that you can get a break and ask friends and family for assistance. There's always that option of hiring a home health aide or getting a respite provider for a few hours and while they're caring for your loved one, use that time for you and basically try to make a routine that incorporates me time for yourself so that you can prepare accordingly and have that time.

Rebecca Gifford: Thank you. Yeah. So Kate, I'm wondering, there's a question that comes up a lot. So how do I maintain my own identity as I'm spending so much time caring for another person. It's important to maintain my own identity. Perhaps a lot of care

partners recognize that, but how do I go about doing that? And what advice would you give to your fellow care partners regarding that?

Kate Harmon:

I think that's so important. I think that having just lost my father, one of my biggest concerns is my mother has given so much and once he's gone and that hole is there, what does she have left? And I know what she has left, I see her, but when she's doing that 24/7, as many people probably are, what have you left of yourself? I think that's why it's so important to maintain who you are and to still make that time and prioritize those things that you need to do so that you have some of yourself left to step back into when you have that time, so that you can't lose yourself in the mix. And I know it's so hard. And that's why having the community around you is so important.

If you're a person of faith, it's probably really hard to take your partner with you to church. So having somebody who can come sit with them on Sunday or Saturday or whenever you go, so that you can then go do that. Maybe you're really into golf and you've stopped doing that or pickleball or walking or running, having somebody who could come sit with them. And if they're not okay with a home health aide, maybe it's just a friend or a family member. Maybe you have a list of chores you want to do and it'll take twice as long if you take your care partner with you. Or you hate cleaning, maybe hire someone to come clean once in a while. Prioritizing those tasks so that you can make time for yourself and then put that community around you to help hold you to it.

The number of times I would call my mother to say, "What have you done for yourself this week?" And she'd be like, "Um." Then I, "Well, by the end of tomorrow, I want to know what you've done, what your plans are for yourself this week," just to kind of hold yourself accountable in it.

Rebecca Gifford:

I love that you brought up community. I think that's a really important bullet of one of the ways that you can manage your stress so that it doesn't become burnout. This was a lesson that it took me a while to learn. Kind of naturally introverted, and so once Larry has diagnosis, everybody's saying, find community, connect, join a social group, join a support group, other things. And I resisted those things for a long time. It took me a while to kind of warm up to that, but I found that once I both engaged with the Parkinson's community and then also engaged my non Parkinson's friends in my Parkinson's journey, which I also was resistant to because I didn't want to burden them, it felt like a lot to manage, once I did that, I added so much richness and support to my life.

And I do also want to say for folks who are new to the Parkinson's community or to the Parkinson's diagnosis, the Parkinson's community is wildly welcoming to newcomers, and I was welcomed with open arms and I've welcomed other people and I've seen that over and over again.

So I strongly encourage that as part of your toolbox to maintain your stress level, use that as a tool for you in your support in your care partnership journey. And I think that building that network of support for both emotional and also practical or the logistical things, which Kate brought up, is such a critical part of reducing the risk of burnout. But let's start with our loved ones, our family and friends and

the people and our neighbors who are right around us. It can be really hard to ask for help, although help is often offered. How do you, I'm wondering, Kate, what did your social network look like and then how did they help you both logistically and emotionally?

Kate Harmon:

It was really hard for me personally and my twin sister who lives in Texas. So you have the parents in Florida and then PA in Texas. So my parents are lucky to live in a wonderful community full of people that love them dearly, but with that, those people are also seeing someone they love change drastically. And it also took me a long time to realize this wasn't just about me and my family, it was also about them. So I also found that men of a certain age have a hard time being there for their male friend and seeing them change and losing that person. So that was an interesting thing to watch. But some of them didn't. So we'd call Fred and he'd come over and he'd watch golf with my dad while my mom went out and did things by herself. We had a home health aide and we had girls that would take my mom out to lunch on the Tuesdays and Thursdays at first that my mom had the home health aide in. Then when it became Monday, Wednesday, Friday.

So I would help kind of, I'm a social butterfly, I get that from my mother. So knowing that was important for her as well, I helped kind of, I would text behind the scenes, "Hey, mom doesn't have plans on Wednesday. Maybe you should ask her to lunch," just to make sure that she was getting that social enrichment as well. But also our Parkinson's family and our support groups that we had, my mother and father ran a support group in that community, were people that I would call behind the scenes and say, "Things aren't going well, could you step in?" And they would do so. It was good to have the non-Parkinson's, and it was good to have the Parkinson's because who else can you talk to about some of the things you have to do as a caregiver other than the people who have to do it too? They really understand.

Rebecca Gifford:

Well, and I think that there can be a resistance to support groups in general and kind of knowing what they look like and what to expect can be really helpful. Erika, very briefly, can you give us a brief overview of what to expect if someone's interested in a support group or curious about that?

Erika Adelman:

There's many type of support groups that exist. Some might involve people living with Parkinson's and caregivers. Some might be exclusive to caregivers, some might be led by professionals, others may be peer-led, and some are a combination of those living with Parkinson's and other Parkinsonian syndrome, as well as other groups that might exist that might be exclusive to each of those.

I can't really speak on how every group individually operates, but in terms of my general support groups, I usually have people who are newly diagnosed to people who had been living with Parkinson's for 10, 20, 30 years plus. And they usually involve both people living with Parkinson's and caregivers, as well as AIDS. And for these groups, we either have open discussions or we have experts in the field come to talk about different topics related to Parkinson's.

And for my caregiver support groups, you're really made up of anyone supporting a loved one that's been diagnosed, whether it's a spouse, partner,

adult, child, aide, friend, or maybe even professionals at times. And we usually have open discussions where we spend time with each participant discussing what's been happening with their loved ones, what's been happening for them, and it's an opportunity for them to pose questions, get feedback or tips and tricks, and hear about resources that are available from both the members of the group as well as myself.

Rebecca Gifford: Well, and I think it's important also to acknowledge online groups and support groups and that some people really like them and other people don't, but that there are a lot available and that can be, especially if you live in a remote area and you don't feel like there's a nearby support group, that can be one way to connect in that way as well.

Erika, we've run several questions from the audience about respite care options. When do you know it's time to get outside professional help and what kinds of options are available? And that's come up briefly before. Can you talk about that quickly?

Erika Adelman: So being that Parkinson's is a progressive condition, there will be a progression of care needs along the way. At first, someone might just need help with the groceries of right now. And as the disease advances, maybe one needs to evolve to include a daycare service or a home health aide for a few hours at a time and eventually full-time care or skilled nursing care might be necessary. But not everyone wants an extra hand even when they really need it. So it's really important as your loved one's needs change, you must continually reevaluate your needs for help.

And in terms of when it's time to get professional help, this will really be dependent upon every individual's respective situation. But what I would say is ultimately when it becomes too difficult to balance your own life with your care partner role or when the physical burden is more than you're capable of, this might be the time to get outside help, if not before.

As far as your options, you can try getting help from friends and family, as mentioned earlier. There are home health aids can sometimes be covered by your loved one's insurance. There are also aids that you can privately pay using your savings, long-term care insurance policies, catastrophic insurance policies, veteran benefits, and there are aids that sometimes can be provided by local community-based organizations or faith-based organizations or your local Department of Aging, depending on where you live, at a low cost or at no cost. There are also respite options where respite can be provided in the home or at an adult daycare center or within a facility. And if you want to see what options are available to you in your loved ones, wherever you reside, I would recommend speaking with a social worker at your loved one's movement disorder center or maybe contacting national hotline, maybe from the Parkinson's Foundation or the American Parkinson's Disease Association, or even by contacting your local Department of Aging who can provide you with further information.

Rebecca Gifford: Thank you. We appreciate that. This has been a great conversation. We do need to move on to Q&A. Our time has flown by. We do have a question that I'd like

to direct to Kate. So what strategies might work with Parkinson's dementia when change to routine makes things worse and they don't adapt to other friends or aides starting being a helper.

Kate Harmon:

So strategies for dementia when change... Obviously change to routines is really hard for people with dementia. Especially when they don't think they need help in the early stages or they get frustrated, it can be really complicated. Personally, I felt like the dementia part of the disease was more complicated for me than the Parkinson's part because it was harder for us to manage and dance around. But I think it's all about trying new things and try, try, try again. You have to continue to try to treat people like a human. There was definitely a lot of times where I felt like I was treating my dad like a toddler, and that's awful, and then that made me feel bad, but I was really trying to make things simpler for him.

And when it comes to aides, you don't have to stick with the first aid somebody gives you. So if the relationship doesn't work out, try a new one. We have some friends that loved my father, some of his closest friends in his regular life, but in his dementia life, he couldn't stand how loud they were. So just really understanding why things aren't working. One of my very close friends, he pushed her out of the house and shut the door in her face because she was too loud. So it's funny now when we laugh about it, but that was why. So maybe that's not the right helper when mom needs to go to the store.

So oftentimes you can figure out what's triggering your person with dementia and then kind of come up with the new... It's all about being flexible, adapting on the fly. And I found too, my mother would say, "How am I supposed to be so creative? You're so creative? But when I'm in the middle of it, I'm not patient and I'm not creative." So what I would do is have her call me later and I would come up with some things that maybe I would've said in the moment or I would've done, and so then she would kind of file that away for next time. So build that team, bring your people in because you cannot have all the answers. None of us are superhuman.

Rebecca Gifford:

Love that and get creative. Yeah. Another question to Donny, how have you adjusted to your changing roles and cope with that?

Donny Moss:

I would say I've adjusted quickly in that my role as a care partner has changed so many times throughout my thirties, forties, and now my early fifties. And so it hasn't been difficult for me to make those adjustments in part because I'm probably, and Jim, I mean we're both a lot younger than the typical people with Parkinson's. I mean, it's hard enough getting old as it is without having a neurological disease like Parkinson's, but because we're both younger and this happened to us when we were younger, it's been probably easier for us to make these adjustments than it would be for people who are diagnosed in their sixties, seventies and eighties.

I would say one thing we've done because we were young and because we didn't know what the future would bring is that we've really tried to live in the moment, especially when he's feeling good. And so we've done a lot of things that most people wait until retirement for. We've traveled, we've had really wonderful

experiences because we just weren't sure if we'd be able to do so in the future. We've really lived in the moment.

Kate Harmon: And to not hide yourself from the world. One of the things I actually, I have a support group at work that is other coworkers who have parents with Parkinson's, and somebody said the other day, "I don't know what to do. I take my dad to dinner with my mom, and I just feel like people are looking at us and I feel bad and I don't know how to deal with that." And I said, oh, if I make a reservation, I put it in a note and I say, my father has Parkinson's and dementia, and if they don't have a note, I'll mention it to the server. Or as we're being seated, I'll walk a little slower and say, "can you let my server know," just so that they don't look at me funny when I'm like, "Do you want the burger? He'll have a Coke." Those kinds of things just to help with that. I hate to see because the social isolation as this disease progresses can be so... So to be able to keep getting out there and doing what you want to do in life is so important.

Rebecca Gifford: And then looking for all the ways that you cleverly found to adapt to that and inform people around you to make it easier for them to be out in the world and have a better quality of life. Great. Love that.

Thank you again for being part of our community and for joining us today. Thank you to our panelists for sharing your time, expertise, your experience so vulnerably, and we hope you found today's discussion helpful. Thank you to everybody who joined us today, and have a great day.

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